Experiences of parents and carers managing asthma in children

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A thesis submitted by Robyn Fawcett as fulfilment for
the award of Master of Clinical Science

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ABSTRACT

Objective

This thesis presents a systematic review of the best available qualitative evidence to understand the lived experiences of parents and carers caring for and managing asthma in a child or children aged 0-18 years in any setting.

Background

Asthma affects around 14% of children worldwide and despite availability of effective therapies asthma control is suboptimal and hospitalisation rates high. Mothers predominantly manage their children's asthma and experience stress and exhaustion due to complex treatments and external factors such as managing work and family life. This review provides an understanding of barriers parents and carers face in managing their child's asthma and highlights the needs of families throughout their asthma journey.

Inclusion Criteria

The review considered qualitative studies examining experiences of parents and carers caring for and managing a child with asthma, wheeze or bronchiolitis. Research designs included, but were not limited to phenomenology, grounded theory, ethnography, action and feminist research.

Methods

A comprehensive search using PubMed, CINAHL, Embase, PsycINFO, Web of Science and hand-searching for both published and unpublished studies was completed initially in June 2017 and repeated in December 2017. Studies published in English with a date range from 1972 to 2017 were included. The recommended JBI approach to critical appraisal, study selection, data extraction and data synthesis was undertaken.

Results

A total of 77 studies were identified following appraisal of the literature with 1,161 findings (966 unequivocal and 195 credible) extracted from included studies and grouped into 41 categories based on similarity of meaning. From 41 categories, seven synthesised statements were produced:

(1) Negotiating the meaning of having a child with asthma,

(2) The process of getting a diagnosis and learning about asthma

(3) Impact on family life,

(4) Relationships with healthcare professionals and the emergency department experience,

(5) Medication beliefs, concerns and management strategies,

(6) With time, parents and carers became more comfortable managing their child's asthma,

(7) The need for support.

Conclusions

Findings of this review highlight the difficulties parents and carers face when caring for a child with asthma and managing their child's condition. Attaining a definitive diagnosis of asthma can be challenging and parents and carers express uncertainty and fear due to continuing symptoms and repeated hospitalisations. Healthcare professionals should ensure a clear diagnostic strategy and treatment plan is communicated so that parents and carers understand the pathway to receiving an actual diagnosis. Comprehensive asthma education is essential at the onset of asthma symptoms, with the provision of accurate, easy to understand and culturally relevant information. Supportive relationships with healthcare professionals are recommended including taking a partnership approach, ensuring adequate time and regular follow-up, continuity of care and addressing psychosocial and cultural needs and concerns of parents. Comprehensive training for education staff is imperative to ensure staff can respond appropriately in an asthma emergency and support students and parents by providing asthma friendly environments. Support groups for parents and carers are also recommended to provide ongoing education and psychological support.

Keywords

Asthma; carers; parents; wheeze; qualitative

DECLARATION

I certify that this work contains no material which has been accepted for the award of any other degree or diploma in my name, in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. In addition, I certify that no part of this work will, in the future, be used in a submission in my name for any other degree or diploma in any university or other tertiary institution without the prior approval of the University of Adelaide and where applicable, any partner institution responsible for the joint-award of this degree.

I give permission for the digital version of my thesis to be made available on the web, via the University's digital research repository, the Library Search and also through web search engines, unless permission has been granted by the University to restrict access for a period of time.

I acknowledge the support I have received for my research through the provision of an Australian Government Research Training Program Scholarship

Robyn
Fawcett…………………………………………………………………………………………………….

Date………………………………………………………………………………………………………

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CHAPTER 1: BACKGROUND TO THE SYSTEMATIC REVIEW STUDY

1.1 Introduction

Chapter one describes the context and personal motivation for the review. It introduces the research question that will be investigated and outlines the structure of the thesis, significance of the research and provides definitions of key terms.

The term “Evidence-based medicine” was first discussed in 1992.[1] Evidence-based medicine is defined as “….the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients…”[1(p1)] Systematic reviews are particularly important for evidence-based practice as they aim to identify, critically evaluate and synthesise results of high-quality studies in order to produce reliable research evidence in a usable form.[2] Best evidence often refers to randomised controlled trials (RCT) and systematic reviews using meta-analysis to describe the effect of the intervention being investigated.[2] In healthcare however, many phenomena are unable to be captured using quantitative study designs and thus qualitative study designs are required to investigate how interventions and healthcare services are viewed by those using the services.[2] Qualitative evidence is particularly relevant in the context of healthcare as it seeks to explore and explain how individuals and communities perceive health, manage their own health and make decisions regarding health service usage. Furthermore, qualitative study designs are useful to examine factors that facilitate adherence to treatment by patients’ and encourage health promoting lifestyles.[2]

In the context of healthcare, qualitative research:

> “*…seeks to understand and interpret personal experiences, behaviours, interactions, and social contexts to explain the phenomena of interest, such as the attitudes, beliefs, and perspectives of patients and clinicians; the interpersonal nature of caregiver and patient relationships; the illness experience; or the impact of human suffering.”*[3(p1)]

This thesis adopts the Joanna Briggs Institute (JBI) systematic review methodology for reviewing qualitative evidence.[4]

1.2 Personal interest in the topic

My personal interest in this topic stems from over nine years working at Asthma Foundation SA as an Asthma Educator and Coordinator of the Asthma Friendly School Program. During this time I had the opportunity to work with many individuals with asthma and provide education to school and child care staff. Throughout my career at Asthma SA I assisted many parents coming into the Asthma Foundation having undergone multiple hospitalisations with their children and struggling to understand and manage their asthma symptoms. Many parents also expressed difficulties with school policies surrounding access to medications and triggers in the school environment. My interest in this topic derives directly from the desire to understand parents' experiences managing their children's asthma and to identify factors that help or hinder in their management of the condition.

1.3 Statement of research question/issue/problem

The overarching objective of this review was to enhance understanding of the lived experiences of parents and carers in caring for a child with asthma and the management of the condition in any setting.

Management of asthma and wheezing disorders in children is based on factors including confirmation of the diagnosis, assessment of symptoms and triggers, discussion around the goals of asthma management, treatment choices and provision of information and skills to manage asthma.[5] In children, the management of asthma is primarily the responsibility of parents and carers with children tending to learn the skills to self-manage their condition as they mature.

Caring for a child specifically relates to the parents' and carers' perspectives of how their child's illness is integrated into family life including contextual factors that influence their response to illness episodes. Furthermore, it incorporates their experiences of living with and caring for a child with a long-term condition.[6] Therefore, managing asthma specifically relates to the medical management of the condition whereas caring for a child with asthma relates to the family, social and emotional impacts of the condition.

The primary question to be addressed is:

- What are the lived experiences of parents and carers when caring for a child with asthma and managing the condition?

Secondary questions to be addressed include:

- What barriers exist for parents and carers in managing their child's asthma?

- What enablers exist for parents and carers in managing their child's asthma?

1.4 Structure of the thesis

This thesis will be presented in four chapters which involves the following:

Chapter 1 introduces the thesis topic and an understanding of the author's interest in the topic. It presents the review objectives, significance of the research and definition of terms.

Chapter 2 provides a review of the related literature, sets the scene for the thesis and provides a comprehensive overview of the research to date and discusses any existing gaps in the research.

Chapter 3 describes the methodology used for the systematic review presented within this thesis. The JBI method for undertaking systematic review was followed and the process is explained in detail as it relates to this review.

Chapter 4, Results and discussion, this chapter details characteristics of included studies and results from the systematic review which are presented by synthesised findings. Additionally, summaries of each synthesised finding are presented with associated categories. Finally, recommendations for clinical practice, education, policy and research are presented which are based upon the synthesised evidence from this review.

1.5 Significance of the study

A substantial volume of research exists studying the experiences of parents and carers in managing asthma in children. This systematic review has synthesised findings from 77 qualitative papers to seek a deeper understanding of the lived experiences of parents and carers in managing asthma in children. Qualitative evidence is particularly relevant as it contributes to research inquiry by providing stories and accounts of living and convey richness of meanings through participants words.[7] Understanding the lived experiences of primary caregivers may help healthcare professionals to better target support to these caregivers and to equip them with the skills, knowledge and confidence needed to empower them to provide better asthma care for their children. Furthermore, understanding barriers that prevent good asthma management can provide evidence for policy makers, governments and asthma peak bodies to develop programs and educational interventions to reduce barriers and ensure high quality care for families and children with asthma. Similarly, understanding factors that enable good asthma management is essential to ensure that these factors are incorporated into existing policy and practice.

For change to occur, evidence-based recommendations based on systematic review of the literature should be provided to guide policy makers, healthcare professionals and asthma peak bodies to improve asthma care and potentially reduce costs associated with poorly controlled asthma. Person-centred approaches recognising parents' beliefs, understandings, concerns and information and care needs should be a central focus in order to dispel myths, improve medication adherence and enhance asthma care and management. Given the vast quantity of studies that exist, it was identified as necessary to synthesise the existing qualitative literature that explores parents and carers experiences of caring for a child with asthma.

1.6 Definition of terms

Asthma is defined as a chronic inflammatory condition of the airways associated with episodes of wheezing, breathlessness and chest tightness.[8]

Asthma control is defined as the response to treatment, in terms of whether asthma exacerbations are kept to a minimum.[9]

Asthma trigger is anything that sets off asthma symptoms and can include colds, smoke, cold air, exercise, dust mites or pollen.

Barrier is defined as a factor or factors that impede the achievement and maintenance of asthma control and could include (but is not limited to) factors such as health beliefs, professional barriers, language and communication, and issues around diagnosis and treatment.[10]

Complementary and alternative therapies is the range of medical and healthcare practices and products that are not generally considered part of conventional medicine provided by doctors and allied health professionals in Australia. These include “natural” products, “mind-and-body” therapies, dietary supplements or restrictions, and physical therapies.[5]

Enabler is defined as a person or thing that enables the achievement and maintenance of asthma control.[10]

Flare-up is worsening of asthma control (increase in asthma symptoms).[5]

Health literacy is defined as an “individual’s capacity to access, understand, communicate, evaluate, utilize, and make decisions based on health information.”[11(p70)]

Indigenous is defined as first people, aboriginal people or native people and ethnic groups who are the original settlers of a given region, in contrast to groups that have settled, occupied or colonised the area more recently.

Inhaled corticosteroids (Preventers) are widely used in the treatment of asthma to reduce bronchial inflammation and hyper-responsiveness. They reduce symptoms, improve lung function, and reduce the risk of exacerbations. Inhaled corticosteroids are most effective when used on a regular basis, either daily or twice daily. In Australian asthma guidelines, inhaled corticosteroids are termed “preventers”.[8]

Patient-centred care is defined as “an approach to the planning, delivery, and evaluation of healthcare that is grounded in mutually beneficial partnerships among healthcare providers, patients, and families.”[12(p7)]

Peak flow measurement is a quick test to measure air flowing out of the lungs. The measurement is also called the peak expiratory flow rate (PEFR) or the peak expiratory flow (PEF). Peak flow measurement is mostly done by people who have asthma.

Reliever medication (bronchodilator) is a type of medication used in the treatment of asthma to relieve symptoms when they occur. These are fast-acting bronchodilators; their effects are evident within five minutes and last for about three hours. They are used to relieve bronchoconstriction and are known in Australia as “reliever” medications.[8]

Spirometry is a measure of lung function performed using a spirometer. It establishes the presence of airflow obstruction and its reversibility in response to a bronchodilator.[8]

Wheeze can be defined as “a continuous high-pitched sound with musical quality emitting from the chest during expiration”[13(p1098)].

Written asthma action plan is an individualised set of instructions for a person with asthma (or their carer) to follow as asthma symptoms change, and which is updated from time to time by their health professional.[5]

1.7 Conclusion

Asthma is a common condition affecting children. Children are at a greater risk of poor health outcomes and have a higher likelihood of being hospitalised for the condition than adults. In particular those from lower socio-economic status groups, culturally and linguistically diverse (CALD) communities and those with limited health literacy have poorer quality of life and higher rates of hospitalisations. Diagnosing asthma in children less than 5 years of age is difficult and diagnosis should incorporate clinical history, family history and clinical response to inhaled preventer or reliever medication. Asthma medications are fundamental for good asthma control, with preventers required daily for overall lung health and reliever medications required for rapid relief of asthma symptoms. Whilst good asthma control is achievable with relatively low doses of preventer medication, adherence to asthma medications and understanding of asthma control by parents and carers is generally poor. Understanding the experiences of parents and carers in managing their children's asthma as well as the barriers faced by parents and carers can provide evidence to inform and improve policy and practice.

Evidence-based practice is vitally important for the delivery of high quality, cost effective healthcare. Quantitative evidence focussing on the effectiveness of healthcare interventions using randomised controlled trials has traditionally been viewed as "gold standard" research, however it is unable to provide the answer to some pertinent questions. Qualitative evidence plays an important role in exploring the complexities surrounding patient preferences, attitudes and beliefs towards healthcare and can expose barriers and enablers that lead to health promoting behaviours and lifestyles.

CHAPTER 2: REVIEW OF ASTHMA RELATED LITERATURE

2.1 Introduction

This chapter provides a comprehensive overview of asthma including prevalence, diagnosis and medications used for the treatment of asthma. It reviews literature around medication adherence and non-adherence and examines parents' and carers' understandings around the term "asthma control". Parents' and carers' management strategies are described including beliefs, cultural differences and impact of asthma on families. Furthermore, parents' choice of where they seek care for their child and their experiences of care received in the Emergency Department (ED) is described. Health professional management is then discussed in detail including importance of the relationship with healthcare professionals, patient-centred care and the role of asthma action plans. Finally, gaps in the literature are discussed.

2.2 What is asthma

Asthma is defined as a chronic inflammatory condition of the airways associated with episodes of wheezing, breathlessness and chest tightness.[8] The underlying process includes chronic inflammation of the airways, reversible obstruction of air flow in and out of the airways and the tendency for airways to overreact to triggers.[14] Although the underlying causes of asthma are still widely unknown, asthma can result from genetic, lifestyle and environmental factors and may be triggered by exercise, infection and exposure to allergens.[8]

2.3 Prevalence

Asthma is a serious health problem affecting as many as 334 million people worldwide.[14] Around 14% of children worldwide experience asthma symptoms and the burden is greatest for children aged 10-14 years.[14] Interestingly, a study completed between 2000 and 2003 surveyed adolescents aged 13-14 years in 97 countries and found that the prevalence of wheeze varied widely between countries and centres.[15] The highest prevalence was reported as ≥ 20% in English speaking countries of Australasia, Europe and North America and in parts of Latin America. In contrast the lowest prevalence of <5% was reported in Indian subcontinent, Asia-Pacific, Eastern Mediterranean and Northern and Eastern Europe.[15]

2.4 Societal and economic impact

Asthma inflicts an unacceptable burden on healthcare systems and on society through loss of productivity in the workplace and particularly in the case of paediatric asthma, disruption to family life.[16] A recent Deloitte Access Economics study calculated the total annual costs of asthma including indirect costs such as lost productivity as A$27.9 billion.[17]

Asthma is one of the most common chronic conditions in Australia, affecting one in nine Australians.[18] Children have a higher risk of poor outcomes, being much more likely than adults to be hospitalised for the condition.[8] Australian Institute of Health and Welfare (AIHW) National Hospital Morbidity Database (NHMD) 2014-15 reveal that overall, asthma was the principal diagnosis for 39,502 hospitalisations, representing a hospitalisation rate of 171 per 100,000 populations. In children aged 0-14 years however, the asthma hospitalisation rate was significantly higher equating to 451 per 100,000 population and for those aged 15 and over 98 per 100,000 population.[19] Furthermore, studies have shown that patients who had a recent asthma exacerbation are at increased risk of future exacerbations.[20] Asthma is more common in populations from lower socioeconomic regions (13%), compared to 10% from higher socioeconomic regions.[21] Among Aboriginal and Torres Strait Islander populations, asthma is 33% more common amongst 0-14 year olds than in the general Australian population.[22]

Uncontrolled asthma is associated with poorer quality of life, impacts on physical and psychological health and is four times more costly to treat than controlled asthma.[8] Studies show that patients with asthma are at a greater risk of depression, with one study reporting 16.3% of children with asthma also suffered anxiety or depressive disorders compared with 8.6% of children without asthma.[23] Importantly, with proper management, control of triggers and the administration of drug therapy the burden of asthma can be reduced.[8]

Whilst asthma treatments have improved considerably over the past 20 years, many patients globally have not benefitted from these improvements.[16] For some, this is due to lack of access to low dose inhaled corticosteroids, which form the foundation of care for asthma patients of all severities. Furthermore, suboptimal asthma management is widespread due to a variety of reasons including poor understanding of asthma, medication concerns, cultural factors and poor relationships with healthcare professionals. These factors need to be addressed to improve asthma management. It is imperative that evidence-based recommendations be developed, disseminated and integrated into clinical practice to reduce the burden of asthma.[24]

2.5 Diagnosis

Diagnosing asthma can be difficult in children under five and a variety of factors need to be taken into consideration when making a diagnosis. These include the history of recurrent or persistent wheeze, cough, presence of or family history of asthma and allergies, absence of physical findings suggesting an alternative diagnosis and a consistent clinical response to inhaled bronchodilator or preventer.[5] Therefore, inhalers are sometimes prescribed to inform a diagnosis and good communication between parents and clinicians is essential to ensure that parents understand that diagnosing asthma is a process and rarely results from a single acute episode.[25] Unfortunately there is no single reliable diagnostic test "gold standard" for asthma and although treatment guidelines support health professionals to diagnose and manage asthma, clinical expertise and interpretation is required in their application.[24]

Spirometry is the best lung function test for diagnosing asthma and for measuring lung function to assess control. It should be performed in children over five years to support the diagnosis of asthma.[5] Spirometry is often underused in general practice due to a lack of training in use and interpretation of results.[8, 26]

In children under five years, the use of spirometry is generally not feasible because of their inability to follow instructions and their lack of physical coordination.[9] Therefore, in this age group a diagnosis of asthma should be considered in any child with recurrent wheeze.[27] Wheeze can be defined as "a continuous high-pitched sound with musical quality emitting from the chest during expiration"[13(p1098)] and should be confirmed by a health professional.[13]

2.6 Asthma medications

Drug therapy is the foundation of asthma management and the aims for treatment are:

- To improve quality of life
- To minimise symptoms, such as breathlessness and wheezing
- To minimise the risk of adverse outcomes due to asthma, such as flare-ups.[18]

Furthermore, taking asthma medications as prescribed and achieving good asthma control is associated with reduced school or work absences, enables children to live a full and active life and keeps the lungs as healthy as possible.[8]

Medications are used to treat asthma in three ways, being to:

1. Relieve symptoms when they occur ("relievers")
2. Control the disease to minimise symptoms and exacerbations ("preventers")
3. Treat disease exacerbations[8]

Relievers are used for the rapid relief of asthma symptoms. Additionally they can be used prior to exercise as a means to prevent exercise-induced bronchoconstriction (constriction of the airways).[18]

Preventers are medications that are used every day to minimise symptoms and reduce the likelihood of exacerbations or flare-ups. The most commonly used preventers are inhaled corticosteroids and some asthma medications include both a preventer and long-acting reliever in a single inhaler.[18] Countries other than Australia refer to these medications as "controllers".[8] A short course of oral corticosteroid medications are sometimes used to treat disease exacerbations.[8]

2.7 Medication adherence

Medication adherence is a voluntary behaviour that is motivated by multiple factors including medication beliefs, concerns, personality traits and co-morbidities.[28] Psychosocial problems and depression have been associated with non-adherence to asthma treatment.[29] A study by Axelsson[30] identified the most common reason for medication non-adherence to be "no perceived need", in that the population felt well without medicine. "Insufficient routines" is the second-most common reason for non-adherence to medication.[30]

Medication adherence can be categorised into two types of behaviours: intentional and unintentional. Intentional being where non-adherence is a result of a conscious decision and can be related to concerns or lack of trust in medications.[30] Conversely, unintentional relates to non-adherence due to lack of awareness, poor inhaler technique or simply forgetting.[30]

Systematic review evidence shows that inhaled corticosteroids are highly effective in reducing symptoms and preventing asthma exacerbations and for most people only low doses are required.[8] However, regardless of availability of effective therapies for asthma, asthma control is often suboptimal.[31] Poor adherence to preventer medication (anti-inflammatory medication) increases mortality risk with people tending to over-rely on their reliever medication (bronchodilators).[5] Whilst non-adherence is a complex issue, the importance of parents and carers understanding what good asthma control is and how to achieve it should not be under-estimated.

2.8 Asthma control

Asthma control is defined as the response to treatment, in terms of whether asthma exacerbations are kept to a minimum.[9] Well managed asthma or good asthma control is categorised by very mild or no symptoms, no exacerbations, no ED visits, no limitation to activities, no sleep loss because of asthma, minimal use of reliever medication (less than two times per week) and few side-effects from asthma medication.[14] Parents and carers, however, tend to underestimate the severity of their child's asthma and overestimate asthma control. For example, parents and carers of children or adolescents with asthma often perceive multiple symptoms (e.g. wheezing, coughing and chest tightness), lifestyle restriction and reliance on reliever medication as good control.[32] Parents and carers underestimation of the severity of their child's asthma is a major barrier to successful management.[32] Developing a deeper understanding of parents' and carers' concerns, understanding of asthma and the purpose of medications prescribed to their children may assist in overcoming poor adherence.

2.9 Parent and carer management

Parents and carers play an important role in management of their child's asthma.[33] Research highlights that before parents and carers can make an informed health decision for their child they need timely, consistent, up-to-date, individually tailored evidence-based information delivered from trustworthy sources; they need to talk with and share information and experiences with others in the same situation; and they need to be an active participant in the decision-making process.[33]

Whilst there is currently no cure for asthma, effective asthma management strategies are available to control the disease and prevent worsening asthma symptoms. Unfortunately, uptake of these strategies is not optimal.[34] In order to reduce the impact of asthma on people and their communities, a better understanding of reasons behind non-adherence is required.

Families experience multiple challenges in managing a child with asthma. Although healthcare professionals play an important role in asthma care and are often the first point of call for the treatment of asthma, much of the burden of treatment lies with parents and primary caregivers.[35]

Parents and carers often encounter difficulties attaining an asthma diagnosis, particularly in young children.[36] In the pre-diagnosis period, a qualitative study has shown that caregivers often experience fear and feelings of uncertainty around managing continuing symptoms with no definitive diagnosis and as a result many make frequent visits to the emergency department.[36]

Further studies examining parental experiences found that parents and carers felt they learnt to care for their child with asthma through "trial and error", often feeling confused and uneducated regarding their child's medication.[37] Moreover, parents and carers decisions and actions regarding asthma management were often based on their subjective assessment,[38] yet some expressed difficulty recognising asthma symptoms, causing uncertainty about when to respond to worsening asthma.[39, 40] Asthma management focused on treating acute episodes, usually with short-acting beta-agonists (reliever medications) rather than prevention of future attacks with inhaled steroids (preventer medications).[38, 39, 41] Parents and carers managed asthma using strategies to achieve a "balance" in order to minimise and "live with" the effects of asthma.[38] This involved adapting professional advice and using personal judgement based on experimentation, past asthma experiences and family and lifestyle factors.[38, 39]

Literature highlights that caring for a child with asthma is stressful. A 2013 systematic review found that increased parenting stress is associated with poor psychological adjustment in both caregivers and children and this may contribute to poorer child health outcomes.[42] Furthermore, it was found that parents and carers who had more caregiving responsibilities were often overwhelmed by treatment demands but encouraging children and parents and carers to manage treatment demands together showed a decrease in parenting stress and increased adherence.[42]

Research reveals that even during adolescence, parents and carers play a supportive role, mainly being involved with reminding their child to take medication and often being responsible for filling prescriptions and joining them at doctors' appointments.[43] A 2015 systematic review reveals that medication management decisions are primarily parent and carer driven with preventer medications sometimes reduced in the absence of observed symptoms.[44] Support from family however, has been shown to reduce adolescents' negative attitudes toward asthma medication and to positively influence adherence.[45]

2.7.1 Beliefs

Patient's beliefs have a "powerful impact on patient adherence" and are thus important to identify.[46] The literature highlights that people who view their disease as unpredictable do not see the need to adhere to prescribed medicine.[30] Similarly, concerns surrounding side-effects or fear of becoming dependent on medication influences adherence behaviour.[47] In contrast, those who believe in the effectiveness of medication are more likely to adhere to it.[47]

2.7.2 Culturally and Linguistically Diverse (CALD) factors

Differing cultures have varying health belief systems that describe causes of illness, symptoms, treatment, possible cures and consequences of medical treatment.

A study of Mexican mothers discovered beliefs around asthma being a "cold" disease based on the notion of humoral balance and thus many treatments are "hot" in nature e.g. teas and keeping children warm.[48] Puerto Rican families believe in the importance of unclogging air passages to improve air intake and this is done using herbal expectorants and humidifiers.[48]

Whilst cultural health practices and beliefs are critical to medication adherence, they are frequently overlooked during the asthma visit.[49] Understanding how the caregiver perceives asthma and their beliefs about medications can lead to effective communication and share decision-making regarding treatment, whilst respecting cultural sensitivity.

2.7.3 The impact of asthma on families

Children's health and development occurs within multiple contexts, including the family, school, local neighbourhood and community environments. Poorly controlled asthma reduces young people's participation in school, childcare, sports and social events and, similarly, affects family members and caregivers. Sleep is disturbed due to recurrent asthma symptoms causing daytime fatigue and reduced activity levels and the need to take days off school and childcare due to asthma symptoms.[23]

2.7.4 Where parents seek care for their child

Parents and carers attitudes towards available asthma services influences their decisions about which healthcare services to use and when. Some choose to go straight to hospital when their child's asthma flares up rather than first contacting their GP.[50] Past experience of using these services plays a role in their decisions, for example if they believe that their general practitioner did not respond appropriately to worsening asthma or if their asthma could only be relieved in the hospital, then going to the GP first was further delaying treatment.[37, 51]

2.7.5 Discharge instructions

A 2017 systematic review investigating parental management of discharge instructions following ED admission revealed that many parents had difficulty following instructions received when their child was discharged from the hospital or ED setting.[52] Difficulties related to areas such as medication dosing errors, poor medication adherence, and poor follow-up appointment attendance.[52] People from low-income groups and those with low-health literacy levels had self-reported medication adherence errors as high as 40% with almost one-third of low income families failing to pick up their child's prescriptions.[52]

Children whose parents have low health literacy levels tend to have worse health outcomes.[53] Providing families with both written and verbal instructions including demonstrating medications, teach-back strategies and pictorial instruction sheets has been shown to decrease error rates and assist families to navigate complex instructions.[54] Furthermore, tailored education sessions[55] and additional time spent with families has been shown to improve their understanding of instructions.[56]

2.7.8 Health literacy

Health literacy is defined as an “individual’s capacity to access, understand, communicate, evaluate, utilize, and make decisions based on health information.”[11(p70)] The ability to obtain and apply asthma knowledge is a key factor for good asthma management.[57] Research reveals that limited health literacy is associated with a lower quality of life, poor physical functionality and increased emergency visits.[58] The provision of asthma education however is associated with effective symptom control, improved disease self-management, better asthma control and improved medication adherence.[59] Importantly individuals within lower socioeconomic status groups and ethnic minorities have less well controlled asthma and poor adherence due to low levels of understanding of health related information, low health literacy and language barriers.[60] Furthermore, complex treatment regimens and lack of understanding of treatment benefits contributes to a lack of trust between patient and healthcare provider and is a barrier to adherence.

2.7.9 Existing systematic review evidence

Several systematic reviews on similar topics have been undertaken, with one focusing on barriers and facilitators to asthma management in South Asian children,[10] two focusing on asthma action plan usage,[61, 62] two on medication adherence[35, 45] one on parental stress,[42] one on parent and child illness representations,[44] and one on decision support needs of parents.[33]

A qualitative systematic review by Santer[35] examining non-adherence in paediatric long-term medical conditions included 6 papers on asthma and revealed treatment non-adherence to be a complex issue which caregivers have to balance along with everyday needs of the child and family. It identified the need for health professionals to simplify treatment regimens and provide support for parents to minimise impact on family life and overcome non-adherence.[35]

A further review in 2016 by Ahmad,[45] examined enabling and hindering factors influencing adherence to asthma treatment among adolescents. Furthermore, it explored the role of caregivers and healthcare providers in supporting adolescents to manage and live with asthma. Factors identified as influencing adherence to asthma treatment among adolescents include: behaviour, belief, self-management, health literacy, role of health provider, assessment of adherence, role of caregiver, role of peers and national asthma guidelines.[45] The role of the caregiver regarding adherence to asthma treatment among adolescents needs to be explored with further research.

A 2014 systematic review by Lakhanpaul[10] included 14 quantitative and 1 qualitative paper examining barriers and facilitators to improving asthma management in South Asian children. Barriers identified included parent and professional knowledge and beliefs, health service utilization including over-reliance on ED use, language barriers and the impact of prejudice and stigmatisation.[10] Poor communication and low English proficiency was identified as a barrier and the importance of cultural beliefs and concerns around food and use of complementary therapies highlighted. Healthcare professionals should take a holistic view of health and see children as existing within their family, social and cultural setting. This research highlights the need for cultural competence as well as awareness of and willingness to discuss barriers that impact asthma management.[10]

A 2012, cross-study synthesis of 19 qualitative studies and 14 quantitative studies by Ring[62] and a 2011 systematic review of qualitative literature by Ring[61] examined asthma action plan usage and existing barriers and enablers. Research reveals that some carers view asthma action plans to be irrelevant, impractical and useful only for those newly diagnosed with asthma and to assist teachers with asthma management at school. There is evidence of a mismatch between what carers want or need from their asthma action plan and what is presently provided by professionals. Plans need to be tailored to needs of carers and address the broader issues of living with a long-term condition. They need to be jointly negotiated, informed by carers and reviewed and refined over time in light of combined experience. Other barriers included differences in language used by carers and professionals specifically around “asthma management” and “asthma control”.[61]

A 2013 systematic review by Cousino[42] examined parenting stress among caregivers of children with asthma, cancer, cystic fibrosis, diabetes, epilepsy, arthritis and sickle cell disease. This review included both quantitative and qualitative analysis and found that general and disease related parental stress to be associated with greater parental responsibility for treatment management and/or less child self-care behaviours. The review highlights the importance of a teamwork approach to disease management and encouraging parents and children to manage the condition together in order to decrease parental stress and increase adherence.[42]

A 2008 systematic review of the decision support needs of parents making child health decisions by Jackson,[33] highlights the need for information that is timely, consistent, up-to-date, evidence-based informed, tailored to the individual and delivered in a variety of formats from trustworthy sources. Furthermore, the need to talk with others in similar situations and to be able to share information, experience and ideas and the need to be in control of one’s preferred level of involvement in the decision-making process.[33]

Finally, a 2016 systematic review by Sonney,[44] investigated parent and child asthma illness representations and their impact on parent-child shared asthma management. Symptoms and controllability appear to have the most impact on parental asthma management practices. Parents favour symptomatic or intermittent asthma management and commonly express concerns over daily controller medication use.[44] Furthermore, parents primarily rely on their own objective observations rather than the child's report of symptoms.[44]

The findings of the systematic reviews mentioned above provide an important knowledge base for managing asthma in children. The findings from this systematic review, however contribute additional information examining the difficulties parents and carers face in obtaining an initial diagnosis of asthma and highlighting the support requirements from healthcare professionals, family members, schools and other education staff. This review provides a comprehensive understanding of parents and carers overall experiences of managing their child's asthma and the barriers that prevent and enablers that facilitate good management. The findings of this review will build an evidence base to inform effective and feasible interventions to support parents to better manage children's asthma.

2.10 Health professional management

Asthma care is provided by a range of health professionals including GP's, primary healthcare nurses, asthma and respiratory educators, Aboriginal health workers, pharmacists, ambulance services, hospital and emergency department staff and specialists.[24] GP's play a pivotal role in managing asthma in the community. Their role includes diagnosis, assessment, prescribing medications, education, regular review and management of acute exacerbations.[8] Healthcare professionals view asthma as a chronic condition requiring long-term prevention. This is in contrast to the views of patients and carers, who generally view asthma as an acute intermittent condition requiring episodic treatment.[61] Research shows that healthcare professionals see themselves as the asthma expert and "allow" patients "to take responsibility" for their condition.[63] In contrast, patients and carers see themselves as capable of asthma self-management and experts in their child's condition.[61] Research reveals that the provider of asthma care can influence asthma outcomes. An American survey[64] found that children under the care of an asthma specialist were significantly more likely to report current use of anti-inflammatory medication than those managed by other clinicians. Furthermore, the study showed that when asthma specialists are involved in the child's care, the care is more likely to be in line with guidelines and use of controller medication is much higher than when care is provided by a generalist. Importantly, research shows that children with frequent emergency department visits for asthma are more likely to be managed by a primary care physician than an asthma specialist.[65]

The patient-physician relationship is another important factor.[66] The ability of the physician to explain asthma management, willingness to spend time with the patient and encourage patient participation in treatment decisions is associated with higher adherence rates of anti-inflammatory (preventer) medication.[66] The importance of the healthcare professional having good communication skills was highlighted in the research. Parents and carers expect to be listened to, feel respected and have their own knowledge and experience of asthma recognized by healthcare professionals.[37, 39, 41] Furthermore, regular routine review by physicians is an important component of asthma care and has been shown to reduce school/work absences, reduce exacerbations, improve adherence to anti-inflammatory medication and improve symptom control.[67-69]

2.10.1 Patient centred care

Research emphasizes the importance of patient-centred care. Patient-centred care is defined as "an approach to the planning, delivery, and evaluation of healthcare that is grounded in mutually beneficial partnerships among healthcare providers, patients, and families."[12]

Patient-centred care comprises healthcare that is respectful of, and responsive to, the preferences, needs and values of patients and consumers and includes respect, emotional support, physical comfort, information and communication, continuity and transition, care coordination, involvement of family and carers, and access to care.[12] Research highlights that when health professionals, managers, patients, families and carers work in partnership, the quality and safety of healthcare rises, costs decrease, provider satisfaction increases and the patient care experience improves.[12]

Concepts commonly included in definitions of patient-centred care include:

- Informing and involving patients
- Eliciting and respecting patient preferences
- Engaging patients in the care process
- Treating patients with dignity
- Designing care processes to suit patient needs, not providers
- Ready access to health information
- Continuity of care[70]

Patient-centred care is particularly important among disadvantaged and vulnerable populations and those from CALD backgrounds who may find communication and collaboration with health professionals difficult.[12] Patient-centred care can involve carers, friends, family, spiritual and pastoral advisers, or the broader community to potentially address the inequities these population groups experience and achieve better health outcomes.[12]

Similarly "family-centred care" relates to children's healthcare encompassing concepts of parental participation, partnership and collaboration between the healthcare team and parents in decision-making, family-friendly environments that normalise family functioning within the healthcare setting as much as possible, and care of other family members.[71]

Changing the expectations of patients and consumers, and the dynamics of relationships between health professionals, patients, families and carers can have significant implications for education and professional development needs of healthcare professionals.[72] In order to promote healthcare delivery in which power and decision making are shared and relationships are more equal, healthcare professionals will need to be equipped with skills, further education and training in principles and application of patient-centred care. Thus, patient-centred care should be a component of undergraduate and postgraduate education programs for all health professionals.[12]

Whilst there is increasing policy emphasis on patient-centred care, many organisations face difficulties actively changing the way care is delivered, and many struggle to involve patients, families, carers and consumers and to learn from their experiences.[73]

2.10.2 Asthma action plans

An asthma action plan is a set of instructions provided to a patient with asthma for use in recognising and managing deteriorating asthma.[74] While written action plans are standard in the treatment and management of asthma, considerable variability exists in the content and format among plans. An individualised written action plan is tailored to the patient's individual asthma severity and treatment needs.[74] It informs the patient how and when to modify medications and when to seek medical attention in response to worsening asthma.[74] Other plans are non-specific or generic in nature, providing general information about the management of worsening asthma.[74]

The purpose of a written asthma action plan is to facilitate early intervention and prevent or reduce the severity of acute asthma episodes.[8] Research reveals ownership of a written asthma action plan to be associated with reduced mortality due to asthma.[75] Furthermore, provision of a written asthma action plan, self-monitoring and routine review reduces the need for additional medication, urgent visits to doctors and hospitalisations and has shown a small improvement in lung function.[67]

Despite the promotion of written asthma action plans in public education campaigns[76] and their inclusion as a part of national guidelines for the management of asthma in Australia since 1989, only 28% of Australians possess a written asthma action plan.[77] Similarly worldwide, asthma action plan ownership is encouraged but no data on their uptake could be located.[16]

GP's are often the first point of call for the management of asthma in children. In healthcare today, many GP's are time poor as they have the responsibility for seeing a high volume of patients. Unfortunately, for this reason they do not have time to formulate comprehensive asthma treatment plans.[9]

Furthermore, systematic review evidence reveals that some professionals overlooked action plans finding them to be "impractical", or "unsuitable"[78] for much of the population, and only useful for those with "serious" asthma[41] and children in the care of schools and others.[79] Parents and carers expressed similar views to those of healthcare professionals with some choosing to adapt the plan provided by their healthcare professional to suit their needs or develop their own plan based on their personal asthma knowledge.[79]

2.11 Research gaps

No research was identified investigating experiences of Indigenous Australians parents. In light of the overrepresentation of asthma in the Aboriginal and Torres Strait Islander population, with the condition being almost twice as high as for the non-Indigenous population[8], this is an area where additional research is required. Furthermore, most of the research undertaken in all populations is from the perspective of the mother and it is possible that fathers' experiences could be vastly different and additional research is required.

2.12 Conclusion

Parents experience multiple challenges when managing their children's asthma. They experience challenges associated with attaining a diagnosis of asthma and without a definitive diagnosis are unsure how to manage their ongoing symptoms. They are confused and uneducated about asthma and express feelings of fear, anxiety and uncertainty, managing acute symptoms usually with reliever medication alone and as a result experience frequent hospitalisations. Furthermore, research shows the difficulties parents experience managing instructions on discharge from the ED and this highlights the importance of comprehensive asthma education at this time to avoid repeated hospitalisations. Parents existing beliefs about asthma and cultural factors influence their treatment decisions and cultural sensitivity and awareness of their beliefs have the potential to influence management. Asthma not only impacts the child with school absences, reduced activity and day time fatigue, it also has a considerable impact on parents due to lack of sleep, disruptions to family life and parents' inability to attend work.

Health professionals play an important role in management of asthma. The patient/physician relationship is a vitally important factor affecting the ability of parents and carers to manage their child's asthma effectively. Patient-centred care has been shown to improve the quality and safety of healthcare, decrease costs and improve both provider and patient care experience. Whilst asthma action plan ownership is associated with reductions in hospitalisations and improvements in lung function, only 28% of people in Australia own an asthma action plan. Specifically tailoring these plans to the suit the needs of parents and carers is one way to ensure they meet their needs and reduce the burden of managing asthma.

CHAPTER 3: METHODOLOGY AND METHODS

3.1 Introduction

This chapter details the methodological approach used in this study and discusses how the JBI meta-aggregative methodology fits within the broader context. Additionally this chapter will explain the methodological basis for the research and provide an overview of the methods used to ensure transparency of the research process.

3.2 Methodological approach

The aim of a systematic review is to identify, critically evaluate and synthesise the best available evidence on the specific topic to inform decision making regarding clinical practice, education, policy, further research and to improve patient care. Systematic reviews are particularly useful in evidence-based practice as they provide the best available evidence in synthesised form. Evidence-based practice refers to the use of the best up-to-date information to aid decision-making regarding patient care.[2]

The systematic review presented in this thesis is based upon the methodology of synthesis of qualitative data, known as meta-aggregation developed by the Joanna Briggs Institute (JBI). The JBI Reviewer's Manual 2017 Edition provides detailed information on conducting a qualitative systematic review.[4]

Qualitative research plays a significant role in understanding how individuals and communities perceive health, manage their own health and make decisions related to health service usage. It can assist in understanding the culture of communities in relation to implementing changes and overcoming barriers.

In the context of healthcare, qualitative research:

"…seeks to understand and interpret personal experiences, behaviours, interactions, and social contexts to explain the phenomena of interest, such as the attitudes, beliefs, and perspectives of patients and clinicians; the interpersonal nature of caregiver and patient relationships; the illness experience; or the impact of human suffering."[3(p311)]

A meta-aggregative approach to the synthesis of qualitative evidence was used in this review. This approach is aligned with the philosophy of pragmatism. The basis of pragmatism is that the meaning and truth of thoughts and ideas are determined by criteria of practical usefulness.[80] Similarly, meta-aggregation is aligned with pragmatism in as much as it helps to understand human experience, beliefs and ideas and form practical and useful solutions to problems.[80]

Meta-aggregation takes an inclusive approach to searching and selecting studies and is based on the development of a rigorous protocol. It emphasizes importance of methodological quality of the included studies in the final synthesis and reduces the risk of bias by eliminating studies with poor methodological quality.[80] The JBI approach to meta-aggregation allows combining results of qualitative studies in a reliable manner.[2] Findings are combined into categories and the categories are then synthesised to form synthesised statements. These synthesised statements then form “lines of action” to inform decision-making at clinical or policy level.[80] JBI’s meta-aggregation uses methods that are specifically designed to address the needs of policy makers and practitioners in healthcare.

The ConQual approach[1] was applied to rate the quality and confidence of each of the synthesised findings produced in this review. This approach involves ranking synthesised findings based on their credibility and dependability. Each synthesised statement is initially assumed to be of high quality and then downgraded for any credibility and/or dependability rating less than high.

3.3 Methods

A qualitative systematic review was conducted according to the methodology of the JBI using a meta-aggregative approach to the synthesis of qualitative evidence.[81] The recommended JBI approach to critical appraisal, study selection, data extraction and data synthesis was used.[81] This review was conducted according to a priori protocol.[82] The protocol was registered with PROSPERO with registration number: CRD42017059360.

3.4 Review question

The overarching objective of the systematic review was to enhance understanding of the lived experiences of parents and carers in caring for a child with asthma and the management of the condition in any setting.

The primary question addressed was: What are the lived experiences of parents and carers when caring for a child with asthma and managing the condition?

Secondary questions to be addressed included: i) What barriers exist for parents and carers in managing their child’s asthma? ii) What enablers exist for parents and carers in managing their child’s asthma?

3.5 Inclusion criteria

3.5.1 Participants

The review considered studies that included parents and carers who had been caring for a child 0-18 years with asthma, wheeze or bronchiolitis.

Asthma was defined as a common chronic condition of the airways characterised by episodes of wheezing, shortness of breath, coughing and chest tightness due to widespread narrowing of the airways.[8] Diagnosing asthma with certainty in a child under five is often difficult as they are unable to perform lung tests to acceptable standards.[5] Often children receive a diagnosis of "asthma", "wheezing illness" or alternatively viral bronchiolitis.[8] For this reason studies that included parents or carers caring for children with wheeze or bronchiolitis were also included.

Parents and carers were defined as individuals with parental responsibility providing unpaid asthma related assistance and care for a child or children 0-18 years. Caregivers are defined "as an individual who provides ongoing care and assistance, without pay, for family members or friends in need of support due to physical, cognitive or mental health conditions."[83(p1)] The term is sometimes qualified as family caregiver to differentiate it from providers or healthcare professionals who provide care.[83] For the purpose of this systematic review, where the term "caregiver" is used, it refers to family caregivers. Parents and carers of children with other long-term chronic diseases such as diabetes and cystic fibrosis or developmental/mental health issues such as opposition defiance disorder (ODD), attention deficit hyperactivity disorder (ADHD) in addition to asthma were excluded as their experiences could be entirely different. Other acute respiratory infections such as croup, pneumonia, influenza and pertussis (whooping cough) were excluded as the focus of this review was primarily the experiences of parents and carers caring for a child with asthma and the management of the condition.

3.5.2 Phenomena of interest

The reviewed examined the experiences of parents and carers when caring for a child with asthma, wheeze or bronchiolitis and the management of the condition. Barriers and enablers to the provision of asthma care by parents and carers were also examined.

A barrier was defined as a factor or factors that impede the achievement and maintenance of asthma control and could include (but was not limited to) factors such as health beliefs, professional barriers, language and communication, and issues around diagnosis and treatment.

An enabler was defined as a person or thing that enables the achievement and maintenance of asthma control; however, this may have been defined differently for each study so to be more inclusive a rigid definition was not provided.

3.5.3 Context

The context for the review focused on all settings, including (but not limited to) the home or community setting, primary healthcare setting as well as the acute setting. An international perspective was taken.

3.5.4 Types of studies

The review considered qualitative studies that focused on the experiences of parents and carers when caring for a child aged 0-18 years with asthma and managing their condition and included research designs such as phenomenology, grounded theory, ethnography, action research and feminist research.

3.6 Search strategy

A preliminary search for previous systematic reviews on the topic was conducted using PubMed, CINAHL, Embase, PsycINFO, Web of Science, Google Scholar, JBI Database of Systematic Reviews and Implementation Reports and Cochrane Library.

A three-step search strategy was utilized in the review. An initial search of PubMed, CINAHL, Embase, PsycINFO, Web of Science and hand searching of World Health Organisation International Clinical Trials registry, the Australian Institute of Health and Welfare, World Health Organisation, National Asthma Council, Asthma Australia, Australasian Society of Clinical Immunology and Allergy, Global Initiative for Asthma and Google Scholar for both published and unpublished studies was conducted in June 2017 and updated in December 2017. Following this, a second limited search of MEDLINE using PubMed and CINAHL was undertaken followed by analysis of the text words contained in the title and abstract and the index terms used to describe an article. Thirdly, a search using all identified keywords and index terms was then undertaken across all included databases. A search strategy (logic grid) was prepared for the initial PubMed search and this was then adapted for each additional database (see Appendix I). The reference lists of all articles identified for full text review was then searched for additional studies. Studies published in English between the periods of January 1972 and December 2017 were considered for inclusion in the review. This timeframe was chosen due to 1972 being the year inhaled corticosteroids were introduced as first line treatment to control asthma.[9]

The databases searched included: PubMed, Embase, CINAHL, PsycINFO and Web of Science.

3.7 Study selection

Following the search, all identified citations were collated and uploaded into Endnote X7.8 (Clarivate Analytics, PA USA) and duplicates removed. Titles and abstracts were screened by two independent reviewers for assessment against the pre-specified inclusion criteria for the review. Potentially relevant studies were retrieved in full and their citation details imported into the JBI System for the Unified Management, Assessment and Review of Information (JBI SUMARI) 2017 (The Joanna Briggs Institute, Adelaide, Australia). Full text studies that did not meet the inclusion criteria were excluded and reasons for their exclusion are provided in Appendix II. Any disagreements that arose between reviewers were resolved through discussion, or with a third reviewer.

3.8 Assessment of methodological quality

Articles selected for retrieval were assessed by two independent reviewers for methodological validity prior to inclusion in the review. The standardised critical appraisal instrument from JBI SUMARI was used to appraise the methodological quality of the articles.[81] The critical appraisal process comprised analysing each individual paper and allocating a response of Yes, No or Unclear to each of the ten questions on the JBI critical appraisal tool. The reviewers agreed prior to critical appraisal that studies must meet certain criteria for inclusion. Of the ten criteria it was essential that the study met criteria two “congruity between the research methodology and the research question or objectives”, criteria three “congruity between the research methodology and the methods used to collect the data”, criteria four “congruity between the research methodology and the representation and analysis of the data”, criteria five “congruity between the research methodology and the interpretation of the results”, criteria eight “participants voices are adequately represented”, criteria nine “ethical approval of informed consent” and criteria ten “conclusions drawn flow from analysis or interpretation of the data”. Any disagreements that arose between reviewers were resolved through discussion, therefore a third reviewer was not required.

3.9 Data extraction

Data was extracted from included studies using the standardised data extraction tool from JBI SUMARI.[81] Data extraction occurred in two phases. In phase one, details about study design, participants, principle experience(s) explored, duration of diagnosis and description of main findings were extracted onto the standardised JBI data extraction template. In phase two data was extracted from the results and discussion sections of each study with an accompanying direct quotation. Data were initially extracted at the theme level as identified by subheadings in the papers, however, after repeatedly reading the text of some papers it was evident that important subthemes existed under each theme, and in papers where this was apparent, data were extracted at a sub-theme level. This was deemed necessary in order to capture a comprehensive understanding of all aspects of parent and carer experiences. Where data were presented in table format it was extracted directly from the table with the accompanying direct quotation.

Data extraction was completed by one reviewer and a random sample of included papers reviewed by a secondary reviewer to provide some quality reassurance regarding the adequacy of data extraction. Any disagreements were resolved by consensus or a third party if consensus could not be reached.

Findings were identified by repeatedly reading the results sections of each paper. A finding in this review was considered to be a verbatim extract of the authors analytic interpretation accompanied by either a direct quotation or participant voice, fieldwork observation or other data.[81] Additionally, experiences reported by participants in original studies, including the authors' interpretations of those experiences, were extracted verbatim and became the data for the synthesis. The reviewer went back and forth between the original papers, the extracted data and accompanying illustrations forming the basis for concepts and themes during the analysis. .

All findings were assigned one of three levels of credibility according to the following JBI criteria:

- Unequivocal (U) - Assigned if the findings were accompanied by an illustration that is beyond reasonable doubt and; and therefore, not open to challenge. These findings were supported by illustrations in the form of direct quotes from participants that supported the finding.
- Credible (C) - Assigned to those findings that were plausible and could be logically inferred from the data. These findings were supported by a direct quote from the participant.
- Unsupported (U) - Assigned where the finding was not supported by any identifiable illustration.

3.10 Data synthesis

Data synthesis was conducted using the meta-aggregative approach. Data synthesis comprised of three steps. Firstly, each finding was printed out with corresponding illustration and these were grouped according to meaning and content. This method provided a basis for some initial categorisation of themes. Qualitative research findings were then pooled using JBI SUMARI.[7] This involved the aggregation or synthesis of findings to generate a set of statements that represent that aggregation, through assembling the findings rated according to their credibility and categorising these findings on the basis of similarity in meaning. Furthermore, due to the large number of findings, an Excel spreadsheet was used to enter and group findings with corresponding illustration. Second, the findings were then read multiple times by the primary author who developed a further subset of categories that were then discussed and agreed on with secondary authors. These categories were then subjected to meta-synthesis to produce a single comprehensive set of synthesised findings that could be used as a basis for evidence-based practice. Again, this was accomplished through discussion with secondary authors. Third, conceptual links among subthemes and themes were identified and analysed. Thematic analysis leads to a more interpretive phase in order to understand how the themes identified may represent barriers and facilitators faced by parents and carers. Main themes were summarised and conclusions drawn, about parent and carer experiences of asthma, as reported in the papers.

3.11 Assessing the certainty of the evidence

The ConQual approach[1] was applied to rate the quality and confidence of each synthesised finding produced in this review. Qualitative papers were initially ranked as high and then moved up or down according to their dependability and credibility score. Dependability was established based on the following specific questions from the critical appraisal scores:

1. Is there congruity between the research methodology and the research question or objectives?
2. Is there congruity between the research methodology and the methods used to collect data?
3. Is there congruity between the research methodology and the representation and analysis of data?
4. Is there a statement locating the researcher culturally or theoretically?
5. Is the influence of the researcher on the research, and vice-versa, addressed?

4-5 “yes” responses means the paper remains unchanged as high ranking, 2-3 “yes” responses means the paper moves down 1 level and 0-1 “yes” responses means the paper moves down 2 levels.

Each synthesised finding is assigned a level of credibility by cross checking how many findings of each type are included in the categories associated with the synthesised finding. Unequivocal (U) relates to evidence beyond reasonable doubt, directly reported and not open to challenge, Credible (C) findings that are plausible in light of data and can logically be inferred from the data and Not Supported (NS) not supported by the data.

A ConQual score was assigned to each synthesised finding and is presented in the Summary of findings table (Appendix VII). Each synthesised statement is initially assumed to be of high quality and then downgraded for any credibility and/or dependability rating less than high. All unequivocal findings remain unchanged, mix of unequivocal/credible findings are downgraded one (-1) and credible/unsupported findings are downgraded three (-3) and not supported findings are downgraded four (-4).

3.12 Conclusion

Using the JBI meta-aggregative approach to the synthesis of qualitative literature ensures that the final synthesised findings can be used as a basis to make recommendations to inform policy or improve healthcare practice. Furthermore, the ConQual approach allows users of qualitative systematic reviews to be confident in the evidence produced and to use the results of the review to guide their decision making.

CHAPTER 4: RESULTS

4.1 Introduction

This chapter is comprised of two sections. Section 4.2 describes the search results and study selection process, the methodological quality of included studies and their key characteristics. Section 4.3 presents the results from the analysis and synthesis of findings from included studies on parents' and carers' experiences of managing asthma in children.

4.2 DESCRIPTION OF STUDIES

4.2.1 Search and study selection

As shown in Figure 1 (PRISMA [Preferred Reporting Items for Systematic Reviews and Meta-Analyses] flow diagram), 6,694 articles were identified based on a detailed search strategy. An additional five articles were identified through hand searching. Articles were imported from databases into bibliographic software and 780 duplicate titles were removed. A total of 5,919 articles were screened by title and abstract and 5,722 records excluded as not meeting the inclusion criteria; 197 papers were selected for retrieval and after reviewing the full text 101 were excluded as not meeting the inclusion criteria. The remaining 96 articles were critically appraised and 19 excluded after critical appraisal. Studies were excluded if they contained individuals with asthma aged over 18 years or if they included a range of ages which extended to over 18 years and data was not specific to individual ages. Studies reporting structured questionnaires or surveys as the sole method for data collection or other quantitative methodologies were ineligible. Furthermore, studies that did not elicit data directly from parents and unpaid family caregivers were also excluded. Parents and carers of children with other long-term chronic diseases such as diabetes and cystic fibrosis or developmental/mental health issues such as oppositional defiance disorder (ODD), attention deficit hyperactivity disorder (ADHD) in addition to asthma were excluded as their experiences could be entirely different. Finally, other acute respiratory infections such as croup, pneumonia, influenza and pertussis (whooping cough) were excluded as the focus of this review was primarily the experiences of parents and carers caring for a child with asthma. Following critical appraisal 19 articles were excluded for reasons including poor methodological quality, uncertainty over collection, analysis and interpretation of data and results, no clear question or objective stated, lack of parent voice and lack of a statement of ethics or consent. A total of 77 articles were included in the systematic review.

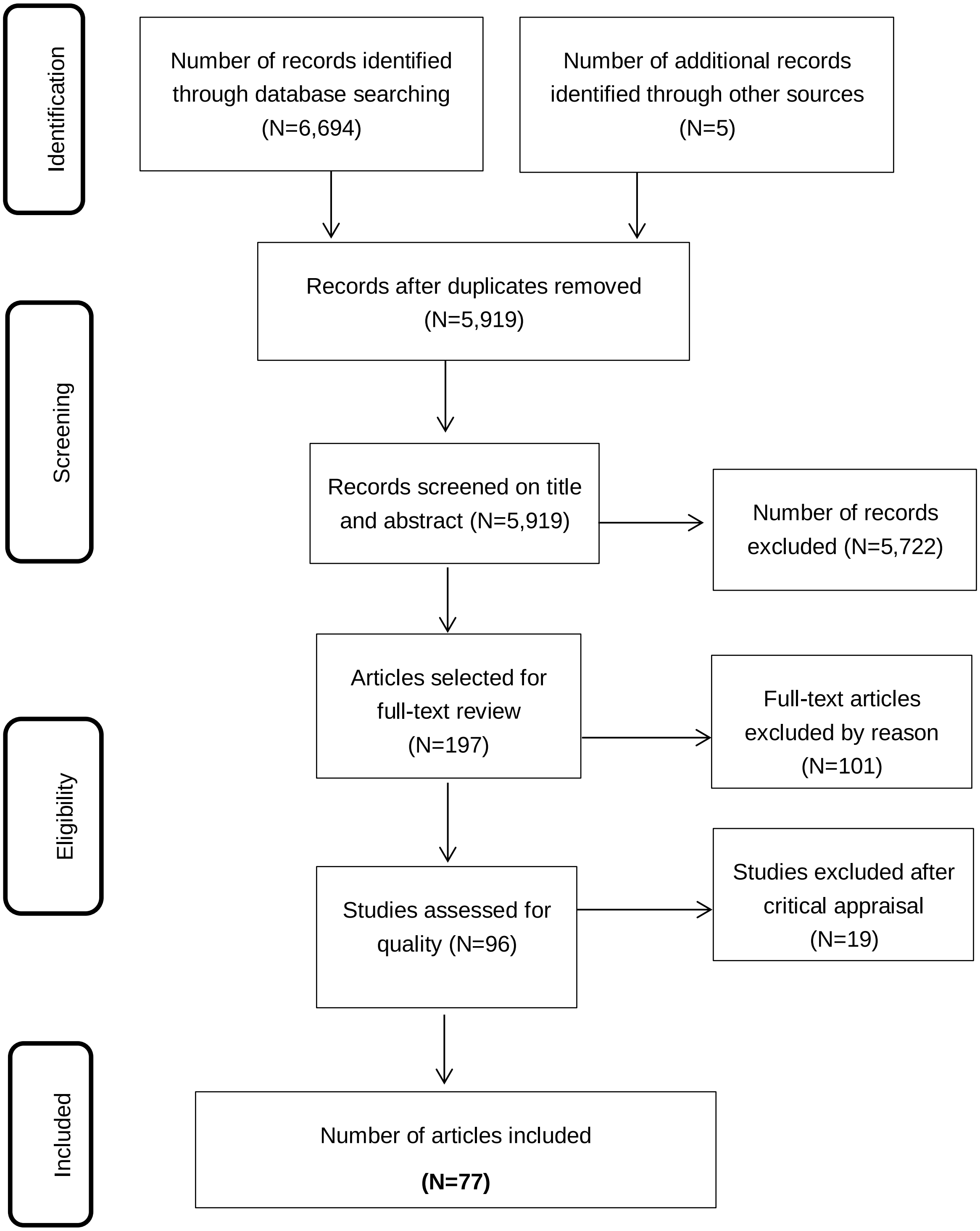

Figure 1: PRISMA flow diagram for retrieved studies, excluded and included studies[84]

4.2.2 Methodological quality

Overall, the methodological quality of the studies included was sound. Criteria 1, 6 and 7 were not consistently addressed across the included studies. Criteria 1 related to congruity between the stated philosophical perspective and the research methodology. Criteria 6 and 7 relate to locating the researcher culturally or theoretically and the influence of the researcher on the research. In order for the qualitative researcher to thoroughly explore his or her purpose, role and potential biases they must locate the study in time, space, and culture, and also locate her or himself in the study. Therefore, researcher bias is a potential concern and could impact the results.

Table 1: Assessment of methodological quality

Citation	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Abdullah et al[85]	U	Y	Y	Y	Y	U	U	Y	Y	Y
Archibald et al[86]	Y	Y	Y	Y	Y	U	U	Y	Y	Y
Arcoleo et al[48]	Y	Y	Y	Y	Y	U	U	Y	Y	Y
Arroyo and Becker[87]	U	Y	Y	Y	Y	N	N	Y	Y	Y
Barrett et al[88]	Y	Y	Y	Y	Y	U	U	Y	Y	Y
Barton et al[89]	Y	Y	Y	Y	Y	N	U	Y	Y	Y
Bellin et al[50]	Y	Y	Y	Y	Y	N	U	Y	Y	Y
Berg et al[90]	Y	Y	Y	Y	Y	U	U	Y	Y	Y
Bokhour et al[91]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Borhani et al[92]	U	Y	Y	Y	U	N	N	Y	Y	Y
Boyle et al[93]	U	Y	Y	Y	Y	N	N	Y	U	Y
Callery et al[38]	U	Y	Y	Y	Y	U	U	Y	Y	Y
Carrillo et al[94]	U	Y	Y	Y	Y	U	Y	Y	Y	Y
Cashin et al[95]	Y	Y	Y	Y	Y	U	Y	Y	Y	Y
Chen et al[96]	Y	Y	Y	Y	Y	U	Y	Y	Y	Y
Cheng et al[97]	Y	Y	Y	Y	Y	U	U	Y	Y	Y
Chiang et al[98]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Clark[99]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Coffey et al[100]	Y	Y	Y	Y	Y	U	U	Y	Y	Y
Crosland et al[101]	Y	Y	Y	Y	Y	U	U	Y	Y	Y
Dickinson and Dignam[102]	Y	Y	Y	Y	Y	U	U	Y	Y	Y
Dixon-Woods et al[103]	Y	Y	Y	Y	Y	U	U	Y	Y	Y
Dowell[104]	Y	Y	Y	Y	Y	U	U	Y	Y	Y
Englund et al[105]	Y	Y	Y	Y	Y	U	U	Y	Y	Y

Citation	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Finnvold[36]	Y	Y	Y	U	Y	U	U	Y	Y	Y
Fleming[106]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Freidin and Timmermans[107]	Y	Y	Y	Y	Y	U	U	Y	Y	Y
Garcia[108]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Garro et al[109]	Y	Y	Y	Y	Y	Y	U	Y	Y	Y
Gibson-Scipio and Krouse[110]	Y	Y	Y	Y	Y	Y	U	Y	Y	Y
Grover et al[111]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Hook[112]	Y	Y	Y	Y	Y	U	Y	Y	Y	Y
Horner[113]	Y	Y	Y	Y	Y	U	U	Y	Y	Y
Horner[39]	Y	Y	Y	Y	Y	U	U	Y	Y	Y
Hudson et al[114]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Jones et al[115]	Y	Y	Y	Y	Y	U	U	Y	Y	Y
Jonsson et al[116]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Kealoha[117]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Klok et al[118]	Y	Y	Y	Y	Y	U	U	Y	Y	Y
Klok et al[119]	U	Y	Y	Y	Y	Y	Y	Y	Y	Y
Koenig[120]	Y	Y	Y	Y	Y	N	U	Y	Y	Y
Koenig[121]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Lakhanpaul et al[122]	U	Y	Y	Y	Y	U	U	Y	Y	Y
MacDonald[123]	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Mansour et al[124]	U	Y	Y	Y	Y	U	U	Y	Y	Y
Meah et al[125]	Y	Y	Y	Y	Y	Y	U	Y	Y	Y
Mosnaim et al[126]	Y	Y	Y	Y	Y	U	U	Y	Y	Y
Newbould et al[127]	U	Y	Y	Y	Y	N	U	Y	Y	Y
Newbould et al[128]	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Nichol et al[129]	U	Y	Y	Y	Y	U	U	Y	Y	Y
Palmer[130]	Y	Y	Y	Y	Y	U	U	Y	Y	Y
Palmer[131]	Y	Y	Y	Y	Y	U	U	Y	Y	Y
Patrick[132]	Y	Y	Y	Y	Y	Y	U	Y	Y	Y

Citation	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Peeler et al[133]	U	Y	Y	Y	Y	Y	Y	Y	Y	Y
Peterson-Sweeney et al[37]	U	Y	Y	Y	Y	Y	Y	Y	Y	Y
Raymond et al[134]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Reece et al[135]	Y	Y	Y	Y	Y	Y	U	Y	Y	Y
Riera et al[136]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Rose and Garwick[137]	Y	Y	Y	Y	Y	U	U	Y	Y	Y
Rydstrom et al[138]	Y	Y	Y	Y	Y	U	U	Y	Y	Y
Samuels-Kalow et al[56]	Y	Y	Y	Y	Y	N	U	Y	Y	Y
Santati et al[139]	U	Y	Y	Y	Y	Y	U	Y	Y	Y
Shaw and O'Neal[51]	Y	Y	Y	Y	Y	U	U	Y	Y	Y
Trollvik and Severinsson[140]	Y	Y	Y	Y	Y	U	U	Y	Y	Y
Ungar et al[141]	Y	Y	Y	Y	Y	U	U	Y	Y	Y
Valerio et al[142]	Y	Y	Y	Y	Y	U	U	Y	Y	Y
van Dellen et al[143]	Y	Y	Y	Y	Y	U	U	Y	Y	Y
Van Sickle and Wright[144]	U	Y	Y	Y	Y	Y	U	Y	Y	Y
Wagner and Steefel[145]	U	Y	Y	Y	Y	Y	U	Y	Y	Y
Wales et al[146]	U	Y	Y	Y	Y	Y	U	U	Y	Y
Walker[147]	Y	Y	Y	Y	Y	U	N	Y	Y	Y
Wallace[148]	Y	Y	Y	Y	Y	U	U	Y	Y	Y
Waters et al[149]	Y	Y	Y	Y	Y	U	Y	Y	Y	Y
Watson et al[150]	Y	Y	Y	Y	Y	Y	U	Y	Y	Y
Williams et al[151]	N	Y	Y	Y	Y	N	Y	Y	Y	Y
Yamada et al[152]	Y	Y	Y	Y	Y	Y	U	Y	Y	Y
Yinusa-Nyahkoon et al[153]	Y	Y	Y	Y	Y	N	N	Y	Y	Y
%	76	100	100	98	98	33	27	98	98	100

4.2.3 Characteristics of included studies

The studies included in the review were published during the period 1999-2017. There were a total of 1,655 individual participants represented in the 77 studies. Of these participants 1,078 were mothers, 127 fathers, 44 others including grandparents, aunts or caregivers with parental responsibility and 406 were unspecified, simply being described as families or parents. Children were aged between 0-18 years and most articles stated that the child had been diagnosed with asthma by a doctor or physician, one study discussed asthma and reactive airway disease and one focussed on the experiences of parents with a child with bronchiolitis.

The stated phenomena of interest within the 77 studies have been broadly categorized into four phenomena. The four phenomena were identified by reading the papers to identify the overarching experiences of parents and carers in caring for and managing children's asthma. Due to the large number of included papers and 1,159 findings it was deemed necessary to broadly categorize into groups and then assemble the findings into categories based on similarity of meaning.

- Parents' and carers' experiences of caring for a child with asthma including their beliefs, knowledge, attitudes and information needs
- Parents' and carers' relationships with healthcare professionals and using the emergency department (ED) for asthma care
- Parents' and carers' asthma management strategies and medication use
- Parents' and carers' experiences with school and educational settings

The settings for the studies included:

- 36 home or community settings[36-39, 51, 85, 87-90, 93, 96, 99, 104, 105, 107, 108, 110, 113, 114, 117, 118, 120, 121, 123, 125-128, 133, 136-138, 144, 147, 151]
- 16 hospital or healthcare settings[48, 86, 91, 92, 95, 97, 98, 100, 106, 116, 119, 134, 135, 139, 146, 152]
- 20 studies did not report the specific settings[50, 56, 94, 101-103, 109, 111, 112, 122, 124, 130-132, 141-143, 145, 148, 150]
- 5 home or hospital settings[115, 129, 140, 149, 153]

Twelve different countries were represented in the review:

- USA[37, 39, 48, 50, 51, 56, 87, 88, 90, 91, 93, 94, 100, 104, 107-110, 112, 113, 120, 121, 124, 126, 130, 131, 134-137, 142, 144, 145, 147-149, 153, 154]
- Canada[86, 95, 99, 123, 141, 150, 152]

- Taiwan[96-98]
- Thailand[139]
- United Kingdom[38, 101, 103, 106, 114, 122, 125, 127-129, 151]
- Norway[36, 140]
- Sweden[105, 116, 138]
- The Netherlands[118, 119, 143]
- Saudi Arabia[85]
- Iran[92]
- Australia[89, 111, 133, 146]
- New Zealand[102, 115]

A range of qualitative methodologies were represented in the studies and these are listed below:

- Grounded theory 13[51, 56, 91, 102, 106, 107, 118, 126, 131, 136, 138, 139, 153]
- Phenomenology 7[48, 88, 95, 100, 105, 133, 140]
- Qualitative descriptive & exploratory descriptive 8[90, 96, 99, 104, 117, 132, 147, 152]
- Ethnography 3[112, 123, 144]
- Interpretive 3[86, 114, 121]
- Participatory action research 1[149]
- Cross sectional qualitative 1[135]
- No other information provided 41[36-39, 50, 85, 87, 89, 92-94, 97, 98, 101, 103, 108-111, 113, 115, 116, 119, 120, 122, 124, 125, 127-130, 134, 137, 141-143, 145, 146, 148, 150, 151]

4.3 REVIEW FINDINGS

A total of 1,159 findings (964 unequivocal and 195 credible) were extracted from the included studies and grouped initially into the four phenomena of interest and then further assembled into 41 categories based on similarity of meaning. Seven synthesised findings were created from the 41 categories and these will form the basis of recommendations for policy and practice aimed at improving care for families and children with asthma. This section is organised by synthesised finding and the included categories with supporting illustrations representing participant voice. A table with synthesised finding, categories and supporting illustrations is included as Appendix VI.

4.3.1 Synthesised finding 1: Negotiating the meaning of having a child with asthma

The first synthesised finding relates to the emotions and anxieties parents and carers experience when their child is suffering from asthma symptoms and their felt need to be on guard and constantly standing by.

Parents and carers experience a range of emotions when caring for a child with asthma. These emotions include fear, anxiety, uncertainty, panic, denial and guilt. They are fearful of asthma and worry that their child may die as they struggle to breathe. The unpredictable nature of asthma and the need for constant vigilance also contributes to their anxiety. Some experience a sense of guilt and use denial as a coping strategy.

The meaning parents and carers attach to asthma is shaped by their existing knowledge, experience and beliefs and this influences their approaches to disease management. For example, those with previous experience managing their own asthma or another family member's asthma were more familiar with the condition, more comfortable managing it and more trusting of medications. Alternatively, a higher level of fear was associated in families who had experienced family members die from an asthma attack, those with severe disease or those with no prior experience of asthma. Similarly, parents and carers who viewed asthma as a mild condition not requiring treatment tended to take a dismissive approach to management.

Seven categories generated by 153 findings contributed to this synthesised finding. A summary of each of the seven categories is provided below, together with a few key illustrations that support them. Full details of findings and illustrations are presented in Appendix V.

Category 4.3.2: Fear of asthma and the possibility of death

Parents and carers describe emotions of fear, anxiety, uncertainty and panic watching their child having symptoms of asthma. They worry that their child may die due to their inability to breathe. Parents emphasized that whilst they experienced feeling scared or panicked, it was important not to reveal this to the child for fear of upsetting the child. Furthermore, calming the child was often problematic due to bronchodilator medication (reliever) being given to the child to relieve asthma symptoms which has the side effect of "hyping up" the child.

Illustrations of the experience described by the findings in this category:

> *"Scary because I feel like OK, there is nothing else I can do. It is out of my hands when it comes to breathing. You [are] scared for them because you know asthma can kill."*[100(p.359)]

*"I think the scary part is that you know that people die from this disease and when I look back and remember seeing my child barely breathing..."*123(p.3)

Category 4.3.3: Feelings of denial

Some parents and carers are unable to acknowledge the diagnosis of asthma and use denial as a coping strategy. Some downplay their child's asthma by referring to it as a mild form of the disease.

*"I didn't believe it. I thought maybe they were wrong. I just did not believe it."*112(p.46)

*"One mother denied ever being told of the diagnosis, did not relate the symptoms she described to asthma and related how her son's illness was different from her sister's, and therefore could not be asthma."*99(p.70)

Category 4.3.4: Feelings of guilt

Parents and carers express feelings of guilt and self-blame due to the repeated episodes of asthma their child suffered, their inexperience and lack of understanding of the condition and the lack of time available for healthy children in the family. Some parents and carers who had asthma themselves feel guilty that they may have been responsible for passing asthma on to their child.

*"It was our first child. We weren't experienced. We could see the child was coughing all the time and wasn't eating well, but we didn't take it seriously. If we had taken our child to the doctor sooner this wouldn't have happened."*92(p.118)

*"And then having asthma myself, I felt a little bit guilty."*108(p.98)

Category 4.3.5: Parents' and carers' asthma knowledge and beliefs

Parents' and carers' have varying levels of understanding of the symptoms and causes of asthma. Knowledge about asthma and its management appeared more likely if participants already had someone in the family with asthma. Most define asthma by the way it was experienced: by its symptoms, of which the most important was having difficulty or not being able to breathe. Many mothers are aware of the genetic nature of asthma and some believe their child will grow out of the condition. Some parents and carers see asthma as a sign of weakness or sensitivity.

"It probably, it probably is that she has weak lungs or I don't know. They said that that could be it. They said she has sensitive lungs and she can get sick like that , real fast."121(p.117)

Some parents and carers are unable to identify the cause of their child's asthma. Others are aware of asthma being caused by environmental triggers, weather, infections, activity, vaccines and use of antibiotics during pregnancy. Some feel that it could be contagious and one child could infect the other.

> *"The weather gets cold and she gets congested. I think the cold started it and the cigarette smoke make it even worse."*[112(p.43)]

Cultural variations are evident with Mexican parents and carers supporting the humoral balance theory of disease in that asthma is linked to hot and cold weather and also hot and cold foods.

> *"…when it gets cold, in the winter well I have them covered up…I cover them because I don't want them to get asthma."*[48(p.703)]

Parents' and carers' underlying beliefs about asthma as well as their prior and personal experiences shape their approaches to disease management.

> *"I think it is helpful that I have asthma. I am compassionate to his situation….I can literally sit there and know exactly….how he feels. I think…that helps me as a parent be able to help him in his situation."*[117(p.75)]

Category 4.3.6: Religious beliefs

Religious beliefs also play a role with some parents and carers turning to prayer as part of their asthma care routine before Emergency Department (ED) visits while others express hope for a cure through spiritual intervention.

> *"Listening to this lady who had faith in the oil and the onion that healed her child…She has faith in this and believed that this healed him. Faith moves mountains and I have faith in Jesus Christ and this is who helped my grand-daughter. He is the main doctor. He listens to our prayers and looks after our needs."*[126(p.480)]

> *"…my brother was preaching..she had an asthma attack…so everybody started praying, they started praying…".*[104(p.846)]

> *"I tell him that God will cure him...we need to ask God to take care of you and to cure you, and he does it, I teach him to pray."*[48(p.704)]

Category 4.3.7: Living with constant concern and worry due to the unpredictable nature of asthma

Parents and carers experience fear, stress and uncertainty due to the unpredictable nature of asthma, unrelenting symptoms and the speed of onset. Many view asthma to be an acute and episodic disease that is only present when their child has symptoms and is described as unpredictable, dangerous, deceiving, and potentially life-threatening. They find themselves in a largely unknown world and feel helpless, guilty and frustrated due to their inability to relieve their children's suffering.

> *"Asthma is changing and the child's condition isn't always the same either. And with asthma, that's another thing, it's so unpredictable and there are so many factors that can cause an attack. It's a very frustrating disease because you just do not know and what might be a trigger to one child isn't for another."*123(p.3)

> *"To not be able to see it [flare] coming, that is rediculously scary…I think I'm gonna lose my mind."*50(p.4)

Parents and carers express living with constant concern in the background of their lives with this concern becoming most prominent when their children became acutely ill.

> *"Your concerns are magnified when the children are not well; they are reduced when they get better. I think we have the tendency to feel very comfortable as to what we are doing when the children are responding and you become really aware of…them [concerns] when the children become ill."*95(p.378)

The major concern of parents and carers however was in respect to their children being on oral and inhaled steroid medications.

> *"Steroid seems to be a bad word."*95(p.378)

Some parents and carers expressed their ability to tell when an asthma attack was beginning and this permitted a degree of planning ahead in regard to taking time off work and care for other children should hospitalisations be required. This was mainly however in parents and carers who had gained experience with asthma over time.

> *"I've become very good at treating it and hearing it, before it comes."*91(p.381)

Furthermore, some parents and carers understood asthma to be episodic based on seasons and some felt that their children's colds and coughs during the winter were prolonged by their asthma.

> *"They just get colds and can't get rid of them."*93(p.201)

*"…they can be fine from January through August and when August ends I know that it will come…."*48(p.702)

Category 4.3.8: The need for constant vigilance

Due to the unpredictable nature of asthma, parents and carers feel the need to be on guard and constantly standing by and for many this includes careful planning and control of the child's daily life. Parents and carers are alert to the earliest warning signs of asthma so that they can start treatment as soon as possible. They are also alert to situations or activities in which their child could be exposed to asthma triggers.

*"You have to watch out for many things….like when he [son] wants to be around me….cleaning the car and stuff like that. I am fearful of atomized sprays that can trigger an attack."*95(p.378)

They carefully plan activities and their child's daily life in order to keep their children safe and avoid triggers.

*"There's a lot of forethought in planning activities. Vacations have to be well thought out."*95(p.378)

Some monitor asthma by keeping a diary of the child's asthma symptoms, documenting peak flow measurements and assessing the child's overall well-being daily. They regularly visited doctors for medical supervision.

*"I used to visit many doctors, I would go anywhere and do anything for my child to get better. Finally, I was given the address of this place and I brought my child here so that he might get better."*92(p.118)

Parents and carers are hesitant to leave the child in the care of others as they do not trust their ability to take care of their child. The need to be ever vigilant contributes to the anxiety and levels of exhaustion parents' face.

*"I am always calling to see if he is ok"; "If he runs, I have to monitor his breathing."*135(p.189)

*"I tend to pay attention to my outer surroundings. And certain surroundings put my antenna up. So, I'm watching her and I'm watching the way she breathes and the way she's coughing. But with us, it has a lot to do with our surroundings, where we're at…you have to watch her, know their every schedule, know certain things, when something's wrong."*50(p.4)

Whilst parents and carers maintain vigilance, they want their children to also be vigilant and encourage children to report symptoms as soon as they become evident. Vigilance also extended to other children in the family who did not have asthma and it was felt that by being watchful for symptoms of asthma in other siblings they would be able to seek medical attention in a timely manner should the need arise.

"We are trying to teach [son] that he must also be vigilant….and that it is not only us [who need to be vigilant]."[95](p.378)

"Because of the older child [who had asthma], there are things that we would pick up on more quickly than before…There is a passive vigilance in that area."[95](p.378)

4.4.1 Synthesised finding 2: Impact on Family Life

The second synthesised finding relates to the impact of asthma on family life and the disruptions and limitations families feel as a result.

Family life and activities are restricted due to asthma and parents long for a normal life. Mothers tend to be the primary caregivers and manage multiple roles including work, household activities and the demands of asthma management and as a result many suffer from stress and exhaustion. Some parents and carers face financial hardship due to their inability to work and the costs of medications, equipment and transportation to hospital.

Five categories generated by 125 findings contributed to this synthesised finding. A summary of each of the five categories is provided below, together with a few key illustrations that support them.

Category 4.4.2: Mothers managing multiple roles

Mothers tend to be the primary caregivers for children with asthma and many manage their asthma alone as well as combining household activities and work. The overall sense of responsibility for primary caregivers permeated most aspects of their lives. Many express feelings of isolation and sadness. They are occupied by the care of their child and miss their female friends and time with their husband. The mother longs for other family members to assist them with the care of the child but is faced with the dilemma of leaving them with someone who may not have the knowledge to manage an asthma exacerbation. Mothers demonstrate great resourcefulness and resilience in coping with crisis situations alone. Many find juggling work and caring to be difficult and a substantial source of stress, however they all put their children's health above their work. They have little time to actively cope with their stress. Furthermore, the need to be available for support of their child's asthma episodes limited their employment opportunities and some caregivers took extended leave or worked part-time in order to get their child "through the winter".

"there isn't any time..I have to work, then I come home and have to clean, wash the boy, etc. It's like a challenge. It costs a lot to have time for yourself when you have a child like this."[149(p.1627)]

"….I stopped working. Sometimes I try to work part-time as I have to take care of my son."[111(p.6)]

"I'm not going to work, I'm going to take him to the doctor and he couldn't breathe. And I went to my job for a little bit, I went to my work for a little bit, and then I left. And, um, I left him with my mother, came back and he was still breathing funny so I took him into his doctor, his paediatrician."[147(p.329)]

"*Some people may think it sounds ridiculous but it just impacts so much. It effects so much…But even while you are waiting there is, I suppose there is feeling of anxiety, paranoia or something and looking for the signs…so it does take over."*[115(p.347)]

Whilst mothers are predominantly responsible for managing asthma in their children, other family members also play a role. Fathers roles were felt to be more rational, action-aimed and liberating than the mothers more emotional role. They endeavoured to build up the child's physical strength, increase the possibility of them living a normal life and to encourage the child to manage situations on their own. Some fathers expressed the desire to be more involved in taking care of their child's asthma but were torn between their responsibilities at work to financially provide for the family and caring for their sick child.

: " *My son was 2 and a half when they discovered he had asthma…[My 2 children, wife, and I] all went in the car…..to Cook County Hospital…[My wife stayed with him all week at the hospital], she slept there every night….and I took my son to work with me…..I went to visit every afternoon when I got off work."*[126(p.480)]

Grandparents were very involved in taking care of their grandchild's asthma and proximity of living arrangements played a role in the extent of social support provided.

Category 4.4.3: Feelings of having an unusual life

Family life and activities are restricted due to asthma and parents and carers long for a normal life. Going away on holidays required careful planning including getting asthma medications together, ensuring that hotels are not dusty or moldy and for some, getting a letter from their respiratory specialist in case hospitalisation is required. Holiday destinations were limited due to a child's asthma with parents and carers expressing the need to be in close proximity to emergency services and have access to mobile telephone coverage.

> *Going away on holiday involved 'getting the kit together' and making sure the child had his or her inhalers. It involved checking that hotels were not dusty or moldy, and for some parents, it involved getting a letter from their respiratory specialist, to give to hospital staff if needed.*89(p.308)

Some mothers' feel that healthy siblings, partners and their own needs are often overlooked as they focused on caring for the child with asthma. Parents and carers discussed the significant psychological burden of having a child with asthma and the need to maintain a vigilant watch over children due to the unpredictability of the disease.

> *"Everything is like life is turned upside down just to keep him healthy."124*(p.515)

Many children miss school as a result of their asthma and parents and carers are troubled about the affect asthma has on their school performance, limitations on their physical activity and the ability to maintain a healthy weight. Some parents and carers recognized these limitations as a source of emotional distress for their children. Some parents and carers express concern about their child going away on school camps. Whilst parents and carers expressed a reluctance to make their children different from their peers by restricting activities, some felt this was necessary to avoid the risk of asthma.

> *"You just have to explain it that she can't, you can't run without getting out of breath and there's no point in pushing it, is there? She'll only end up ill."38*(p.188)

Many parents and carers restricted their child's physical activity based on lack of knowledge or misinterpretation of the advice of healthcare professionals.

> *"What I wanted to know about is how….how the children act when they are playing. I was watching this program where they say it is good for a child to exercise while they have asthma. I'd never heard of that."124*(p.515)

Some parents and carers restrict their child's outdoor play on windy days.

> *"Yeah and I feel bad when these days are windy and she wants to cry and cry. She wants to go out. The air, you know it has too much pollen and that's what the doctor told me too, that it could be the air. When I see that it's sunny and it's not too much windy. I just let her go out. I let her go out all the day." 121*(p.231)

In contrast, other parents and carers did not restrict their child's activities as they worried that restricting activities would have a detrimental psychological impact on their child. They were uncertain if allowing their child to be physically active contributed to increased symptoms in their child.

> *"That is why I am allowing him to play football and all. I went through the whole mind set with my husband – like he shouldn't be playing that, but if I stop him from living and growing, then I will hinder him more on the positive state of mind that can really make him physically not want to do nothing."*124(p.515)

Furthermore, some parents and carers carefully supervised their children's contact with other children for fear of them being exposed to germs.

> *"We don't really want, I mean it's not that we don't want her around kids. It's just that you know kids have a lot of germs and with her asthma we get scared of her getting sick. So it's like "Don't touch her. Don't." So nobody never comes over that much. But I mean she does play with her cousins. When they're not sick."* 121(p.231)

Parents and carers are also concerned about the child's future, the duration of the disease and whether their asthma would become more severe in the future.

> *"…first when he [son] had asthma….I wondered, 'How bad is this going to get? Is he going to be on medication for the rest of his life?...Now that his asthma is under control….it doesn't bother me as much as it did….but it still concerns me."*95(p.380)

Parents and carers worried about how their children would manage their asthma when they became teenagers. They voiced concerns that asthma management may not be given a high priority or may be neglected by children as they got older. Parents and carers dealt with this concern by educating their children about asthma and equipping them with necessary skills to effectively self-manage their asthma.

> *"And I can see that is going to be an increasing problem. I think that [son] is going to want to minimise it [his asthma] because it's not an adventure to go to the hospital anymore because it takes him away from other things that he'd rather be doing."*95(p.380)

> *"One of my biggest concerns…is to make sure that the children are armed with as much knowledge as possible to be able to cope with their asthma effectively when they are teenagers."*95(p.380)

The worried about the ongoing discomfort their children experience. Many parents and carers do not feel comfortable leaving their child with others due to the difficulty of their caring role.

> *"You see, I don't only have him to take care of and then rest. I have two other children. Sometimes I feel sad, I get angry, I don't know what I get angry at, but I cannot express my feelings. I want relief. I just want somebody to come and say "It will be all right. Now we will take care of him for a while, you can relax." This is the way you want it to be."*[105(p.369)]

> *"That affects us, the fact that it's very difficult for me and my husband to get time together. Which sounds very selfish but it's also quite important. I do not really get any time to myself because I'm either in work or looking after them. It's even silly things like we can't organize to go out because you can bet your bottom dollar that would be the night that one or the other of them would decide they're going to be poorly. I think we went out last weekend. That is the first time we've been out in nearly a year because we've arranged to go out and then one or the other of them has got poorly and it just hasn't happened. If there's any doubt in my mind, I won't leave them."*[106(p.150)]

Category 4.4.4: The labour intensiveness of asthma

Asthma is quite labour intensive for parents and carers due to the extra work of day-to-day asthma treatments, complex treatment regimens and ensuring triggers are minimised in the home setting which necessitates extensive cleaning and dusting. The labour intensiveness of asthma impacts on the time available for other family members including siblings and partners and some parents and carers are of the opinion that healthy siblings feel resentful.

> *"Besides the attack, you put him down for 10 to 20 minutes on the nebulizer; I need to keep the house clean, change the linens weekly; I try to keep her healthy as possible because if she gets viruses it contributes to her asthma."*[135(p.189)]

> *"the compliance thing is real tough, it's a daily ongoing thing. You know that you have to do it because that's what is going to prevent him from being sick. You have to just stick with it day in and day out."*[123(p.4)]

Category 4.4.5: Stress and exhaustion

Mothers experience stress and exhaustion due to asthma attacks frequently occurring at night and early hours of the morning. They describe staying up throughout the night watching their child struggle to breathe, and for many, this was a frequent occurrence. Many mothers slept with their children at night so that they could monitor their condition.

*"I feel so tired because we have a child with this condition at home. It is like he will never recover by taking medication. We feel powerless and helpless, at midnight, he coughs and cannot sleep. He often gets up at midnight and consequently has low energy during the day."*97(p.1966)

*"I stayed up with my baby every night when he had problems. I laid him down and he'd start coughing and wheezing, and then I'd have to lay with him propped up at 45 degrees. Otherwise he didn't sleep. And then I never got any sleep because I was waking up every 20 minutes."*132(p.29)

Category 4.4.6: Financial Burden

Some parents and carers struggle with the costs of medications and equipment such as spacers, dust mite protection supplies, nebulizers and transportation to hospital. The cost of recommended therapies including allergy testing was also discussed as being unaffordable, as well as equipment such as specific vacuum cleaners and home filter systems. Although affordability of medications and devices is a common concern raised by parents and carers, they reported willingness to spend money for medication if there were evident benefits to their child. Some parents and carers made choices to purchase reliever medication only and forgo preventers when they were short of funds. The inability to maintain continuous employment due to their intensive caregiving responsibility, food and insurance insecurity, poor housing conditions and allergen and environmental exposures are for many, out of their control.

*"There's totally no choice involved. If you have a child you have to get that medication whether you have to rob a bank to do so. You have to get that medication."*141(p.358)

*"Sometimes I buy Ventolin only because the money's short….it helps the most immediately."*141(p.359)

*"We cannot afford anti-mite bed sheets. They are too expensive."*98(p.91)

*"That Hepavax" cleaner," she stated, "is what I wanted, but we just couldn't afford it. But they told us to get one. We just couldn't."*88(p.388)

*"I had a car, but I don't have a car anymore. I was told by a [medical] resident, "Maybe you need to get a new car." How am I gonna get a new car if I can't keep hours on the job, if I'm here coming to see you guys? They say inconsiderate things like that, I'm here. Do you understand that I'm here? I'm an hourly person, and I'm screwed."*50(p.7)

4.5.1 Synthesised finding 3: The process of getting a diagnosis and learning about asthma

The third synthesised finding relates to the expressed difficulties in getting an initial diagnosis and the process of acquiring information.

Parents and carers express uncertainty in the period prior to their child being diagnosed with asthma due to lengthy delays in receiving a diagnosis, repeated symptoms and hospitalizations and feeling that health professionals did not take their concerns seriously. Many parents and carers had suspected their child had asthma and for many, knowing the diagnosis brought a sense of relief. Armed with a diagnosis, parents and carers focus on learning about asthma by networking with friends and colleagues and self-teaching due to a perceived lack of education provided by health professionals. Parents and carers identify the need for formal asthma education at the time of diagnosis including information on symptoms, triggers, medications, possible side-effects and how to achieve good asthma control.

Seven categories generated by 245 findings contributed to this synthesised finding. A summary of each of the seven categories is provided below, together with a few key illustrations that support them

Category 4.5.2: The process of getting a diagnosis of asthma

Parents and carers struggle to make sense of the subtle, indistinct, confusing symptoms their child is experiencing. Parents and carers feel confused and uncertain due to delays in receiving a diagnosis of asthma and many have multiple respiratory illnesses and complications before a diagnosis is made. Parents and carers who perceive their child to have more severe asthma expect a more expedient asthma diagnosis. Conversely, parents and carers of children with milder perceived illness felt that diagnosing asthma is a process that evolves over time. Regardless of this, without an official diagnosis, parents and carers are unsure whether to give medications and how to manage symptoms. Furthermore, prior to diagnosis, children's illness is often managed in a fragmented and reactive manner by treating symptoms as they occur. Additionally, parents and carers feel that healthcare professionals do not acknowledge or take their concerns seriously.

> *"It's just getting people to listen, that's what used to get me so angry because nobody would listen to me. When I used to take him doctors I used to mention my nephew had the same symptoms and now he is on all these inhalers. 'Because your nephew has got these symptoms don't mean to say that you have got the same thing, it's just chest infection it's just something it's just common to him', that's what I used to get. I used to go in there and come out upset all the time."*[122(p.6)]

Once a diagnosis is realised a treatment plan is implemented. However, for many parents and carers, attaining a diagnosis of asthma sometimes took periods ranging from 6 months to 3 years. Furthermore, families with only one child with asthma and for the first child in the family with asthma it seemed to take longer to receive a diagnosis than for subsequent children. Once a diagnosis of asthma is confirmed, parents and carers express a variety of emotions including fear and denial however for many the predominant feeling is that of relief at finally knowing the diagnosis.

*"I think after this first episode it was obvious. And I don't know what they are waiting for….they tell me they don't want to do it that young, but they don't want to tell me when they want to do it."*109(p.706)

*"I think I knew, but I was hoping that wasn't what they were going to tell me. Yet, I was relieved in a sense because, I didn't know what was wrong with him."*108(p.97)

Parents and carers described asthma preventer medications being prescribed before they were told their child had an official diagnosis of asthma and some were happy with early treatment.

"As long as they are treated, I don't care if I have a name on it or not." 109(p.707)

In contrast however, some parents and carers believed that children who are not diagnosed with asthma should not be treated for the condition.

"[Referring to asthma medications]…there are so many side effects…are they sure enough that he has asthma to give that to him?" 109(p.707)

Parents and carers express satisfaction with the diagnostic process when the health professional communicated a pathway to obtaining a diagnosis, especially in children with severe asthma. They also express satisfaction when providers were perceived to listen to, and respond to their concerns.

Category 4.5.3: Educational needs at the time of diagnosis

Parents and carers perceive a lack of asthma education provided by healthcare professionals at the time of diagnosis. They express fear, anxiety, stress and uncertainty due to a lack of the required knowledge and self-management skills to care for a child with asthma. Parents and carers struggle to differentiate asthma symptoms from other health concerns and emphasize a need for consistent, simple, written information on asthma symptoms, triggers, side effects and medications.

*"When she gets sick…I can't really tell is it a cold, or is it her asthma kicking in? So it's like I [am] trying to treat both things. Because it really acts up when she gets sick, and it acts up when the weather changes….and it's just so much. So it's like I can't really tell when it's her asthma."*50(p.4)

*"He never explained to us what the medications do, what the side effects were….it was just here, give this medication to her."*86(p.24)

Parents and carers require information in order to understand the disease and know how to manage asthma symptoms including during emergency situations. Furthermore, parents and carers require information about when to seek emergency care for their child with some parents and carers feeling they waited too long before seeking professional care. Some parents and carers expressed the desire for information about herbal and alternative medicines and their efficacy in treating asthma. Face-to face interactions for education and support were preferred by parents and carers. Lack of education is felt to impede the ability of some parents and carers to identify information deficits and ask questions during interactions with healthcare professionals.

*"So, that's the thing. And that's why sometimes we do wait so long to bring them because we think we can turn them around.")*50(p.4)

"The thing is, what questions do you ask?"86(p.24)

Similarly, parents and carers who attended the ED for an asthma exacerbation expressed the need for more information about managing their child's asthma at the time of the emergency department visit.

*"It was like I had stepped into another reality - a black hole. This medical world suddenly became my reality and I couldn't get my head around it at first. It was so foreign and I didn't know what was happening. I didn't know if she was going to get better. I didn't understand her illness, I just didn't know anything. I felt so ignorant."*133(p.220)

Parents and carers discussed the importance of the provision of written information and educational materials that use simplified terms and avoid medical jargon on discharge from the ED.

"They'll give you a printout at the end of the day when you leave about what happened with the visit. But I know that a lot of times I'll go home and Google because I really didn't understand like what that meant…what it really mean in layman's terms….for me it would be more helpful if it was already written in those terms, in just like general speaking terms."56(p.283)

In addition to the provision of written information, parents and carers also emphasized the need for verbal teaching as well as demonstration.

"Actually show me, so that way I know exactly everything instead of me, you know, guessing or assuming…I had to give him 5.2mls, and the-what is it called-the medicine tube thing, it only had

> *5mls on there, so like I didn't know like where the two point was at, like 5.2. So if someone would have showed me like this is where 5.2 is, I would know."*56(p.283)

Furthermore, parents and carers emphasized the importance of adequate time and a suitable quiet space for discharge communication.

> *"If we could have just like a room right before we leave, like a nice little room where it's quiet and he's treated and everything, and we could just actually sit down and just talk with our physician and our nurse, like what can we do to like make sure this doesn't happen again, and there's no distraction."*56(p.284)

Parents and carers with limited health literacy discussed concerns regarding conflicting information. In particular, parents and carers described inconsistencies between medication package instructions and instructions provided by the physician.

> *"I think sometimes it can be the doctors or nurses, respiratory…and it's just like one person can say this, then the next moment, somebody else is saying this, and sometimes makes you a little confused."*56(p.284)

Some parents and carers reported the desire for a follow-up call from the ED provider to check on the child's progress or for waiting time in the ED to be used as an opportunity for teaching opportunities. Additionally, some parents and carers discussed the challenge of learning complex new information while trying to supervise one or more children. They suggested that child care assistance for a brief period could improve their ability to focus on the information being provided and thus improve their retention of this information.

Furthermore, some parents and carers with limited literacy identified concerns about feeling judged by their healthcare professional.

> *"Some people, they just don't want to ask questions because they don't want to feel like they're being like a bother or a pest."*56(p.284)

Some parents and carers did report receiving the information they needed and felt the education provided by asthma clinics to be of high quality. They appreciated the personalized nature of the visits and the follow-up they received and their levels of confidence in their asthma knowledge increased. Some parents and carers however still expressed some information deficits. Inhaler administration technique and levels of confidence were felt to improve after attending asthma clinics.

> *"We didn't know how to use (the inhalers) until we went to the asthma clinic."*86(p.25)

Category 4.5.4: Learning the ropes

Parents and carers focus on learning about asthma, the nature of the disease, triggers, the purpose of medication, side effects, how to identify symptoms, how to administer a nebulizer and other treatment strategies. Some parents and carers learned about asthma from their healthcare professional, asthma educator or their child's paediatrician. Learning as much as they could about the condition was a priority for parents and carers. They became "tuned in" to asthma and motivated to seek information and ask questions in their quest to learn. Furthermore, they had to learn how to manage their children's medication regimen and make it part of their everyday routine.

> *"We had to be more regimented because….the medications that were prescribed for [daughter] were not part of our daily routine….It took some getting used to."*95(p.377)

> *"I mean it's, [thinking about what I could do] just drove me nuts. It was like, it drove me nuts thinking about it all the time. It's like God. ... I would always sit there and while the therapist was giving him treatments. I would sit there a lot of the times and just talk to them. And why is he like, why is it, why, I would always ask him questions constantly. ... Look if you get tired of me asking you questions you can tell me to stop. And they're like no no, it's okay. I was always just wanting to learn something from what happened or why are you guys going to do this or just learn things so that I would know."*121(p.236)

> *"And the other thing is don't wait for information to come and land in your lap. It was hard to realize it wasn't going to. They gave us a little book for her to read called "You Have Asthma Now" or something like that. I don't remember what it was. And they gave us one little pamphlet. I'm like, "Hey, wait a minute. You want to pump my kid full of drugs, but you don't want to tell me about it?" That's why we got on the internet... And then there was — I don't even remember the name of the place. But there's an 800 number to call that we got from somewhere. I don't even remember what the 1800 number was for. I just remember I was trying to gather every little ounce of information I could."*132(p.31)

Furthermore, parents and carers learned about their children's asthma triggers and strategies to control triggers. They learned about the need to modify their home environment to reduce their children's exposure to allergens that could trigger an asthma episode.

Category 4.5.5: Sources of asthma knowledge

Doctors and health personnel are key sources of information for parents and carers. Many parents and carers hear about asthma for the first time when their child is diagnosed with asthma, and they learn about it as they struggle to control their child's illness. Many parents and carers report not receiving enough information from their healthcare professional and so commence seeking information on their own. Lay sources of asthma knowledge were primarily obtained from personal experience, relatives, friends, the media and self-teaching using the internet. Lay knowledge was felt to change with caregiving over time.

> *"….knowledge about asthma changes as you live the experiences of asthma with your children."*48(p.702)

> *"I've learned from talking to other people who have asthma and who have children with asthma…Things that have caused triggers for them you are now aware of and you watch for in your own child. Things that are beneficial for their children you may also try with your child."*95(p.377)

> *"But I myself went out, I researched it. I read books and I sort of became a self made expert because at that point I figured if they didn't even tell me at the hospital what was wrong with her I wasn't going to count on anybody to inform me."*130(p.91)

Some parents and carers expressed a lack of accurate, consistent information provided by their healthcare professional.

> *"….I've also done some research, spoken to different doctors, nurses, providers…The frustrating part is that, depending on who you speak to you get a different answer. There's no consensus…[for] best treatments for asthma…."*48(p.702)

Parents and carers generally sought information only when they identified a gap in their knowledge. Information-seeking behaviour was often motivated by a change in their child's condition or emotional responses such as the desire to be comfortable with an aspect of asthma management.

Category 4.5.6: Parents ability to recognise symptoms and determine severity

Parents and carers struggle with the ability to recognize asthma symptoms and determine the severity of an asthma episode. Generally, this is most common immediately following diagnosis but for some parents and carers persists for many years. Severity was determined by the frequency and severity of symptoms and whether they could adequately treat their child at home or if they needed to go to the doctor or emergency room. Parents and carers perception of severity is also influenced by how well controlled their child's condition is.

*"…there are times that at the first dose the whistling goes away, but there are times I have to use 2-3 doses a day so the whistling would go away…there's very aggressive [asthma]".*48(p.703)

Severity was also determined by the extent of the activity limitations faced by their child.

*"…it's a horrible illness for them…to have all of these things prohibited so it doesn't cause them asthma…"*48(p.703)

Some parents and carers recognize worsening asthma through changes in mood and behavior.

*"Oh, he's wheezy, coughin', very arrig…., very bad mood he is, you can't really talk to him, (right) really stroppy he is and then he'll start on his brothers and sisters for no reason."*38(p.188)

Some parents and carers recognize other behavioral signs such as lack of appetite as a sign of asthma.

*"[H]e has very good eating habits. If he didn't eat, there was really something wrong. Cause he has very god eating habits. He wouldn't eat at all. He wouldn't even take a bottle. He'd probably just hold it in his mouth, but if you go look at it in 30 minutes, he's still on the same amount of liquid that it was when you gave it to him. So it was scary because he would have, when he would go to the hospital he would have, probably mostly, well twice, he had to have an IV, because he had gotten dehydrated cause he wouldn't eat or anything."*121(p.142)

Furthermore, parents and carers viewed the use of the "spray" (reliever) to be routine, whereas using the "machine" (nebulizer) indicated more severe illness.

*"….the doctor decided to not give it to her in the machine…she had a strong reaction….and with the inhaler she had no reaction…it's asthma but not a strong asthma."*48(p.703)

Parents and carers with less asthma experience demonstrate more uncertainty in recognizing asthma symptom patterns, identifying triggers and implementing treatments. Parents and carers of young children also express difficulties due to the young child's inability to verbalize their discomfort.

*"So the things I've asked about asthma is: How crucial is it? How long does he have to get to the hospital? When would I know when an attack is coming? That's how I know about the ribs. I asked the doctors that. And they say to keep him away from cigarette smoke, but I don't smoke cigarettes."*121(p.149)

Category 4.5.7: Learning about asthma triggers and strategies for trigger minimisation

Managing the complex allergies experienced by their children was identified by parents and carers as a significant caregiving responsibility. Parents and carers identify a range of triggers for asthma including environmental triggers such as pollen, mold, dust, chemicals, perfumes, pollution, pets, exercise and smoke. Cold weather, cold liquids or foods are also identified as asthma triggers. Poor living conditions such as dampness and mold contribute to additional triggers. Some parents and carers reported having no pets in the home or having given away the family pet. In contrast others still had the family pet and felt that it did not cause the child any problems.

> *"I have a cat. And so the doctor said she was allergic to the cat. But I've had my cat for almost ten years. So, I know she ain't allergic to mine."*[50](p.3)

Once asthma triggers were identified, parents and carers change their routine in order to help their children avoid asthma attacks. Parents and carers use a variety of strategies to minimise triggers in the home environment including keeping their home clean, washing bed linen, damp dusting, vacuuming, keeping stuffed animals out of their child's room, banning indoor smoking and the use of hypoallergenic mattress and pillow covers.

> *"My house is carpet free and we wash blankets and pillows every week. Everything in the room that they lay on gets washed"…."We don't use spray for household cleaning we use oil, and it keeps her breathing better" "….I noticed when I had those oil scents that you put in a little container that seemed to make it worse."*[110](p.246)

> *"She [sister] smokes like a chain smoker and she's always embracing and hugging. I have to say to her, "Girl, you can't do that." She'll wash her hands…but it's in her clothes. It's in her skin. And she would wear wigs. It's in her wig. And she's always hugging…I have to explain. "You cannot do that. You're sending me to the Emergency Room."*[50](p.6)

Some parents and carers had eliminated carpets and rugs from their home and replaced curtains with blinds. They felt hypoallergenic mattress and pillow covers to be effective in reducing dust mite exposure.

> *"And I think probably the thing that made the most difference for him was putting his pillow, hypoallergenic cover on there. That made an immediate difference, in my opinion?"*[88](p.388)

Taking preventative action for some parents and carers helped them to assume a sense of control over the situation, however if their preventative action was unsuccessful they felt a sense of personal failure.

"I felt I probably hadn't cleaned enough so I sort of set to…pulling the books out and wiping the tops so I felt I had…maybe I was just being sensitive about not having cleaned thoroughly enough."[101](p.112)

Although aware of particular triggers, some parents and carers did not prevent exposure, believing that a physical barrier like a door, offered adequate protection. This was most commonly the case with family pets with parents and carers electing not to allow them in the bedroom with their children. Furthermore, some parents and carers expressed a preference for not knowing too much about triggers, particularly about house dust mites.

"I do have a lot, quite a few animals. I raise animals…..but nothing in the room with them….nothing sleeps with them in bed."[86](p.23)

"No I don't want to know, bad enough looking at the picture without finding out what they actually do as well."[101](p.112)

Some parents and carers limit their child's physical activity in order to prevent attacks.

"When he runs a lot he can't breathe well and....feels pain in his chest and has to use his inhaler fast...it's not constant, only when he runs."[48](p.703)

Many parents and carers recognized the importance of reducing their child's exposure to second-hand cigarette smoke and acted as advocates for their child's health in social situations.

"One time he [adult friend] was about to [smoke], I said no, I'm not trying to go to the hospital, I'm not trying to be in there for 12 maybe 24 hours. Can you take it across the street?"[50](p.7)

Category 4.5.8: Challenges in minimising triggers

Parents and carers face a variety of challenges identifying asthma triggers and trying to minimise these. Some weigh the risks versus benefits of environmental and lifestyle choices. Some parents and carers are uncertain about the source of triggers for their child's asthma and others feel helpless due to failed attempts to reduce their child's exposure to allergens discussing "no carpet, no dust mites, no pets*"*. Thus the ability to minimise environmental triggers is felt for some parents and carers to be beyond their control and others identify incomplete efforts to minimise triggers. Family poverty and housing instability was felt to leave children vulnerable to allergen exposures that were out of the control of parents and carers. Cooperation from family members in minimising triggers in the home environment was important; however parents and carers emphasized the difficulties in reducing their child's exposure to triggers whilst still maintaining good family relationships. This is particularly the case in regards to limiting family members smoking in the vicinity of children. Some parents and carers smoked themselves and lacked awareness of how smoke permeates the home or used ineffective strategies to remove smoke from the environment. Parents and carers identified some level of conflict over family pets and whilst aware that pets were a trigger for asthma, some still allowed pets in the home.

"Well, I was told to pull the carpet up all over and get rid of the dog, but I just – I don't think that has enough of – I mean- it doesn't trigger it that much. Now if they was worse-a lot worse-then, yes, we probably would have done something like that, but we just didn't feel like they was severe enough to go to that extent."[88](p.388)

"The allergy doctor said she didn't want my sister smoking in the house anymore. So my sister goes to the kitchen now and turns on the fan, but it still bothers my son. We just give him his breathing treatments and hope we don't have to go to the emergency room."[88](p.388)

"Smoking can make it worse, I know….I never smoke in my house ever. Um, I have to quit smoking in my vehicle."[86](p.23)

"I have done everything that I feel like I possibly can…I clean so much because I feel like if I clean, I'll keep everything out, keep everything away. But I still feel like it's not enough. If I see some dust, I'm gonna go crazy, and I drive my landlord crazy. "I want my vents cleaned. I want everything to be cleaned"….I don't know what else to do."[50](p.6)

4.6.1 Synthesised finding 4: Relationships with healthcare professionals and the emergency department experience

The fourth synthesised finding relates to parents and carers interpersonal relationships with healthcare professional and their levels of satisfaction with the care received. The decision making process surrounding parents and carers choosing to seek care at the Emergency Department (ED) is examined and their levels of satisfaction and dissatisfaction with the treatment received.

Parents and carers express varying levels of satisfaction with the knowledge and quality of the encounter with the healthcare professional. Parents and carers are satisfied with their healthcare professional when they consider their opinions, provide high quality care, adequate time, respect, culturally appropriate information and resources, are available when they need them and address their medication concerns. Many parents and carers who are unsatisfied with information or care received seek a second opinion from a specialist. Parents and carers struggle with the pros and cons of hospitalisation. Parents and carers seek ED care for acute asthma attacks and some find their professional guidance reassuring whilst others find the hospital experience to be a difficult one and traumatic for parents and carers and children alike.

Seven categories generated by 205 findings contributed to this synthesised finding. A summary of each of the seven categories is provided below, together with a few key illustrations that support them.

Category 4.6.2: Emergency Department treatment and decisions to go to ED

Parents and carers lack confidence in their ability to manage acute asthma and during an acute exacerbation many seek ED care. Many seek professional guidance in a situation they felt was confusing and unfamiliar. Furthermore, they feel that as asthma is a breathing disorder it should be treated as an emergency, a belief that is reinforced by some healthcare professionals advising them to take their child to the ED for an asthma exacerbation. The decision to go to the ED is not an easy one and mothers feel that making this call is primarily their responsibility. Inability to control asthma symptoms and timing of the asthma exacerbation (often at night) necessitates trips to the ED.

> *“Um I think I get nervous, scared, cause my son had an attack and I panic. I think I was panicking more than he was (laughing), so my first reaction was emergency room”.*[87(p.37)]

Deciding when asthma warranted ED treatment is complex and in most cases parents made this decision alone, however parents and carers with older children discussed a shared decision-making approach.

> *“When we get to a hospital is because he’s like mom, I need to go to the hospital. He’s been having asthma since he was a baby so he is well aware of when he feels like he can manage through it or when he’s like no, I need to go….I’m like at the first, I’m like let’s go, you know, because that’s how I was but now I’m learning to allow him – it’s because I want him to start being more independent and responsible when it comes to his asthma.”*[50(p5)]

Some parents and carers express satisfaction in the quality of emergency care available and feel comforted that they would be seen quickly by an emergency physician. Transferring the responsibility to healthcare professionals was reassuring as this meant that they were no longer responsible for the child's care and assisted them to remain calm. Furthermore, some parents and carers felt their child's recovery might take much longer without suctioning and IV medications.

*"Once you're there [at the ED], you're relieved because you know it's not your responsibility anymore. They've got to fix him, you don't have to anymore."*89(p.308)

*"In the hospital, you know, I was a lot more comfortable with them giving him really high doses of the albuterol 'cause they could monitor his heart and make sure that he's doing okay. They seemed to get it under control and he was sleeping really comfortably."*51(p.302)

*"[It] would have probably made it a little bit easier….To bring her home. But I felt that I wanted her well quick. Because she had suffered already for two or three days…[B]ecause they intravenously have her steroid in her and they're just constantly suctioning her so she could breathe and that muscle could open up in her lungs and I mean stuff that we couldn't do here. We couldn't do that here at home. I could have brought her home and it could have taken us three weeks for her to get well, when it took her five [days]…"*121(p.239)

The ED environment is busy and crowded and the acute care system fails to meet the needs of some parents and carers. Some parents and carers presenting to the ED for the first time discussed that they were not told their child had asthma.

*"I was a bit scared because my oldest son had never had any of that. Therefore I thought that my son had something wrong and that would possibly die. Unfortunately, the hospital only told me that it was a bronchial problem that they were going to treat; they never told me "asthma".*90(p367)

One parent and carer explained that she did not know what was happening with her child in the ED. Additionally, clinicians and staff may not recognise the extent of the parents' and carers' fear and their inability to comprehend instructions due to high levels of fear and anxiety. Furthermore, language barriers pose additional complexities, with parents and carers from CALD backgrounds being unable to explain what they thought was wrong with their child.

*"There are some doctors that don't know Spanish and I cannot speak with this person and say, 'My child has this, has that, this happens, take care of him quickly, and things like that."*90(p.367)

Some parents and carers find the hospital experience to be a difficult one, traumatic for both the child and parent and carer and as a result try to avoid hospitalisation. Some discussed the use of restraints on the child and this was felt to be distressing. Some parents and carers express difficulties when forced to leave their child in the care of healthcare professionals. They feel left out when the care is taken away from them, they feel they know their child best and that their explicit knowledge about their child is not taken into consideration. Conversely, some parents and carers discussed the pressure they felt from hospital staff to be fully responsible for the care of their child.

> *"On the ward I find that you are made to feel the pressure's on, that you have to stay all the time and sometimes you just want to get out of there, you know both of you. You want to get out of there and unless we can call on our parents, we can't do that."*[115](p.347)

> *"So we ended up staying at….for like six, seven hours and he had to have like five breathing treatments…he was screaming and I didn't know what was wrong with him because you know, he is so little, he can't tell you what is wrong. So it was very nerve-wrecking…we ended back up at the hospital like four time since, before he turned one and a half, because of his breathing. It was traumatic."*[117](p.77)

> *"I would do everything I could to avoid going to the hospital."*[121](p.179)

> *"Well she doesn't like to be like strapped down. Probably no kids like that. You confine her and she snaps."*[121](p.277)

Others discussed stories of cold, rude treatment that they had received in the ED.

> *"How can I explain it….[it's] as if they are giving the services for free. They just tell you to "Wait a while" or "We will see you soon," but they are very cold since they can't feel the pain that one is experiencing and you feel so hopeless because you can't do anything."*[90](p.367)

Parents and carers expressed feelings of helplessness and lacked understanding about the disease process and required treatments. Parents and carers emphasised the importance of information so that they know what to do for their child with asthma, including during emergency situations.

> *"Well the most difficult is to see him [my child] there [in the emergency room] without knowing what to do."*[90](p.367)

Category 4.6.3: Communication issues with health professionals

Some parents and carers find communicating with health professionals difficult and some are conscious about words and expressions used during conversations with the doctor. Parents and carers with Low English Proficiency (LEP) express difficulties getting their message across to healthcare providers and feel dissatisfied with the exchange. Some parents and carers feel the need to be assertive in order to receive appropriate treatment.

*"you have to struggle to get help from someone and you have to be strong and communicate well."*116(p.188)

*"…two days later his condition became worse, and I called again, or was it my sister that told me to call…..when we arrived, the doctor said that he had to be admitted to the hospital…we might have said the right things, and that is very important, that you know what to say…we were talking about inhalation devices, but really, we didn't have a clue…it is too bad that you have to get the words right, but I also think it is very important."*36(p.303)

*"I felt like K could be damaging something internal. I got angry with the doctors because I finally went in to [the pedatrician] and K was having an attack every 2 weeks, they were lasting 16 hours or so and the child would turn blue. I said, 'Is it time to go see a specialist or something?' He says 'Well you might want to try that'.*113(p.662)

Parents and carers with professional status indicated that their child's physician "assumed" a level of asthma knowledge due to their professional status.

"No information of any type was given to me at diagnosis, as I a working in the hospital and when they see that I am wearing a lab coat, they assume I know everything."85(p.951)

Some parents and carers expressed that their child's physician had communicated information to them at the time of diagnosis and indicated that their child's physician had verbally explained to them how to respond to an asthma attack.

"The doctor explained to me how to use inhaler, how to change the use of drug based on symptoms, and how to avoid triggers. He explained that verbally and showed me how to use inhaler. In addition, he provided me with written materials about asthma."85(p.951)

Category 4.6.4: Language barriers

Parents and carers felt that cultural differences have the ability to distort communication between parents and healthcare professionals of differing cultures. For this reason, seeking out a health professional that could speak their language and having access to CALD resources including asthma action plans is important. Some feel there is a lack of cultural understanding of the importance of the extended family/kinship network. Some parents and carers lack trust in the use of professional healthcare interpreters and find them to be unavailable when they need them. Thus, they prefer to rely on family members or children to interpret.

> *"especially in regards to your child's health…it's better to hear everything well, and that if you have any doubt you can ask and have it explained in your language."*149(p.1628)

> *"And usually the security guards will walk up and say, "You know what, you guys can't all be here." They don't realize just because that isn't our child, it's a member of our family and we feel deeply, and I mean we're very close. I mean you can see that I have a very small house, but come Christmas time every family member that I have will be in the house, including extended family members. And we're all very close, and that's something that a lot of hospitals don't understand, and then it's like they stick their security guards on you."*137(p.6)

Category 4.6.5: Concern about provider judgement

Some parents and carers, particularly those from low socio-economic or CALD communities, feel misunderstood, inferior and judged by providers and as a result are reluctant to ask questions without other family members present. Parents and carers discussed the importance of self-advocacy in encounters with healthcare professionals with many feeling that providers do not value parents and carers as experts on their child's life. Some feel accused of neglecting their children, not controlling their symptoms and delaying seeking emergency care.

> *"Especially people in specific socioeconomic backgrounds are treated like they don't have a clue about what is going on. That is a main concern. People are not treated across the board in terms of attitude and knowing what is going on….with their child's body."*124(p.516)

> *"It is hard for Indian people to ask for the services they need, because it is our way that you should have your family members there to help you. If we don't ask a question, it's not that we know it all, but it's just that we might be afraid to ask the question because of feeling inferior."*137(p.7)

Category 4.6.6: Parents and carers dissatisfaction with the knowledge and quality of the encounter with the healthcare professional

Some parents and carers express a lack of trust in the knowledge and care provided by their healthcare professional and feel it is important for healthcare professionals to listen to parents' and carers' needs and respond to their medication concerns. Parents and carers expect to be treated by a competent healthcare professional, to be provided with consistent information, continuity of care and regular follow-up. Some feel that it had taken too long to achieve the asthma diagnosis, that a diagnostic strategy was not communicated and some parents and carers expressed high expectations from health professionals. Lack of adequate information, not recognizing their expertise and unclear treatment decisions also contributed to parents' and carers' dissatisfaction.

> *Five mothers in our study, however, expressed frustration when they brought up concerns with health care providers. They felt that their concerns were not taken seriously and that their questions were dismissed.*107(p.51)

> *"..[T]here should be more monitoring of the patient [.....] they get them on a level, you know, you're issued with your inhaler and that's it. I think it would be a good idea at least once a year, to call that patient back, and monitor how he's going, you know, is the inhaler effective, are you using it too much, are you doing this and that."* 103(p.508)

> *"I don't really think they know a lot I was at Wal-Mart one day and they had an asthma clinic set up there and my interest was, whether there were new medications out that could reduce some of his other medications. And she didn't even know what I was talking about. I knew more than the nurse there and the pharmacist knew."*99(p.80)

> *"Lately, I've been feeling like they aren't as understanding when it comes to him. I don't know if they're just trying to get you in and get you out or what it is. It's kind of rushed and they are dismissing what I'm saying as a parent….I just feel like they don't listen as much as they used to when he was younger."*50(p.7)

Parents and carers discussed their preference for healthcare professionals to take a more holistic approach to managing their child's asthma and include both their physical and mental well-being.

> *"They deal with medications and treating symptoms, and it's not holistic approach to managing care."* *124*(p.516)

Category 4.6.7: Parents and carers satisfaction with healthcare professionals

Parents and carers stated that trusting their healthcare professional was imperative to receiving quality care. Parents and carers are satisfied with their healthcare professional when they are competent, supportive, have good verbal and non-verbal communication skills, consider their opinions, provide high quality care, allow adequate time, are available when they need them, culturally competent, respectful, address parents' and carers' concerns and include them in the healthcare decision-making process. Many parents and carers who were happy with the care provided by their general practitioner were willing to travel long distances in order to maintain the relationship with the healthcare professional.

> *"It takes the worry off me…The hospital is just down the road [Paediatrician] even gave me his home phone number, so if we had any questions anytime whatsoever, [we could] give him a call."*[95](p.381)

> *"I think the time changed that doctor's as the "all-knowing". Therefore, nowadays it is more a two-way conversation. Again, it is your child, you know the best if he is ill."*[119](p.250)

Parents and carers expressed satisfaction with their child's healthcare professional when they communicated a plan of action to diagnose asthma after multiple respiratory episodes.

> *"Our doctor laid it out for us what the possibilities were. And then as time went by she would reevaluate what she felt my daughter's condition was. And she was reluctant to say that is was asthma until she was sure that it was asthma but we always had a course of action when we left there."*[109](p.706)

> *"Doctors here are fantastic, we have a really good relationship with them. I just ring them and they see him straight away….the GP talks to them as a person, you know (son) wasn't taking his medication one period and so I just marched him in there and I says well (son) seems to think he doesn't need this and he goes, "Oh come on (son) you're 14, your mother doesn't need to tell you or hold your hand anymore."*[115](p.346)

Some parents and carers form relationships with specialist respiratory nurses and find that they provide them with the support they need to manage their child's condition.

*"And she actually talks to you and asks him to show her exactly how he uses his inhalers and the spacer as well….The practical side; and how many seconds to wait between puffs and….So he actually has to do it in front of her so she knows he's going it properly…I think the asthma nurse is vital."*114(p.5)

Category 4.6.8: Seeking out alternative sources of care

Parents and carers who are unsatisfied with the information or care received shop around for a second opinion. Many parents and carers view asthma specialist referral as important and feel that families should be referred to an asthma specialist for their child's asthma management. Some parents and carers felt they had to be assertive in order to obtain a referral to a specialist and expressed concern over wait times and delays in organising follow-up appointments.

*"I mean our primary care physician was bumping us off….saying "she doesn't have that many asthma episodes…." And nobody did any tests…so I said, "I want to go to an asthma doctor."*131(p.77)

*"There was one time I wasn't getting through to the doctor, our eight year old has really bad coughing asthma, when his is acting up, and we'd go into the office and his lungs would be clear, there'd be no wheezing, no nothing. He'd walk out of the office, and he's coughing his lungs out, to the point where he pulled groin muscles. He burst vessels in his eyes, until then we got no where.... That was frustrating because I knew he needed prednisone, and I was really ticked off that they thought there was nothing wrong with him. It was difficult to explain how severe the coughing was. We ended up in emergency with a different doctor and we got it that way."*99(p.93)

4.7.1 Synthesised finding 5: Medication beliefs, concerns and management strategies

The fifth synthesised finding relates to parents' and carers' beliefs, concerns and confusion over medications and their reasons for adherence or non-adherence.

Parents and carers express concern regarding the side effects of asthma medications, particularly preventer medications due to them containing corticosteroids. They are confused over the actions of different medications and use a variety of strategies to manage asthma according to their medication beliefs. Parents and carers sometimes struggle to administer medication to young children and children are at times perceived to resist medications. Some parents and carers understand the importance of regular inhaled corticosteroids whilst others chose not to adhere to medication regimens. Reasons for non-adherence included forgetting, hassles with medication administration and intentional non-adherence with some parents and carers preferring the use of complementary and alternative medicine. Some parents and carers found using an asthma action plan to be beneficial whereas others found them to be confusing.

Six categories generated by 177 findings contributed to this synthesised finding. A summary of each of the six categories is provided below, together with a few key illustrations that support them.

Category 4.7.2: Confusion over the actions of medications and lack of understanding of asthma control leads to asthma management driven by parental beliefs

Some parents and carers have difficulties differentiating reliever medication from preventer medication. They are confused over the actions of different medications and many lack an understanding of what constitutes good asthma control or how it is achieved.

> *"To me, it's when you're giving them the Flovent like they're supposed to have it, when you know when it's time for the albuterol, and when you know that it's time that the albuterol won't work again, you know that it's time for the Emergency Room. To me, that's when it's well controlled."*[50(p.3)]

Even parents and carers who had children with long-standing asthma express a lack of understanding or confusion about how medications worked. Some lack understanding of how to use inhalers, required dosages and when to administer medications. Parents and carers communicated that healthcare professionals used different inhaler techniques and rarely checked parents' and carers' inhaler techniques. Some parents and carers felt that hands-on learning with their healthcare professional would be beneficial.

Some parents and carers equate use of an inhaler with asthma management, often at the exclusion of other approaches to management and prevention.

> *"The only thing I really know is the um albuterol If I don't have that, no then I would be kind of lost in not know what would be the next step." "we would like to know what cause the episode so we can keep the child away from it so we're not constantly giving the child albuterol."*[87(p.37)]

Parents and carers use a variety of strategies to manage their children's asthma according to their beliefs about asthma and the perceived benefits from medication use. Some parents and carers try to reduce symptoms by encouraging their child to use preventer medication and to be physically active to help build their strength and to try to prevent severe attacks.

"I push them to do all the sports as it will build their lungs up rather than them just sitting as couch potatoes and then the next thing you know they've got to run down the street and cannot even run."[101](p.112)

Some parents and carers wait until an asthma attack occurs before taking action to minimise its effects. This group is less likely to seek professional advice and even when advice is provided does not always take it on board. They reported receiving mixed messages from healthcare professionals and demonstrated a lack of trust in the advice provided.

"Sometimes I feel that they [the doctors] don't know enough about it."[101](p.112)

Furthermore, they tended to minimise the risks to their children and see their children's asthma as a mild form of the disease.

"I've never needed any support, its just very mild asthma and it doesn't really get in the way of his daily living so, not that bothered."[101](p.113)

They adopted strategies such as hot baths, chest rubs and keeping their child home from school should an attack occur.

"I just do, like, what I've always done, if they are bad I keep them in do you know what I mean, lie them on the settee just give them Calpol or Paracetamol and use the em, the smelly for them."[101](p.112)

These parents and carers were more likely to rely on the use of reliever medication and often expressed confusion over the purpose of other medications. Some parents and carers expressed concern about the effectiveness of the drugs. Inhaled relievers tend to have immediately noticeable effects, whereas long-term preventer medications show no or less dramatic effects and mothers questioned the need to expose children to medications where positive changes are not observable.

"He's only been taking the blue one like when and if needed. He's never really needed his brown one."[101](p.112)

Those who believe asthma to be a chronic disease that children have all the time regardless of symptoms, practice strategies such as developing routines to ensure children receive their asthma medication as prescribed, whereas those who view it as an acute condition that comes and goes tend to wait until an asthma attack occurs before taking action to minimise the effects.

"Well, we leave his puffer by his toothbrush so every morning, ok before school, go brush your teeth and take your puffer and at bedtime you know obviously brush your teeth and take a puff,

right?...We've tried calendars, we've tried notes on the mirror and that type of thing. It's you know, constant monitoring.*"*[152(p.9)]

Some parents and carers believe that some level of asthma is tolerable and seek to minimise the physical, psychological and social impacts of asthma and treatments. For example, some families kept pets, despite knowing that these could worsens their child's symptoms and there was a sense of denial as to the harmful nature of these exposures.

"He's not [allergic] to the dog we've got, but he is allergic to my sister's dog."[101(p.113)]

Parents and carers use a process of trial and error to test medication regimens and non-pharmacological interventions. Many use trials without preventer medications to decide whether the side effects of preventer medication outweigh their effectiveness in precluding asthma. Some parents and carers view their children as being vulnerable to weakness and sensitivity but believe in the possibility of the child growing out of their asthma.

Some parents and carers use the Peak Expiratory Flow (PEF) to check their children's asthma symptoms and as a tool to determine when it is time to increase medication.

"You can see from the values when she starts to get worse, then it will only reach a level of 90 when it should be 130 and then you know that it's time to inhale lots of drugs, because you see that an infection is on the way."[116(p.188)]

Category 4.7.3: Caregiver concerns over medication side effects

Parents and carers are concerned about the amount of medications their children are taking. Additionally they are concerned about the long-term effects of oral and inhaled steroids and also the effects of reliever medication. Some parents and carers felt that there was a degree of uncertainty in the medical community about the effects of long-term use of inhaled corticosteroids.

"…I know they test them [inhaled steroids]…but the effect that something may have over a 2- or 3-year period many be different than if it is over a 15- or 20-year period. I guess nobody knows the answers to these questions."[95(p.379)]

Some parents and carers refuse to administer daily medications due to concerns about possible side effects experienced by the child. Asthma medication side-effects included sore throats, heart palpitations, oral fungal infections, problems with teeth, weight gain and sometimes more severe effects such as bone problems. Some fear their child will become dependent or immune to steroids.

Others fear that steroids will inhibit their child's growth or affect their bones or other organs. Some parents and carers are also concerned about the side effects of reliever medications.

*"If he's going to use 'Singulair' then why give him 'Zyrtec' at the same time? And why use 'Albuterol' and then 'Advair' too and the shots for the allergies, for a kid that's 10 years old? I understand it's for his health but it's a lot for a 10 year old child…..like an old man, he takes three types of inhalers, three types of pills, and shots for his allergies…."*48(p.703)

*"He has really bad teeth and the dentist thinks it's because of medications he is taking for his asthma."*111(p.6)

*Many mothers noted that their children became hyperactive after taking the drug. They mentioned that it negatively affected their children's concentration level in school, interrupted their sleep, and made them tired, cranky, restless, and jumpy.*107(p.49)

*"With time, I noticed that my son started limping. I took him to an orthopedic specialist. He made some examinations and he said that the laboratory tests showed that the cortisone had affect his [my son's] bone and he prescribed Vitamin D drops for him. In the mornings he [my son] complains about his feet, that he feels some pain."*85(p.949)

*"The biggest thing with my son would be the weight gain due to the steroids so initially he put on a lot of weight and we really had to keep after him not to over eat, try to be active and things like that."*110(p.246)

Although some parents and carers were troubled about their children's medications, they acknowledged that their symptoms had improved since using the medications.

Category 4.7.4: Medication issues – Adherence

Although parents and carers do not like giving medications to their children, some understand the necessity of inhaled corticosteroids and this is generally due to an observed improvement in their child's symptoms. Parents and carers actively evaluate the effectiveness of medications and make treatment decisions based on the perceived risks versus benefits of medications.

*"Her asthma may not disappear, but with the medicines you can suppress it." "The well-being of my daughter depends on the use of the medication."*119(p.250)

"But it's one of those… it's catch 22. You know if you don't take them you hit problems so you know if I think we can sort this out and then deal with the issues later. You know like they say about weight

*and everything. I just think if she is not on them, she's not well so you really haven't got much choice really."*106(p.173)

Category 4.7.5: Medication issues – Non-adherence

There are a variety of reasons for non-adherence to medications. These include: intentional non adherence, forgetting medications and hassles with medication administration. Lack of family routine and complicated home circumstances affected the ability of parents to adhere to regular asthma medications. Home life was described by some as being an endless juggling of competing priorities such as inadequate housing, financial difficulties and other family illnesses. This is particularly evident in families of lower socio-economic status. Family life lacked routine, particularly regarding adherence to medication with some parents and carers discussing that they were not home when the child needed to take their medication which meant the child was solely responsible for this. Some parents and carers were of the opinion that children often younger than 10 years of age were old enough to manage their own medications. Thus, for low-income families daily life complications seem to be a barrier to consistently administering medications to their children.

Some parents and carers adjust their child's medication according to what they think is the desired level of asthma control for their child whereas others lack the drive to achieve good adherence.

*"No, I don't follow each of the paediatrician's recommendations. I look at my child, whether he needs the meds or not."*118(p.109)

Furthermore, some parents and carers try not to use asthma medications even when the child has symptoms feeling that discontinuing medication would let the body react naturally.

"I just wait and see. I don't give him his inhaler or….none of his medications at first, because I just kind of want to wait and see if his own body, you know, his own immune system will boot it out and will take care of it. But it hasn't yet. Always at the end, I have to use his meds."107(p.51)

Administering daily preventer medications consistently was challenging for parents and carers and particularly so in the absence of asthma symptoms. Parents and carers understand the concept of preventing asthma symptoms, but often do not connect the concept of prevention with medication use. Some prefer non-medical alternatives such as calming techniques, breathing exercises and dietary manipulation. Some only use preventer medications when their child has symptoms, cease medications when their child appears well or asymptomatic or use medications intermittently. Others negotiate with their healthcare professional a season, usually summer, without using preventers and then restart them again the following winter. Some parents and carers modify instructions given by their healthcare professional in order to reduce the amount of medication their child was taking, particularly when the child was well. Modifications to medications were predominantly based on health beliefs about the use, safety, and long-term complications of using medications. Often these beliefs led to suboptimal management of their child's asthma.

> *"They were meant to be supposedly on the daily medications….then they'd go through a time where they were symptom-free…you're meant to carry on and we get carried away with life and the asthma inhalers have fallen under beds."*[86(p.24)]

Many parents and carers lack understanding of how to use inhalers and spacers correctly and some perceive children to resist medications due to difficulties using inhalers, emotional discomfort, medication side effects and taste or smell of the medication. Some parents and carers chose to resolve the conflict of giving their child medication by delaying or even omitting treatment altogether.

> *"He did not like the taste and smell of the medication."*[85(p.949)]

> *"Sometimes I would feel so bad to give it to her, that I maybe skip."*[121(p.188)]

Parents and carers discussed the need for parental assistance with medications and the necessity of reminding children with asthma to take their medications. Furthermore, a child's family structure also affects the taking of medications. Following a divorce, the care of a child had been fragmented and whilst one parent ensured her child took medication when the child was with her, she was unsure what occurred during the custodial changeover.

Category 4.7.6: Complementary and alternative medicine

Parents and carers make choices whether or not to use complementary, alternative medicine or homeopathy. Some parents and carers prefer the use of home and comfort remedies such as relaxation, steam therapy, herbal medicine and vitamins to traditional medications. These choices are often based on their level of satisfaction or dissatisfaction with prescribed medications, cultural backgrounds and beliefs and advice provided by family members and support networks. Some use complementary and alternate therapies due to the physician's inability to satisfactorily address parents' and carers' medication concerns. Others use alternative medicines until the child has an acute attack, when they opt for traditional Western medicine. Furthermore, some parents and carers chose not to disclose the use of complementary and alternate medicines to their healthcare professionals.

Hispanic mothers, fathers, and grandparents all demonstrated strong beliefs in the use of folk medicines and natural remedies to treat asthma. Some used natural remedies due to their lack of resources and their inability to access a doctor.

*"I also had asthma symptoms, and they went away with possum oil."*126(p.480)

*"We had very few resources and we couldn't go to the capitol where the doctor was, so people were cured with herbs."*126(p.480)

*The first mother interviewed talked about her great grandmother and the use of herbal treatments: "…she used to always be creative with ginger (jengibre) and made tea out of ginger and some other green leaves from Puerto Rico."*100(p.359)

*"Besides the nebulizer - what do you call it? I don't like putting all that stuff on him. I have a thing where you filter the air. You put Vicks in the water and let it boil. The humidifier? Right, I don't have one right now. It's gone. But I put a little pot on the stove and we sit there in the kitchen because it circulates the air."*145(p.95)

Category 4.7.7: Use of an asthma action plan

Asthma action plan usage varies amongst parents and carers with some expressing their intrinsic value whereas others find them to be unhelpful. Those who find them unhelpful, lack understanding of how to follow the plan, find them to be too generic and generally not beneficial. In contrast, other families feel empowered by the asthma action plan and know how to follow the steps without hesitation. They feel that the written asthma action plan is easy to follow, is useful for all family members in the absence of the primary caregiver and improves their child's care.

*"they all reads the same…yea I don't think it's more individualize, I would like for it to be more individualize per child because whereas like her child has asthma but his trigger is not as bad as her child's trigger."*87(p.37)

*"the doctor gave us the Asthma Action Plan, it is easy to follow. We have stuck it on our fridge, so that I and my husband can follow it when required."*111(p.6)

4.8.1 Synthesised finding 6: With time, parents and carers became more comfortable managing their child's asthma

The sixth synthesised finding relates to parents' and carers' acceptance of asthma and their ability over time to accept and manage their child's condition.

With time, parents and carers become more comfortable managing their child's asthma and they use their initiative to change medications based on symptoms. Parents and carers accept asthma into their everyday life and establish routines, plan ahead with family activities and encourage children to self-manage their condition.

Seven categories generated by 119 findings contributed to this synthesised finding. A summary of each of the seven categories is provided below, together with a few key illustrations that support them.

Category 4.8.2: Adaptation and coping strategies

Parents and carers adapt to caring for and living with a child with asthma. They make lifestyle choices such as whether or not to have pets in the home, the decision to smoke or allowing smoking in their child's immediate environment, home cleanliness, and the choice to work or be available for their child. Parents and carers modify everyday life so that children can participate in the same activities as children without asthma. Parents and carers express hope that their children may "grow out of the asthma" as informed by healthcare professionals and are optimistic that research would produce new and improved treatment for asthma. Some express an interest in learning deep breathing techniques, yoga and mindfulness in order to manage their stress. Finally, they accept asthma, adjust to life's situation and try to see positive aspects of their situation.

> *"It's easier now, it's second nature. It was hard to learn it, the what to do and how to do it but once I've learnt it, it's just do what you have to do not, it's not that panic situation any more.... You have to control asthma, you can't cure it, you have to maintain and control it. I control it by not giving him foods that are going to set off an allergic reaction., by not having animals, and by trying to keep the dust bunnies down."*[99(p.100)]

> *"How to eat right, exercise properly, even, you know, maybe some type of exercising that you could do with your child. I know they have like yoga and baby-type thing, you know, things like that, maybe something that you and your child could possibly do together, just to kind of maybe ease some of the stress or what have you. I think things like that would be definitely helpful…Deep breathing would be great. My child could use that. Maybe he'll calm down a little bit. But I would definitely do that."*[149(p.1627)]

> *"…it's a part of life. So you have to say, 'Fine. That's the cards that were dealt to me…"*[95(p.381)]

Category 4.8.3: Becoming experienced at managing asthma

With experience, parents and carers become more comfortable managing their child's asthma. Parents and carers felt that they had a better understanding of the disease process and the medications used to manage their child's asthma. They understood the rationale behind the treatment plan and this helped them to correctly manage their child's asthma.

"We feel quite comfortable, you know, in dealing with the situation now."[95(p.380)]

"I think understanding the disease, understanding why you're doing what you're doing makes it a lot more comfortable to deal with….I think that it is invaluable in your overall acceptance of it."[95(p.380)]

Furthermore as they gained experience treating their children's asthma, they felt more comfortable recognising and managing symptoms of asthma, dealing with acute episodes and knowing when to take their child to the hospital.

"After you experienced it [acute episode] a few times and saw that you knew how to deal with it, you [became] more comfortable in dealing with it."[95(p.380)]

Mothers expressed that they could tell when their child was becoming ill by changes in their activity levels, decreased appetite, the need for additional sleep, or just by the way they looked.

"I can tell, I can tell, pretty much every time I knew that something was wrong with him, I was always right all the time. Maybe once or twice I was wrong and they'd send him home, but hardly ever am I wrong. Practically every time [he'd be hospitalized] unless it was just for an ear infection or something. You know mainly every time I take him in for his asthma and his wheezing, usually they admit him. Most of the time. 75 per cent of the time."[121(p.234)]

The ability of parents and carers to recognise their information needs improves and some parents and carers express the need to direct the interaction with their healthcare professional and explicitly ask for more information.

"I have to do a lot of thinking before we come to make sure that I have all my questions ready to go."[86(p.24)]

Parents and carers take control, become vigilant with medications and begin to feel comfortable managing their child's asthma. Parents and carers with experience managing asthma reported that initially they would present at the ED all the time, but once more confident, they would "try to ride it out" at home.

*“She was sick for about 3-4 days, but she hasn’t deteriorated…Like if I could see that it wasn’t helping her then I would go to the doctor. But if I know that, you’ve got to ride it through and it will get better, because everyday it was getting a bit better and then towards the end it just stopped by itself.”*89(p.307)

Additionally, parents and carers felt more comfortable with asthma management when they saw their children responding favorably to the prescribed treatment plan. Children reported feeling better and parents and carers felt satisfied that their efforts were having a positive effect.

*"After she [daughter] was diagnosed and after she was on medications for a while, she said one night, "You know, Daddy, it’s like I can breathe again"….She could breathe again and things became a lot easier for her. That made it a lot easier for me."*95(p.380)

Parents and carers find that as children get older they are able to articulate their level of discomfort and medication needs and this also makes things easier.

Parents and carers emphasize the importance of knowing their child and being in tune to their child’s behaviour and symptoms in relation to activity, medications, climate changes and seasons.

*"And then over this last year, we were able to see better what times of the year she’s more affected. She’s definitely affected more in the fall... Uh-huh, when all the leaves and stuff are falling and rotting.... We just medicate her right off. When school starts, we just give her Singulair at night, and then we try to remember to give her Ceravent before she does running club."*132(p.34)

Category 4.8.4: Trial and Error

Once comfortable with asthma management, parents and carers use their initiative to change therapy based on symptoms. Some work collaboratively with their physician to adjust their children’s medications in circumstances that could cause a flare-up and at times when early symptoms were present, and to wean children off stepped-up treatment. Some parents and carers use a “trial and error” approach to assess the benefits and harms of particular treatments and to increase and decrease medications as parents deem necessary. Thus, they learn to take a proactive approach to asthma treatment.

*"When he starts getting better, I switch him from the Pulmicort to the Intal. I make those decisions on my own, but often still get them checked, just pop into the doctors office and have it confirmed. I pretty much have a handle on it now."*99(p.108)

*"He lived with a runny nose....I was very frustrated, I would try anything on the market....One night we gave him Sudafed for the first time and he ran up and down the hallway throwing toys...He just went crazy on us."*39(p.360)

*"The Ventolin has really cut down since Seretide. It took a few weeks though to kick in and what not, but I found even now that I'm starting to miss the evening with the preventative whereas I never used to, it's only been the last 6 weeks or something."*89(p.310)

Category 4.8.5: Children and self-management

As children gain more independence, parents and carers educate their children about asthma and encourage them to take an active role in asthma self-management. Parents and careers identified the need for their children to become more independent and responsible for recognizing their symptoms, administering medication and controlling their asthma. They also express the need for children to take preventative measures by avoiding triggers. Furthermore, they want their children to be able to recognize a severe exacerbation and verbally express their asthma symptoms and needs to others. Parents and carers often feel relieved when children can do this.

"Trying to have her watch out for triggers and especially animals because she loves animals."110(p.245)

"Having my children speak up. Teaching them not to be scared to say I need my inhaler or I can't breathe."110(p.245)

*"...Now, if he's feeling crummy, he'll come and ask for it [medication], the first day that that happened, I thought this is wonderful. It just takes all the guessing out of all your wondering."*99(p.105)

Some parents and carers continue to play a supervisory role by reminding their child to take medications and watching to make sure they take them correctly.

*"Not easy to remember to take it by herself, I should remind her".*85(p.949)

*"I often tell him how to use the medicine. Now, he is more active in taking his medication on his own because I tell him and also because I have trained him to do it. When he goes to school, we cannot care for him, therefore we tell him to take it by himself. Now, he also sometimes takes medication at night by himself."*97(p.1965)

Others give full responsibility to the child and some parents and carers and children work together in the management of the young person's medication. Parents and carers seemed to attribute their children's competence to being able to trust their children to be responsible rather than basing competence on the children's age. Girls were seen by carers as being responsible enough to be trusted to take their inhalers without supervision and some parents and carers were of the opinion that coping with a chronic illness resulted in their children being more responsible.

*"And she's a big girl. Like, like literally she'll go, go take your blue medicine. She'll go. Twist and squeeze it, and squeeze it back in the in the mask, and put the mask on, turn the machine on."*87(p.39)

"Because it's not my body or my husband's body…and I think largely I do trust her and I think it has given her a sense of responsibility. I think to be that chronically ill for nearly, most part of her life. I think it's sad that someone has such a thing but I think it has made her quite sensible."106(p.183)

Category 4.8.6: Establishing routines with medications

As parents and carers strive for their children to become independent with medications they identify strategies to help their children develop the necessary skills to manage their medications. Routines are established to remind children to take medications and to ensure that there is always an adequate supply of medication available. Some parents and carers use devices, charts, systems or diaries to keep track of asthma management. Others try to set a good example for their children by ensuring they have their own medication with them at all times. Furthermore parents and carers try to maintain continuity of care for their children by seeing the same healthcare professional and pharmacist.

"We don't go regularly but we keep the same provider, so that she's come to know her over the years. She knows when I call her I can get in that same day."110(p.245)

"I lead by example. She sees mine (asthma inhaler) in my purse and she doesn't see me using it all the time but because she sees it in my purse she's like 'oh okay, so you have it on you.' Kids are recorders she's using exactly what I do so that she'll have it case she needs it as well."110(p.245)

"I had his doctor prescribe two at a time, so, like you said, I can have one, and he can have one. They never tell you they ran out until they're completely gone."50(p.4)

*"I've set a routine when my son gets up in the morning. Generally I tell him to take a shower and immediately use his inhaler that way I know he's done it before he goes out the door. And then after hopefully he's good for the day but if not he's got an extra one in his pocket that goes to school with him or in his backpack just in case. I just keep my son's medication in the cabinet next to the toothpaste so he brushes his teeth, he takes his medicine. He doesn't have to take it during the day. That's not an issue."*110(p.245)

*"We had to be more regimented because…the medications that were prescribed for [daughter] were not part of our daily routine….It took some getting used to."*95(p.377)

Category 4.8.7: Normalising

Whilst parents and carers try to shield their children from situations that can trigger asthma they endeavor to maintain a normal family life. They are constantly watchful of their children however they try not to overprotect them. They do not want their children to be treated differently because of their asthma.

*"…so you try to compromise a little bit and you medicate them when they go, when they come home, and you monitor the amount of time that they are there….You can be as vigilant as you can, but.you want them to be like their friends."*95(p.378)

One mother made the decision not to tell her daughter or siblings about the daughter's asthma diagnosis as she did not want to worry them.

"I don't know if it's bad that I haven't told her what she has exactly, since she hasn't had it that strong I try not to worry her."48(p.704)

Some parents and carers express concerns around deciding appropriate ways to discipline the child with asthma without upsetting them and triggering another asthma attack.

*"Well I'm still afraid to discipline him because I worry whether getting him upset by disciplining him will bring on another asthma attack."*39(p.363)

Category 4.8.8: Planning ahead

Parents and carers plan ahead in regard to making appointments with healthcare professionals, filling medications, household cleaning and family activities in order to anticipate and avoid triggers and minimise symptoms.

*"There's a lot of forethought in planning activities. Vacations have to be well thought out."*95(p.378)

*"But just to make sure you're prepared is the biggest thing. Because I would hate to be somewhere and not have the machine….and be like stuck with my baby who can't breathe."*117(p.991)

4.9.1 Synthesised finding 7: The need for support

The seventh synthesised finding relates to the support needs of parents and carers, in particularly mothers as they shoulder the majority of burden of care for their children.

Mothers are predominantly the primary caregivers for children and many feel alone in managing the burden of asthma. They rely on family members, healthcare professionals, education setting staff and other networks for support.

Two categories generated by 135 findings contributed to this synthesised finding. A summary of each of the two categories is provided below, together with a few key illustrations that support them.

Category 4.9.2: The need for support from family members, the community and health professionals

Mothers are predominantly the primary caregivers for children with asthma and many feel alone in managing the burden of asthma. They rely on family, healthcare professionals and other networks for support. Family members were identified as an important support system for their children especially in relation to medication management.

*“Yeah I just wanted to add that I think it was important for me to tell my family how important it is for them to keep up with my daughter to take her medicine.”*110(p.246)

*“My sister had it [asthma] when she was younger really bad. So, she had a whole lot of hospital stays and things like that. So, we, my mother and we know how serious it is. So, my whole family, they be on it.”*50(p.5)

*"When [my children] are having an attack, it is really hard watching them suffering. Talking helps me cope. I have a really good support network with my sisters and my mother, family, and friends….you just don’t feel so alone and my sisters, 2 of them have kids with asthma, so it helps talking to them be cause they know what you’re going through."*150

Mothers depend on extended family members, particularly their own mothers for support and although this solved the problem of child care it sometimes resulted in additional stress due to the reliance on others to manage their child’s asthma. Furthermore some caregivers limited their child’s social outings to those where they knew that adults had knowledge of asthma management.

*“Their children have asthma too so they know the drill. They got the EpiPens…And I feel actually, sadly enough, I feel more comfortable with some who do have it and know the drill rather than someone that don’t.”*50(p.5)

Fathers expressed the importance of spousal support. They felt that ongoing discussion and collaboration with their spouses about asthma provided a sense of togetherness and a feeling of teamwork in day-to-day asthma management. Like mothers, fathers too receive support from other family members and friends, particularly those with personal experience of managing asthma.

*"We are in this together. We lean on each other."*95(p.380)

*"I….used my sister as an example…She was doing a good job [in managing her son's asthma]…I just saw how she was taking care of her situation…I felt if she could do it, so could I. I didn't think it was a big job for her."*95(p.380)

Some parents and carers feel unsupported by family and friends due to their lack of understanding of the labourious nature of asthma and some feel a sense of blame due to children always being unwell. Some mothers expressed difficulties in preventing other family members from overreacting to their child's asthma.

*"My aunt called me yesterday and said that she was real scared because I had let my little boy go out of town for the weekend with his daddy. She said she was real scared because he'd been coughing for three weeks and that medicine don't seem to be helping. I told her it's helping for what it is for. It's not to help him stop coughing. It is to help him loosen up his chest. And she said, "Well, I don't know about that, I'm just worried to death." I tried to tell her, but it don't do no good."*93(p.201)

*"I think that it is very difficult to ask people for help here. People think that when you come here, you know it all."*126(p.480)

*"No one could bring my son to hospital. They always said they couldn't communicate with doctor. I was the only one who knew everything about my daughter's symptoms, all treatments, and her medications so I had to do this. My husband had to work and couldn't desert his work so I had to manage by myself. When my child got worsen, the doctor gave him an appointment during the month that I was sick so I didn't have any day off left…I was so stressed."*139(p.193)

*"I was just by myself... Everybody thought I was always exaggerating about it (crying)."*99(p.92)

A lack of an adequate social support system for immigrant mothers of a child with asthma was expressed. Parents and carers feel that support groups are an important opportunity to connect with other parents and learn about coping with asthma and stress.

*"We need support groups….I really don't have anybody else to go [to] other than my doctor."*150(p.5)

Although mothers expressed the need to rely on family members for support, some felt sometimes this proved to be problematic, for example one mother was reluctant to let her child visit her father because he did not keep his house dusted and he smoked cigarettes and the child would become sick following each visit.

*"Sometimes its just more trouble than it's worth."*93(p.202)

Furthermore, parents and carers need support from their healthcare professionals. They need to feel that they can readily access their doctor, have a continuing, trusting relationship with one healthcare provider or clinic, access to asthma education, psychological support and ongoing reassurance that they are controlling their child's asthma. Barriers to asthma management include lack of continuity of staff, difficulties getting appointments, lack of psychological support and lack of education provided by healthcare professionals.

*"I am quite happy about my doctor because the first time I had to give it (Betnesol), this is what happened: I gave him Betnesol. I gave it at home. I have given it in the morning, and he (the doctor) said, "well, you've done just the right thing." You just need someone to say that to you, to reassure you exactly about what you need to do."*102(p.12)

Category 4.9.3: The need for support from school / childcare

Parents and carers experience a lack of support from education staff and policies that create barriers to children accessing their asthma medications. Parents and carers are concerned about triggers in the school environment such as poor indoor air quality, physical education, school cleaning, maintenance and renovations as well as outdoor trigger such as pollen and cold air.

*"…one day when it was cold and raining, he [son] was out at lunchtime. That upset me…because that [the weather] causes his asthma to act up. So I phoned the school. The principal told me, 'Well, there's lots of children with asthma in the school and it doesn't seem to bother them."*95(p.379)

Parents and carers are also concerned about the social impact of asthma on their child. They worry about their relationships with their peers and the effect that asthma might have on their learning.

*"She's the only one with the asthma at her little school, it's only such a tiny little school…So what, you know, it's just the stigma, isn't it, it's just the standing out."*129(p.421)

They also expressed concern about their children's safekeeping at school and much of the concern centred on school policies pertaining to the use of medications. Parents and carers discussed that their children felt embarrassed taking their medication in front of their peers, and were afraid to participate in sports as they felt they would not be able to perform well. Parents and carers emphasized their children's limitations in regards to physical activity and the importance of having medications close by.

"I told them that he had asthma, and that he can't participate in gym or something like that. He can participate in certain things but there are certain things he can't participate in, like running and jumping because he gets so excited to where he can't hardly breathe. Then I tell them that he has to keep his book bag outside or keep his pump in his pockets just in case he should need it. I ask them to keep a close eye on him."[93(p.200)]

Parents and carers lack confidence in the ability of school and childcare staff to manage their child's asthma and many chose to keep their child at home when their asthma was likely to flare up. Some parents and carers expressed concern over the perceived lack of adequately trained staff that can recognize asthma symptoms and the need for prompt treatment with medication. Parents and carers were also concerned about the lack of credibility given to their teens when reporting asthma symptoms and this often resulted in ineffective actions by staff.

"I am absolutely not confident about the school to take care of my child when he has asthma attacks. I forced him to absent himself from school for a week...even though he become better."[85(p.950)]

"From the time she was little I had to drag this nebulizer to childcare with me, and the childcare providers that we found, when they saw something like that they looked at you with horror. They did not want to be responsible for operating this machine."[131(p.77)]

"Well my daughter says I need my inhaler….well they're not going to let you go to the locker room to get it or wherever it is. The problem is they won't believe the child."[110(p.247)]

Parents and carers are particularly concerned about the lack of access for children to their asthma medication, with many school and childcare policies stating that they are to be kept at the front office or in the first aid room. Most parents and carers felt that policies should be flexible regarding inhaled medications for children with asthma. Conflict sometimes arose between parents and carers and school personnel when parents and carers tried to intervene to change school policies for their children. Some parents and carers however admitted to allowing their children to carry their puffers with them while in school knowing that this was against policy.

"If someone was having an asthma attack and they needed their inhaler right then, I don't think it's such a good idea to have it at the other end of the school and have to get permission, and sometimes

*it's a student in the office, and not a person who can get the medicine, and that sort of thing. It's unfortunate because it ends up hurting the kids."*88(p.388)

"So we sent him to school with it [the puffer] and said, 'Just keep it in your book bag and if you got to use it, just use it, and we'll take it from there."95(p.379)

Parents and carers discussed the importance of parent-school communication, with many reporting this to be lacking. Communication appeared to be superficial, relating to recording a diagnosis of asthma or alternatively reactive, occurring following an asthma attack, with some schools not requesting an asthma action plan.

In contrast however, some parents and carers recall positive experiences with asthma care provided by schools, in particular that the school kept records detailing which children had asthma and allowed children to bring and use their own inhalers at school. Furthermore, some parents and carers described positive actions that had been taken regarding caring for their child when they suffered an asthma attack at school. Parents and carers felt that services provided by school nurses were excellent, but many felt that they were insufficient due to the part-time nature of their employment. Parents and carers act as advocates for their child and regularly communicate with education staff to ensure they have an understanding of their child's health needs.

*"Each year…I would have to go to school and give my standard asthma spiel to the teacher to make sure she understood what he needed and when he needed it."*108(p.117)

Parents and carers convey the importance of schools adopting a stronger advocacy role in relation to asthma. They advocate for school policies to be developed involving multiple stakeholders. They articulate the need for asthma education at schools and that parents and carers, teachers and students, including those without asthma should be participate in this education. Education should take the format of workshops and educational programs for teachers, group sessions and online programs for parents and carers and online games and videos for students.

"I would suggest going to the school board meeting the one that the superintendent attends or let it come from the top down because traveling to one school or each school on an individual basis is going to be troublesome"110(p.247)

*"I think the most important need is education to children [students without asthma as well] inside schools regarding asthma."*85(p.950)

4.10.1 Conclusion

Caring for a child with asthma and managing their condition is challenging for parents and carers. Attaining a definitive diagnosis of asthma can be difficult and parents and carers express fear and uncertainty due to continuing symptoms and repeated hospitalisations. The relationship with their healthcare professional is vitally important and a clear diagnostic strategy and treatment plan needs to be communicated so parents and carers have an understanding of the pathway to receiving an actual diagnosis. Supportive relationships with healthcare professionals taking a partnership approach, ensuring adequate time, continuity of care, regular follow-up and addressing psychosocial and cultural needs and concerns of parents and carers is essential. Comprehensive asthma education is important at the onset of asthma symptoms, with the provision of accurate, easy to understand and culturally relevant information. Support groups and training for education staff is imperative to ensure they can support parents and carers, provide asthma friendly environments and respond appropriately in an asthma emergency.

4.4 DISCUSSION

4.4.1 Introduction

This section describes a summary of the findings of the review, review limitations, implications for clinical practice and future research recommendations. This is the first systematic review of qualitative studies exploring the experiences of parents and carers in caring for and managing asthma in children. Parents and carers experiences were captured within seven over-arching themes:

1. Negotiating the meaning of having a child with asthma
2. The process of getting a diagnosis and acquiring information
3. The impact asthma has on family life
4. Relationships with healthcare professionals
5. Medication beliefs, concerns and management strategies
6. Over time, parents and carers become more comfortable managing their child's asthma
7. The need for support.

Several limitations are possible however, and although a systematic search was carried out and every effort made to identify relevant studies, it is possible that some may have inadvertently been missed. Furthermore, studies conducted since the search was undertaken have not been included in the review.

4.4.2 Negotiating the meaning of having a child with asthma

One of the key themes highlighted by the review is the range of emotions experienced by parents and carers when struggling to understand the meaning of asthma symptoms and negotiate their child's asthma care. Emotions such as fear, anxiety, uncertainty, panic, denial and guilt are common and parents and carers worry that their child may die as they struggle to breathe.[90, 104, 126, 132] Asthma's unpredictable nature, relentless symptoms and speed of onset contributes to the fear, stress and uncertainty that parents' and carers' experience.[50, 106, 123] Many view asthma as an acute, episodic disease that is present only when their child has symptoms.[91] They find themselves in a largely unknown world and feel helpless, guilty and frustrated due to their inability to relieve their child's suffering.[48, 96, 121]

The constant concern that parents and carers live with is highlighted in many studies and this concern becomes increasingly prominent when their children become acutely unwell. They feel the need to be constantly vigilant, on guard and always standing by so they can administer treatment promptly. [115, 145] They carefully plan and control their child's daily life in order to keep them safe and are alert to situations or activities in which their child may be exposed to allergens that trigger their asthma.[105 95] Parents and carers are hesitant to leave their child in the care of others as they lack trust in their ability to care for their child.[89, 115]

Parents and carers existing knowledge, prior experience and beliefs about asthma shape the meanings they attach to asthma and influence their approaches to disease management.[51, 99] Those with previous experience managing their own asthma or another family member's asthma were more familiar with the condition, more comfortable managing it and more trusting of medications.[106]

This is consistent with literature highlighting that caregivers of children with chronic illness exhibit greater general parenting stress than caregivers of healthy children.[42] Research reveals that improving medication adherence and asthma knowledge in families has been shown to be associated with less parenting stress.[155]

4.4.3 The impact asthma has on family life

The review also highlights the impact asthma has on family life. Mothers are primary caregivers for children with asthma, and for some, the overall sense of responsibility permeates most aspects of their lives.[115] Many express feelings of isolation and sadness.[105] They struggle to balance work, family life, siblings and partners with labour intensive asthma treatments, household cleaning to minimise triggers and the financial burden of medications.[93, 135] Mothers experience stress and exhaustion due to asthma attacks frequently occurring at night and in the early hours of the morning.[89, 97, 113] Mothers often stay up throughout the night watching their child struggle to breathe or sleep with their child in order to monitor their condition.[117, 147]

Furthermore, many mothers feel that siblings, their partners and their own needs are often overlooked as they focus on caring for the child with asthma.[51, 96] Some parents and carers experience financial hardship due to their inability to work and the costs of medications, equipment and transportation to hospital.[85, 99, 137] Some make choices to purchase reliever medication only and forgo preventers when funds are short.[141] For low income families, the ability to maintain continuous employment, food and insurance insecurity, poor housing conditions and environmental exposures are factors they feel are out of their control.[50] Furthermore, family tensions and disagreements sometimes arise regarding the correct approach to managing asthma.[96]

Family life and activities are restricted due to asthma and parents and carers long for a normal life.[92, 156] Meticulous planning is required for family holidays to ensure hotels are not dusty or moldy and holiday destinations are often limited due to the need to be in close proximity to emergency services and have mobile phone coverage.[156] Many children miss school due to their asthma and parents and carers express concern about the affect asthma has on their school performance, limitations on their physical activity and ability to maintain a healthy weight.[111] Some are concerned about their child going away on school camps.[89]

Parents and carers express a reluctance to make their children different from their peers by restricting activities however some felt this was necessary to avoid the risks.[38, 121] Some parents and carers carefully supervise their children's contact with other children for fear of them being exposed to germs.[48] Conversely, other parents and carers did not restrict their child's activity as they worried that restricting activities would have a detrimental psychological impact on their child.[124] Parents and carers are concerned about their child's future, the duration of the disease and whether it will become more severe in the future.[50, 92, 95] Parents and carers worry about how their child will manage their condition when they become teenagers and voice concern that their children may not give this a high priority.[95] Thus, they educate their child about asthma to ensure they have the necessary skills to effectively self-manage their condition.[97] Healthcare professionals need to understand the complexities around treatment adherence and support caregivers to develop treatment regimens that minimise the impact on everyday life and family relationships.

4.4.4 The process of getting a diagnosis and acquiring information

Parents and carers experience considerable difficulty obtaining a definitive diagnosis of asthma.[130] In the pre-diagnosis period, caregivers often experience feelings of fear and uncertainty around managing continuing symptoms with no definitive diagnosis and as a result many make frequent visits to the ED.[36] Family members feel confused, anxious and frustrated due to the perceived reluctance of healthcare professionals to make a diagnosis.[36, 114, 126] Furthermore, without an official diagnosis, parents and carers feel unsure whether to give medications and how to manage symptoms.[114] Parents and carers feel that healthcare professionals do not acknowledge or take their concerns seriously and this contributes to further delays in receiving a diagnosis.[116] Therefore, asthma is often managed in a fragmented and reactive manner and symptoms treated as they occur.[101] Research reveals that parents and carers express satisfaction with the diagnostic process when the health professional communicated a pathway to obtaining a diagnosis, especially in severe asthma.[109] This highlights the importance of health professionals providing a plan for managing symptoms and asthma education even in the absence of a definitive diagnosis.

For many parents and carers, attaining a diagnosis of asthma took periods ranging between 6 months to 3 years. In families with only one child with asthma and for the first child in the family with asthma it seemed to take longer to receive a diagnosis than for subsequent children.[95] Although many parents and carers had suspected their child had asthma knowing a diagnosis brought with it a sense of relief.[120] Armed with a diagnosis, parents and carers focus on learning as much as possible about asthma by networking with friends and colleagues and self-teaching due to a perceived lack of education provided by health professionals.[131]

Parents and carers require information to understand the nature of asthma and know how to manage asthma symptoms, especially in emergency situations.[126] They struggle to differentiate asthma symptoms from other health concerns and stress the importance of simple, consistent, written information on asthma symptoms, triggers, medications and their side-effects.[50] They perceive a lack of asthma education provided by healthcare professionals.[86, 96] Furthermore, their perceived lack of knowledge and inability to manage their child's condition contributes to their fear, anxiety, stress and uncertainty around caring for their child with asthma.[90] Lack of education is also felt to impede parents' and carers' ability to identify information deficits and ask questions during interactions with healthcare professionals.[86]

Parents and carers who had attended asthma clinics reported receiving the information they required and felt this to be of a high quality, personalised in nature and provided much needed follow-up.[86] This resulted in increased asthma knowledge, improved inhaler technique and improvement in overall levels of confidence.[86]

Parents and carers describe difficulties recognising asthma symptoms and determining the severity of an asthma exacerbation.[108] Those with less asthma experience are generally more uncertain in recognising asthma symptoms, identifying triggers and carrying out treatments.[117] Parents and carers of young children in particular express difficulties due to the young child's inability to verbalise their discomfort.[117]

Severity is generally determined by the frequency and severity of symptoms and the ability of parents and carers to adequately treat the child at home or whether ED or medical treatment is required.[48] Severity is also determined by the extent of limitations of activities for the child and some parents and carers recognise worsening asthma through mood and behaviour changes.[38, 48] Some parents and carers view the use of the “spray” (reliever) medication to be routine, whereas the need to use the “machine” (nebuliser) was felt to be indicative of more severe asthma.[48]

Managing the complex allergies experienced by children is identified by parents and carers as a significant caregiving responsibility.[50] Parents’ and carers’ knowledge of asthma triggers includes environmental triggers such as pollen, dust, mold, chemicals, perfumes, pollution, pets, exercise and smoke.[48, 50, 97] Cold weather, cold liquids and foods are also identified as triggers for asthma. Once asthma triggers are identified, parents and carers implement strategies to minimise triggers in the home environment including keeping their home clean, washing bed linen, damp dusting, vacuuming, banning indoor smoking, using hypoallergenic mattress and pillow covers and removing stuffed animals from the child’s room. Some parents and carers limit their child’s physical activity in order to prevent exacerbations.[94, 97]

Parents and carers face challenges identifying asthma triggers and trying to minimise their child’s exposure to them.[48] Some weigh up the risks versus the benefits of their lifestyle choices.[99] Some are unsure about the source of triggers for their child’s asthma and feel that it is beyond their control to reduce exposure.[142] Family poverty and poor housing in particular leave children vulnerable to triggers that for many families are out of their control.[87]

Parents and carers emphasize difficulties reducing their child’s exposure to triggers whilst still maintaining good family relationships especially in regards to limiting family members smoking in the vicinity of children.[88] Furthermore, some parents and carers identified conflicts over family pets with some choosing to eliminate pets from their home whereas others, whilst aware that pets were a trigger for asthma, still allowed pets in the home.[88]

4.4.5 Relationships with healthcare professionals

Another key theme highlighted by the review is the importance of the relationship with the healthcare professional on overall health experiences. Parents and carers require information about asthma in order to make an informed decision and many parents and carers perceive a lack of education.[48, 86] Research reveals that whilst parents and carers desire information they are often reluctant to ask questions.[157] Some parents and carers feel intimated by healthcare professionals and unaware of what questions they should ask.[50, 86]

Communication issues with healthcare professionals are evident for some parents and carers with some discussing the need to be conscious about words and expressions used during conversations with the doctor.[36] Some parents and carers feel the need to be assertive in order to receive the appropriate treatment.[99, 119] Further parents and carers with professional status, in particular those working in hospitals indicated that their child's physician "assumed" a level of asthma knowledge due to their professional status.[85] Healthcare professionals should be mindful not to "assume" that parents and carers have existing knowledge about asthma and should provide education at every available opportunity.

Cultural differences add further complexities with parents and carers from CALD backgrounds expressing that language barriers make communicating with healthcare professionals difficult and they have difficulty explaining what is wrong with their child.[90, 149] Parents and carers therefore seek out a healthcare professional who can speak their language and provide them with resources including an asthma action plan in their language.[114, 136] Some parents and carers feel that healthcare professionals lack cultural understanding of the importance of the extended family/kinship network for these families including the need to have multiple family members present.[137] Additionally, parents and carers from CALD communities and lower socio-economic status groups express feelings of being judged, inferior or misunderstood by providers and reluctant to ask questions without other family members present.[124, 137] Some feel accused of neglecting their children, not controlling asthma symptoms and delaying seeking emergency care.[130] Furthermore, some parents and carers lack trust in the use of professional interpreters, feel they are unavailable when they need them and prefer to rely on family members to interpret.[136] They feel that providers do not value parents and carers as experts on their child's life and discussed the importance of self-advocacy in encounters with healthcare professionals.[50, 121, 140]

Parents and carers lack confidence in their ability to manage acute asthma and as a result many seek ED care.[86] The decision to go to the ED is not an easy one and mothers feel that making this call is primarily their responsibility.[102] Furthermore, the inability to control asthma symptoms and timing of exacerbations (often at night) makes trips to the ED necessary.[87, 90] Parents and carers seek ED care for acute asthma attacks and some parents and carers find professional guidance reassuring and feel relieved to transfer responsibility for the child's care to healthcare professionals.[50, 51, 139, 148] Some feel that their child's recovery might take longer without IV medications and suctioning.[121, 144]

In contrast, however, some parents and carers find the hospital experience to be a difficult one and traumatic for both parents and carers and children.[121] Parents and carers feel the ED environment to be busy and crowded and those presenting for the first time discussed that they did not know what was happening with their child and were not told their child had asthma.[90, 100] Some parents and carers discussed cold, rude treatment that they received when they presented to the ED.[90] Some discussed the use of restraints and this was distressing for both parent and carer and child.[121] Some parents and carers express difficulties when required to leave their child in the care of healthcare professionals and feel left out and that their expert knowledge about their child is not taken into consideration.[105] On the contrary, some parents and carers discussed the pressure they felt from hospital staff to be fully responsible for the care of their child.[123] This is consistent with literature highlighting the importance of healthcare professionals understanding the role that parents and carers prefer to have in decisions about their child's medical care.[71] Furthermore, healthcare professionals may not recognize the extent of the parents' and carers' fear and anxiety and their inability to comprehend instructions due to this fear and anxiety.

Parents and carers discussed the importance of written information and educational materials being provided on discharge from the ED.[56, 86] The importance of consistent information is highlighted.[48, 56] Parents and carers with limited health literacy discussed concerns regarding conflicting information, in particular where medication package instructions differed from advice provided by the physician.[152] Their preferences were for written material in a simplified format that avoided the use of medical jargon.[56] Parents and carers also emphasized the importance of a suitable quite space and adequate time for discharge communication.[56] Furthermore, some parents and carers discussed the challenges of learning new and complex information in the ED whilst trying to supervise other children and suggested that access to child care could improve their ability to focus and retain information.[56]

Parents and carers have expectations to be treated by a knowledgeable, competent, supportive healthcare professional, to be provided with consistent information, continuity of care and be provided with regular follow-up.[103, 116, 119] Some parents and carers develop relationships with specialist respiratory nurses and many feel that they provide them with the support required to manage their child's condition.[114-116, 129] Trust in their healthcare professional was crucial to receiving quality care. Parents and carers discussed the importance of healthcare professionals having good verbal and non-verbal communication skills, considering their opinions, providing high quality care, allowing adequate time, being available when they need them, culturally competent, respectful, addressing parents' concerns and including them in the decision-making process.[103, 142, 148] This is consistent with research highlighting parents' and carers' desire for healthcare professionals who will listen to them, acknowledge their concerns and include them in the healthcare decision-making process.[108] A study from Kuethe et al reported that adherence to asthma treatment could be improved with a strong healthcare professional patient partnership.[119]

Healthcare professionals should be aware of the need to initiate discussions with parents and carers and encourage open communication to ensure all their questions and concerns are addressed. Referral to a specialist should be offered if parents and carers are unsatisfied with the treatment outcomes. Literature highlights that for optimal treatment, patients/families and healthcare providers need to have a shared understanding of the nature of asthma, treatment goals, the role of medications, and self-management practices.[37] Shared decision-making, involves the family and physician working together to select evidence-based treatment options in line with the family's values and preferences.[158] However, not all parents and carers may want shared decision making in all cases and it is important for healthcare professionals to understand the role that parents and carers prefer to have in decisions about their child's medical care.[71]

Additionally, parents and carers express satisfaction with their child's healthcare professional when they communicated a plan of action to diagnose asthma after multiple respiratory episodes.[109] Interestingly, parents and carers who were happy with their general practitioner reported being willing to travel long distances in order to maintain the relationship with the healthcare professional.[89] Furthermore, parents and carers discussed the importance of healthcare professionals taking a more holistic approach to asthma management and consider not only the child's physical but also mental well-being.[124]

Parents and carers who were unsatisfied with the information and care received reported they shop around for a second opinion.[99, 139] Many parents and carers view referral to an asthma specialist as important and stress that families should be referred to an asthma specialist for management of their child's asthma.[109, 130] Some parents and carers feel the need to be assertive in order to obtain a referral to a specialist.[130]

4.4.6 Medication beliefs, concerns and management strategies

As documented in the literature and highlighted in the review, parents and carers express concern over the long term use of asthma medications. Many do not view asthma as a long term condition requiring continuous preventer medication and many do not perceive inhaled steroids to be a safe treatment.[119, 143] In contrast, parents and carers who had observed an improvement in their child's symptoms from inhaled corticosteroids tended to adhere to medications.[95, 119] Many parents and carers discuss the challenges surrounding administering daily preventer medication consistently, particularly so in the absence of asthma symptoms.[91] Although many understand the concept of preventing asthma symptoms, they do not connect the concept of prevention with medication use.[91]

Parents and carers express confusion over the actions of the different medications and have difficulties differentiating preventer medication from reliever medication.[111] Even those with children with long-standing asthma express a lack of understanding or confusion about how medications worked.[37] Furthermore, many lack understanding of what constitutes good asthma control or how it is achieved.[50]

Parents and carers are concerned about side-effects of asthma medications, particular cortico-steroid medications (preventers).[87, 91, 137] Concern is also expressed over side-effects from reliever medications.[99, 107] Preventer side-effects included sore throats, oral fungal infections and weight gain and side-effects from reliever medications are generally related to heart palpitations or hyperactivity.[110, 122] Parents and carers express concern that their child will become dependent or immune to steroids (preventer medication) and others fear that steroids will inhibit their child's growth or affect their bones or other organs.[152] They feel there is a degree of uncertainty in the medical community about the side effects of long-term use of inhaled corticosteroids.[95] As a result of their concerns about medications, some parents and carers refuse to administer daily medications to their children.

Parents and carers also express concern about the effectiveness of medications.[88] Inhaled relievers tend to have immediately noticeable effects, whereas long-term preventer medications show no or less dramatic effects and mothers queried the need to expose children to medications where positive changes are not immediately obvious.[124]

Although parents and carers do not like giving daily medications to their children, some understand the necessity of inhaled cortico-steroids and this is primarily due to an observed improvement in their child's symptoms.[119] Parents and carers tend to weigh the risks versus benefits of medications and make treatment decisions based on whether the effectiveness of medication outweighs the perceived risks.[106] Some use a process of trial and error to test medication and non-pharmacological interventions.[101]

Parents and carers who believe that asthma is a chronic disease that children have all the time regardless of symptoms, practice strategies to develop routines to ensure children adhere to their medication as prescribed.[91, 95] They try to reduce symptoms by encouraging children to use preventer medication and by being physically active to help build strength and try to prevent severe attacks.[106]

Some use Peak Expiratory Flow (PEF) to check their children's asthma symptoms as a tool to determine when they need to increase medication.[116]

In contrast, those who view asthma as an acute condition that comes and goes tend to wait until an asthma attack occurs before taking action to minimise the effects.[91] Some equate the use of inhaler with asthma management, often at the exclusion of other approaches to management and prevention.[145] Some parents and carers try not to use asthma medications even when the child has symptoms believing that discontinuing medication would let the body react naturally.[124] Some parents and carers attempt to minimise the physical, psychological and social impacts of asthma and treatments and view some level of asthma to be tolerable.[38]

There are a variety of reasons for non-adherence to medications. These include intentional non-adherence, forgetting medications and difficulties administering medication.[85, 91, 118]

Some parents and carers only use preventer medications when their child has symptoms, cease medications when their child appears well or asymptomatic or use medications intermittently.[48, 119] Others negotiate with their healthcare professional a season, usually summer, without using preventers and then restart again the following winter.[48] Some modify instructions given by their healthcare professional in order to reduce the amount of medication their child was taking, particularly when the child was well.[79] These modifications were primarily based on health beliefs and the use, safety and long-term complications of using medications.[124] Often these beliefs led to suboptimal management of their child's asthma.

Lack of family routines and complicated home circumstances affect the ability of some parents and carers to adhere to regular asthma medications.[152] Some mothers discussed that they were not home when their child needed to take their medication leaving the child responsible for managing their medication.[153] Some parents and carers believed children often younger than 10 years of age were old enough to manage their own medications.[118] For some, home life was described as an endless juggling of competing priorities including inadequate housing, financial difficulties and family illnesses.[152] Furthermore, family structure also affects the taking of medications with one parent discussing that following a divorce, the care of her child had been fragmented and whilst she ensured the child took medication when they were with her, she could not be sure of what happened when she stayed with her father.[85]

Parents and carers sometimes struggle to administer medication to young children and children are sometimes perceived to resist taking their medications due to medication side-effects, taste or smell.[111] The emotional discomfort and conflict of giving their child medication is sometimes resolved by delaying or omitting treatment altogether.[118] Furthermore, some parents and carers lack understanding of how to use inhalers, required dosages or when to administer medications.[86] Parents and carers communicated that healthcare professionals used different inhaler techniques and rarely check parents' inhaler technique.[86] Some felt that hands-on learning with their healthcare professional would be beneficial.[86]

Parents and carers make choices whether or not to use complementary, alternative medicine or homeopathy. Some parents and carers adopt home remedies such as hot baths, steam therapy, chest rubs, breathing exercises, dietary restrictions, herbal medicine in preference to using medications.[107, 117] These choices are often based on their level of satisfaction or dissatisfaction with prescribed medications, cultural backgrounds and beliefs and advice provided by family members and support networks.[139] Some use complementary and alternate therapies due to the physician's inability to satisfactorily address parents' medication concerns.[139] Others use alternative medicines until the child has an acute attack and then adopt traditional Western medicine.[98] Interestingly, some parents and carers choose not to disclose the use of complementary and alternative medicine to their healthcare professional.[100]

Hispanic mothers, fathers and grandparents have strong beliefs in the use of folk medicines and natural remedies for the treatment of asthma.[126] Some used natural remedies due to lack of resources and their inability to access a doctor.[99]

Asthma action plan usage varies amongst parents and carers with some expressing the intrinsic value of using a plan, whereas others find them to be unhelpful.[87, 111] Those who find them unhelpful lack understanding of how to follow the plan, find them to be too generic and generally not beneficial.[87] In contrast, other families feel empowered by the asthma action plan.[51] They have a good understanding of how to follow the steps, feel the plan is easy to follow, useful for all family members in the absence of the primary caregiver and improves the child's asthma care.[51]

4.4.7 Over time parents and carers become more comfortable managing their child's asthma

Over time, parents and carers accept their child's asthma and become more comfortable managing the condition.[95] They express a better understanding of the disease process and medications used to manage their child's asthma, understand the rationale behind the treatment plan and take a proactive approach to asthma treatment.[95] Some work collaboratively with their physician to adjust their children's medications in response to changes in their asthma and others use "trial and error" approaches to assess benefits and harms of treatments and increase and decrease medications as deemed necessary.[38] They feel more comfortable recognising and managing symptoms, dealing with acute episodes and knowing when to seek emergency care.[31] They accept asthma into their everyday life, establish routines, plan ahead and encourage children to self-manage their condition.[38] They find that as children get older they are able to articulate their level of discomfort and medication needs and this makes things easier.[117] Parents and carers make lifestyle choices regarding pets in the home, allowing smoking in their child's immediate environment, home cleanliness, environmental exposures and the choice to work or be available for their child.[99] They modify everyday life so that children can participate in the same activities as children without asthma.[95] They hope that their child may "grow out of the asthma" and are optimistic that research will produce new and improved asthma treatments.[114] Finally, they accept asthma, adjust to life's situation and try to reflect on the positive aspects of their situation.[48, 95]

As children gain more independence, parents and carers educate them about asthma and encourage them to take an active role in managing their asthma.[50] Parents and carers feel that children need to become more independent, responsible for recognizing symptoms, administering medication, avoiding triggers and controlling the condition.[97] They want children to be able to recognize a severe exacerbation and to verbally express their needs to others and parents often feel relieved when children can do this.[99, 110]

Some parents and carers however continue to play a supervisory role, reminding their child to take medications and watching to make sure that they do this correctly.[85] In contrast, others give full responsibility to the child and some work together in the management of asthma.[128, 144] Parents and carers assess the child's competence to manage asthma on their ability to be responsible rather than being related specifically to age.[106] Girls were seen by carers as being responsible enough to be trusted to take their medication without supervision and some parents and carers feel that coping with a chronic illness has made them more responsible.[147]

Over time as the illness symptoms and treatments are better understood, strategies are implemented to deal with events that emerge and parents and carers establish routines and plan ahead with family activities to maintain a normal family life.[110] Routines are established to remind children to take medications and ensure that adequate supplies of medication are always on hand.[95] Some parents and carers use devices, charts, systems or diaries to keep track of asthma management.[37] Whilst parents and carers try to protect their children from situations that could trigger asthma, they also try to maintain a normal family life.[95] They do not want their children to be treated differently because of their asthma.[95] This is consistent with literature on parenting interaction styles which include: compensating, restricting or normalizing.[159] The normalising style involves parents and carers giving their child every opportunity to be like other children despite their illness.[132] In contrast, some parents and carers adopt the compensating style, reducing age-appropriate demands and doing extra things for their child.[159]

4.4.8 The need for support

The need for support was expressed by parents and carers, in particular mothers who tended to carry the majority of the caring role.[37] They rely on family members, healthcare professionals, education setting staff and other networks for support.[130] Family members are identified as an important support system for their children particularly in relation to medication management.[104] Whilst mothers depend on extended family members, particularly their own mothers for support this can in itself be stressful due to the reliance on others to manage their child's asthma.[115] Some caregivers limited their child's social outings to those where they knew that adults had knowledge of asthma management.[50] Similarly, fathers express the importance of spousal support and how ongoing discussion and collaboration about asthma provides a sense of togetherness and feeling of teamwork in day-to-day asthma management.[92]

Some parents and carers discussed feeling unsupported by family and friends due to their lack of understanding of the arduous nature of asthma, difficulties preventing family members from overreacting to their child's asthma and their child being continually unwell.[93, 138] Immigrant mothers in particular express lack of adequate social support and feel the need for support groups to connect with other parents and carers and learn about coping with asthma and stress management skills.[150, 151]

Parents and carers require support from their healthcare professional. In particular they need to feel that they have ready access to their doctor, have a continuing, trusting relationship with one provider or clinic, access asthma education, psychological support and ongoing reassurance that they are controlling their child's asthma.[92, 99, 148]

Finally, parents and carers require support from school and child care staff. Many feel a lack of support from education staff and policies that create barriers to children readily accessing the asthma medication.[88, 131] Parents and carers are concerned about their children's safekeeping at school due to school policies requiring asthma medications being kept in the front office or first aid room.[95] Most parents and carers expressed the need for flexible policies regarding inhaled medications for children with asthma and conflict sometimes arose between parents and carers and school personnel around this.[39] Some parents and carers, whilst aware of it being against school policy, admitted to allowing their children to carry their puffers with them while in school.[110]

Additionally, parents and carers are concerned about the school environment and the potential triggers including poor air quality, physical activity, cleaning chemicals, maintenance and renovations, pollen and cold air.[85] They also express concern about the social impact of asthma on their child and worry about their relationships with peers and the effect asthma may have on their learning.[97] Parents and carers discussed that children felt embarrassed taking their medication in front of their peers and were afraid to participate in sports for fear of not being able to perform well.[111]

Parents and carers lack confidence in the ability of school and childcare staff to manage their child's asthma and many chose to keep their child at home when their asthma was likely to flare up.[85] Some parents and carers express concern over the perceived lack of adequately trained staff that can recognize asthma symptoms and the need for immediate treatment.[110] They also expressed concern about the lack of credibility given to their teens when reporting asthma symptoms resulting in ineffective actions by staff.[110]

Parents and carers act as advocates for their children and regularly communicate with education staff to ensure they have an understanding of their child's needs.[110] The importance of parent-school communication was discussed, however many felt that this was lacking.[39, 110] They discussed the superficial nature of communication, often relating to recording a diagnosis of asthma.[110] They feel that a reactive approach is taken following an asthma attack with some schools not requesting an asthma action plan.[110]

In contrast, some parents and carers recall positive experiences with asthma care provided by schools. Schools with asthma nurses were felt to provide excellent service, however they were insufficient due to the part-time nature of many of the school nurses.[153]

Parents and carers express the need for schools to adopt a stronger advocacy role in relation to asthma.[85] School policies should be developed involving multiple stakeholders.[110] The need for asthma education at schools was discussed and it was felt that parents and carers, teachers and students, including those without asthma should participate.[85] Education should be provided in multiple formats including workshops, educational programs, group sessions, online programs, videos and games.[148]

The process of becoming comfortable with asthma management tends to follow a cycle as outlined in Figure 2 below:

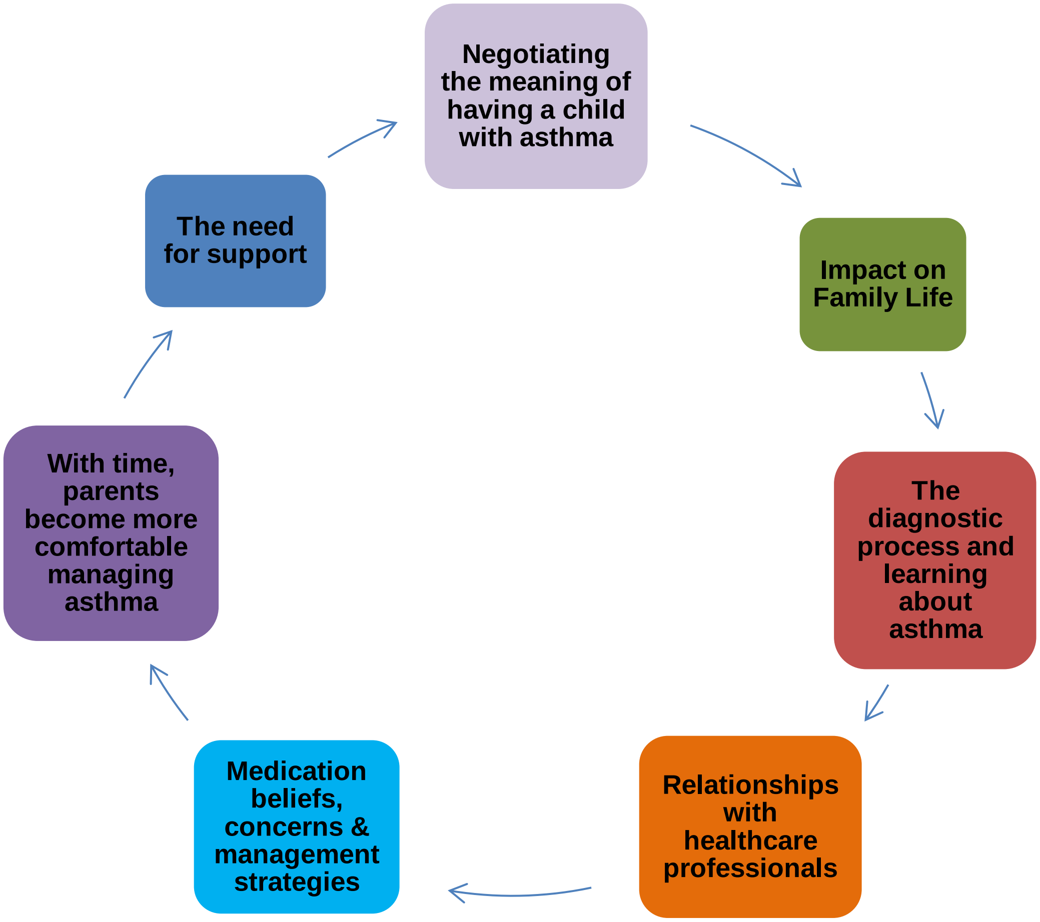

Figure 2: The process of becoming comfortable with asthma management

4.4.9 Barriers to asthma management

Difficulty obtaining a definitive diagnosis of asthma is a barrier to asthma management. Prior to receiving a diagnosis caregiver's experience fear and feelings of uncertainty around managing continuing symptoms and many make frequent visits to the emergency department. Parents and carers express that a diagnostic strategy was not communicated to them and that health professionals had high expectations of them regarding treatments. Furthermore, the time taken to achieve a diagnosis of asthma was felt to be too long, sometimes between 6 months to 3 years.

A frequently mentioned barrier identified by parents and carers was relating to the amount and quality of the information they received about asthma. In many cases, parents and carers felt the information provided by healthcare professionals was inadequate and unclear. Parents and carers are confused over the actions of different medications and concerned about the long-term side-effects of medications. They discuss inadequate time with their healthcare professional and lack of continuity, with many parents and carers seeing multiple healthcare professionals.[137]

The relationship with the healthcare professional is important for good asthma management. Some parents and carers lacked trust in the knowledge and care provided by the healthcare professional. They feel mistreated or misunderstood by healthcare professionals and some felt that healthcare professionals talked down to them and did not listen to them.[137] Some described feeling inferior in the presence of healthcare professionals and reluctant to ask questions without other family members present.[137]

Parents and carers identified barriers associated with ED healthcare professionals including the use of medical terminology and the lack of adequate time or opportunity for discharge communication. Furthermore, parents and carers with limited health literacy identified conflicting information from healthcare professionals as a barrier to the discharge process.[56]

Language can be a barrier to asthma management. Parents and carers from CALD backgrounds have difficulty communicating with healthcare professionals and find it hard to explain what is wrong with their child. Parents and carers describe a lack of cultural understanding with healthcare professionals not understanding the importance of the extended family network.[137] Additionally, parents and carers from CALD communities and lower socio-economic status groups express feelings of being judged, inferior or misunderstood by providers and reluctant to ask questions without other family members present. Some feel accused of neglecting their children, not controlling asthma symptoms and delaying seeking emergency care. Furthermore, some parents and carers lack trust in the use of professional interpreters, feel they are unavailable when they need them and prefer to rely on family members to interpret.

4.4.10 Enabling factors

Whilst numerous barriers exist for parents and carers in managing asthma, this review also highlights factors that enable good asthma management. Caregivers feel satisfied with the diagnostic process when their doctor communicated a plan of action to diagnose asthma after the child experienced respiratory symptoms.[109] The provision of accurate, consistent information[48] and educational opportunities[148] to learn about asthma including recognizing symptoms, assessing severity, asthma triggers, medications, side effects and how to achieve good asthma control is a fundamental learning need to enable parents and carers to manage their child's asthma.[117, 137, 142] Understanding asthma to be a chronic condition that children have regardless of whether they are actively symptomatic and the need for daily medications in order to keep the airways healthy is essential.[91] In addition, minimising asthma triggers in the home environment is shown to decrease the child's chance of having an asthma exacerbation and lead to improved management.[88, 94]

Supportive relationships with healthcare professionals are essential[116] including culturally competent providers[104] who have good verbal and non-verbal communication skills, are good listeners, willing to spend time with both the caregiver and the child with asthma,[142] acknowledge parents and carers concerns and include them in the decision-making process.[108] The availability of healthcare professionals, access to appointments,[103] continuity of care,[132] regular follow-up[152], having an asthma action plan[51, 145] and providers considering the psychosocial and socioeconomic needs of families are also important factors.[88, 111] Specialist respiratory nurses were also felt to provide the support parents and carers needed to manage their child's asthma.[115, 116]

Furthermore, supportive family and spousal relationships have been shown to lead to better asthma management.[104, 110] The establishment of routines to ensure consistency with medications[37, 110] and planning ahead for family activities in order to anticipate and minimise triggers has been shown to result in improved asthma management.[95, 108] Encouraging children to take an active role in managing medications with parents and carers overseeing this has also been shown to allow children to become more autonomous and relieve the burden on parents and carers.[38, 110]

Supportive school environments, including school policies that allow children to carry medications and for staff to have access to comprehensive asthma training in order to provide safer, more supportive environments is recommended.[50, 131]

This review includes the experiences of parents and carers caring for and managing asthma in children from 0-18 years of age and it is likely that the experiences of parents and carers vary according to the child's age. However, due to a lack of uniformity of children's ages reported in included studies, it is difficult to ascertain with certainty if this is the case. Nine studies however, examined experiences of parents and carers of preschool aged children and these have been analysed separately for similarities.

Parents expressed difficulty recognising asthma symptoms in young children compared to older children due to young children being unable to verbalise their discomfort.[117] It is possible however that this could also be due to the parent's lack of experience with the condition. In younger children, parents identified the need for constant vigilance and the desire to watch the child's activities during the day in order to anticipate asthma symptoms early and begin treatment.[92, 108] Furthermore, the young age of the child and the need to provide medications on a regular basis meant that child care was a concern, work was disrupted and some parents were reluctant to allow the child to be away from their supervision at all.[89, 99, 112] Importantly, many of these families were either single parent families or had low incomes. The emergency department experience was particularly traumatic for parents and carers of young children. It was viewed as a life-threatening crisis and compounded by their lack of information and understanding, long waits and fear that their child might die.[109, 121, 133]

The experience of parents and carers changes as children become more independent and able to recognise symptoms and self-administer medication. This transfer of responsibility from parent to young person most commonly occurred in response to specific occasions or circumstances.[128] Many parents and carers take on a supervisory role, reminding children to take medications[85] and supervising asthma care.[50]

As this review contained studies from 12 countries, analysis was undertaken to identify similarities and differences in findings across countries and cultures. Thirty nine papers were from USA, seven from Canada, three from Taiwan, one from Thailand, 11 from United Kingdom, two from Norway, three from Sweden, three from The Netherlands, one from Saudi Arabia, one from Iran, four from Australia and two from New Zealand. The majority of papers in this review were from the USA so this country is over-represented.

Studies from USA, UK and Norway reveal that parents and carers feel confused and express that physicians did not give them a clear diagnosis.[36, 90, 126, 131] A Canadian study by Cashin reveals that it took periods ranging from between six months to three years before a diagnosis was confirmed and fathers were of the opinion that it took longer to receive a diagnosis among families with only one child with asthma and for the first child in a family of three than for subsequent children.[95] Studies from USA, Thailand and Canada reveal that parents and carers express feelings of relief at knowing the diagnosis and obtaining a management plan.[95, 120, 132, 139] In contrast, some parents and carers from USA, Canada, Australia and Taiwan describe negative emotions and feelings ranging from anger and frustration to fear and devastation on receiving a diagnosis[111, 131] and some parents and carers express difficulties accepting the diagnosis.[96, 99] This highlights the importance of healthcare professionals providing support, education and information for parents and carers at this time to ensure they have the necessary skills, information and support to manage their children's condition.

Parents and carers from USA, Canada, Taiwan, The Netherlands, Australia, Saudi Arabia and UK report receiving little or no education at the time of asthma diagnosis or during subsequent medical visits.[85, 86, 94, 96, 99, 119, 126, 133] Many parents and carers in Australia, Norway, USA and Canada however, express satisfaction with medical care and are comfortable with the care their children receive.[111 36, 93, 95] However, whether or not caregivers had received asthma education, they expressed a desire for continuous educational information on medications, asthma triggers and symptoms[142] and the importance of written information[56] and demonstration of medications at the time of emergency department discharge.[56] Studies from UK, New Zealand and Sweden reveal the high levels of confidence parents and carers had in asthma nurses who could provide them with more dedicated time.[114-116]

Overall, parents and carers experiences of caring for and managing asthma in a child across countries is similar in that they all experience living with constant concern, fear and frustration due to the unpredictable nature of asthma. In Australia, caregivers reported that asthma often left them feeling frustrated.[89] Parents and carers in Taiwan discussed the inability to control the symptoms of the disease often results in feelings of sadness, anxiety, helplessness and frustration.[96] Similarly a Swedish study discussed parents feelings of inadequacy and frustration when their child had exacerbations[116] and a USA study described parents and carers feelings of desperation or hopelessness.[48] Ongoing education is important so that parents and carers can understand the importance of preventer medication on a daily basis, recognise early symptoms, treat exacerbations and know when to seek emergency assistance.

Similarly parents and carers from a variety of countries express feelings of having an unusual life. Studies from the UK, USA, Australia and Canada reveal that parents and carers are highly conscious of the impact of asthma on the whole family[89, 108] and on the limitations of the child's activities.[48, 99, [112, 121] A study by Borhani reveal that mothers are saddened by the fact that they cannot have a comfortable life like others and are stressed by their child's illness.[92] Similarly Swedish studies reveal the dominant feeling for mothers was one of sadness and they long for a relationship between mother and a healthy child and a life with less restraint.[105, 138] Australian parents express concerns over their child missing school due to acute asthma exacerbations and the effect that asthma has on their performance in class.[111] Healthcare professionals should be mindful of the impact of asthma on family life and provide simplified treatment plans that minimise the impact on family life.

Studies from USA reveal that parents and carers emphasise their child's limitations with physical activity and the importance of access to medication particularly at school.[93, 94, 97, 110, 124, 131] One study from Saudi Arabia reveals that children are afraid to play sports at school as they feel they will not be able to perform well.[85] In contrast, in a UK study parents and carers encourage children to be physically active to build strength in order to prevent attacks.[101] A further UK study describes parent and carer reluctance to make their children different from their peers by restricting activities, however some describe this as necessary to avoid risks of asthma.[38] Furthermore, another UK study reveals that GPs encourage children to exercise stressing that asthma should not prevent the child engaging in physical activities.[151] The child's willingness to take part in exercise, parent and carer beliefs about the child's physical capability and the safety of exercising in the presence of perceived triggers seems to influence parent and carer support of the child being physically active.[151] Healthcare professionals should educate parents and carers on the importance of their children being physically active and that if their asthma is well controlled it should not impact on their performance.

Financial burden due to costs of medications, equipment and transportation to hospital was expressed in a number of studies across countries. In particular, an Australian study discusses the struggle for many families to find the money needed to replenish medications on a regular basis.[89] Similarly, a Canadian study expresses parents and carers feelings of helplessness regarding obtaining financial help to cover drug costs.[141] A Taiwan study highlights the costs of supplies like anti-mite sheets as being too expensive,[98] hospital treatment in Thailand being expensive[139] and the high cost of asthma friendly materials in Saudi Arabia.[85] USA studies however focussed more on socio-economic barriers such as finding and paying for transportation to the hospital or primary care clinic,[137] insurance instability, food insecurity,[145] poverty and housing instability[50] as impacting on parents and carers ability to provide care for children with asthma.

Use of complementary and alternative medicines was examined for differences across countries and cultures. Some parents and carers had concerns over healthcare professionals' treatment of their child's asthma and chose to use complementary and alternative medicines. Studies of Puerto Rican, Hispanic, Hawaiian, African American, Mexican and Taiwanese parents and carers reveal strong beliefs in the use of folk medicine and natural remedies in the treatment of asthma.[97, 98, 100, 117, 126, 145 48, 107] Taiwanese parents and carers tend to use alternative treatments and traditional Chinese medicine until the child had an acute attack and then they opt for Western medical care. Herbal medicines, vitamins and steam therapy were used by parents and carers in one Australian study.[111]

4.4.11 Limitations

There are several potential limitations with this review. Although a systematic search was carried out and every effort made to identify relevant studies, it is possible that some may have inadvertently been missed. However, the systematic approach involving review of the literature by two independent reviewers coupled with a search of multiple databases including searches of several "grey sources" of potential evidence, does provide a comprehensive search platform to answer the review questions.

Additionally, studies may have been conducted since the search was undertaken and subsequently have not been included in the review. Only studies published in the English language were included in the review and the review was limited to the following geographical areas: USA, Canada, Taiwan, Thailand, UK, Norway, Sweden, The Netherlands, Saudi Arabia, Iran, Australia and New Zealand. In addition, the participants are predominantly female so may not be representative of the full diversity of men's experiences.

4.4.12 Recommendations for Practice

The collation of the voices of parents' and caregivers' from the 77 research papers reinforce that the needs of parents and carers in caring for a child with asthma are still not being adequately met. The synthesized findings have been carefully considered and recommendations for practice developed from these findings in order to reduce the barriers faced by parents and carers in the management of the condition. It is evident however that many of the synthesized findings crossover into more than one of the recommendations for practice. The way the recommendations for practice were developed from the synthesized findings will now be discussed.

Synthesized findings 4.4.2 Negotiating the meaning of having a child with asthma and 4.4.3 The impact asthma has on family life both emphasize the difficulties parents and carers face and the emotions they experience as they struggle to understand asthma symptoms and negotiate family life in light of the restrictions and limitations asthma imposes. From these two synthesized findings recommendation one was developed highlighting the need for information and education to help parents and carers to prepare for and adjust to this new situation. These findings also contribute to recommendation three and the need for health professionals to link parents and carers to support networks such as asthma clinics for ongoing support.

Synthesized finding 4.4.4 The process of getting a diagnosis and acquiring information discusses the difficulties parents and carers face in obtaining a definitive diagnosis of asthma and from this finding recommendation two was developed highlighting the need for health professionals to communicate a clear pathway to attaining a diagnosis. This finding also contributes to recommendation one focussing on the need for education at first hospitalisation or GP visit for the condition.

Synthesized finding 4.4.5 Relationships with healthcare professionals leads into recommendation two and the importance of a supportive relationship, good communication and partnership approach to healthcare decision making.

Synthesized finding 4.4.6 Medication beliefs, concerns and management strategies similarly leads to recommendation two and the need for healthcare professionals to acknowledge parents and carers concerns and recognize their expertise.

Synthesized finding 4.4.8 The need for support leads to the development of recommendation three (health professional support) and recommendation four (support at school and child care).

Synthesized findings 4.4.9 Barriers and 4.47 Over time parents and carers become more comfortable highlights the barriers and enablers to asthma management.

The Summary of findings table (Appendix VII) provides an indication of the level of confidence we have in the synthesised findings outlined in the review. Given the multitude of barriers parents and carers face in managing their child's asthma, a variety of recommendations are suggested to help breakdown these barriers.

(1) Asthma is a major disruption in family's lives and parents and carers value information and education that helps them prepare for and adjust to this new situation. Education should be provided at first hospitalisation or GP presentation for the condition and include information on the chronic nature of the condition, symptoms, assessing severity, triggers, medications and ongoing management. Information should be provided in simplified language and include visual learning aids and demonstration. (Grade A)

(2) A partnership approach to the management of asthma with families being included in the healthcare decision-making process. In the absence of a diagnosis, communicating a clear pathway to attaining a diagnosis and an immediate treatment plan for current management should occur. There is a need for supportive relationships with healthcare professionals, for them to be readily available, take time to listen to parents and carers, be culturally sensitive, acknowledge their concerns and recognize their expertise. (Grade A)

(3) Healthcare professionals should assist parents and carers to identify support networks including specialist respiratory nurses, asthma clinics or asthma foundations for ongoing support and to access asthma education programs to develop knowledge and skills. (Grade A)

(4) Schools and educational settings should provide supportive environments including asthma friendly school policies ensuring students have quick access to asthma medications. Staff training is essential to increase staff knowledge in asthma management, how to minimise triggers in the school environment and asthma first aid to treat an asthma exacerbation. (Grade A)

Overall, the evidence-based findings from this systematic review are valuable and should be used to inform and improve both existing services, supports and programs as well as develop new supports to ensure that parents and carers receive high quality care and education. Healthcare professionals need to have the necessary skills to diagnose and manage asthma appropriately and parents and carers need to receive adequate support from schools and educational settings.

4.4.13 Recommendations for Research

There has been no research investigating the experiences of Indigenous Australians parents. In light of the overrepresentation of asthma in the Aboriginal and Torres Strait Islander population, with the condition being almost twice as high as for the non-Indigenous population[8], this is an area where additional research is required. Furthermore much of the research is undertaken from the perspective of the mother and it is possible that fathers' experiences could be vastly different and additional research is required.

4.4.14 Conclusion

Childhood illness places extreme stress and burden on the primary caregiver. This review highlights the emotional and psychological pressures faced by parents and carers and the worry, fear, frustration and helplessness they experience as they negotiate their child's asthma. They express fear that their child might die during an asthma attack and nocturnal asthma attacks contribute to poor sleep quality and adversely impacts their own quality of life. Daily life is disrupted as they attempt to minimise triggers in the home environment, control symptoms, administer medications and manage attacks. Many feel helpless and unable to provide what their children require in an emergency or know how to relieve their suffering. Furthermore, many mothers are juggling work responsibilities, household tasks, other children and family responsibilities. The unpredictability of the disease necessitates keeping a watchful eye over their children and this results in limitations in children's physical activity and social interactions.

Economic hardship is faced by many parents and carers due to costs of treatments and products to maintain their child's health and an allergen free environment. Furthermore, many experience income losses due to the inability to maintain continuous employment whilst caring for a chronically ill child.

Children who have had a previous hospital admission for asthma are at higher risk of subsequent hospital visits. This highlights the importance of the provision of information and education at the time of discharge from the ED or alternatively referral to an asthma educator for education. The perceived lack of information about asthma, difficulty attaining a diagnosis and the unpredictability of its outcomes impair the ability of caregivers to cope with the illness. Healthcare professionals should provide consistent information in simplified language as well as combining visual learning aids and demonstration. Additionally, parents and carers need to feel heard by providers and families be engaged in discharge teaching.

Parents and carers require the provision of information regarding the illness, its management, medications and side-effects as well as coping and decision-making strategies. Instructions need to be clear and individualized to assist them in the planning and management of future asthma episodes. As families learn through experience of caring for a child with asthma, it is important to consider past experiences and observations of the caregiver.

The importance of the parent/healthcare professional partnership based on mutual respect, acknowledgement of expertise, sharing of information, open communication, affirmation and reassurance cannot be underestimated. This partnership approach between healthcare professionals and families holds the key to improving the health outcomes for children and their families.

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APPENDICES

Appendix I: Search Strategy

PubMed: 1+2+3 = 3,013 results

Search on 31st December 2017

Search	Query
#1	"parents" [mh] OR "parenting" [mh] OR "family" [mh] OR Famil* [tw] OR "caregivers" [mh] OR Caregiver* [tw] Parent* [tw] OR Caregiver* [tw] OR Father* [tw] OR Mother* [tw] OR Carer* [tw]
#2	"Qualitative research" [mh] OR qualitative research [tw] OR "interviews as topic" [mh] OR interviews [tw] OR "attitude to health" [mh] OR attitude to health [tw] OR attitude* [tw] OR lived experience* [tw] OR perception* [tw] OR perceived [tw] OR understanding [tw] OR ethnograph* [tw] OR phenomenol* [tw] or feminist and research [tw] OR critical and research [tw] OR action and research [tw] OR focus groups [tw] OR "focus groups*" [mh] OR illness perceptions [tw]
#3	"asthma" [mh] OR asthma* [tw] OR "respiratory sounds" [mh] OR respiratory sounds [tw] OR bronchial asthma [tw] OR bronchiolitis [tw] OR wheez* [tw] or respiratory sounds [mh:noexp] OR bronchial spasm [mh] OR bronchial spasm [tw] OR bronchospasm [tw] OR bronchoconstriction [tw] OR "Respiratory hypersensitivity" [mh] OR medication use [tw] OR adheren* [tw] OR "dyspnea" [mh] OR dyspn* [tw] OR shortness of breath [tw] OR breath shortness [tw] OR breathlessness* [tw]
#4	#1 AND #2 AND #3
Limit to 1972-2017, English language	

Embase: 1+2+3 = 1,512 results

Search	Query
#1	parent/exp OR caregiver/exp OR “care giver”:ti,ab OR caregiver*:ti,ab OR carer:ti,ab OR “family caregiver”:ti,ab OR family/exp OR “family attitude”/exp OR parent*:ti,ab OR care*:ti,ab OR “parental behavior”/exp OR “parental behaviour”/exp OR Father:ti,ab OR Mother:ti,ab OR “parent* experience*”:ti,ab
#2	“qualitative analysis”/exp OR Qualitative:ti,ab OR “qualitative research”/exp OR “health behavior”/exp OR “health behaviour”/exp OR interview/exp OR “attitude to health”/exp OR “lived experience”:ti,ab OR experience*:ti,ab OR Perception:ti,ab OR “perceived understanding”:ti,ab OR ethnograph*:ti,ab OR phenomeno*:ti,ab OR “feminist research”:ti,ab OR “critical research”:ti,ab OR “action research”:ti,ab OR “focus groups”:ti,ab OR “thematic analysis”:ti,ab OR “Illness perception*”:ti,ab OR experience*:ti,ab
#3	asthma/exp OR asthma*:ti,ab OR bronchiolitis/exp OR bronchiolitis:ti,ab OR wheezing/exp OR wheez*:ti,ab bronchoconstriction:ti,ab OR bronchospasm:ti,ab OR “bronchial asthma”:ti,ab OR “respiratory sounds”:ti,ab OR “bronchial spasm”:ti,ab OR “respiratory hypersensitivity”:ti,ab OR dyspn*:ti,ab OR “shortness of breath”:ti,ab OR “breath shortness*”:ti,ab OR breathlessness*:ti,ab
#4	#1 AND #2 AND #3
Limit to 1972-2017, English language	

CINAHL: 1+2+3 = 647 results

Search	Query
#1	MH parents+ OR TI parent* OR AB parent* OR MH caregivers+ OR TI caregiver* OR AB caregiver* OR TI father* OR AB father* OR TI mother* OR AB mother* OR TI carer* OR AB carer* OR TI family attitude OR AB family attitude OR TI parental behavior OR TI parental behavior OR AB parental behavior OR TI parental behaviour OR AB parental behaviour
#2	MH qualitative studies+ OR TI qualitative stud* OR AB qualitative stud* OR MH interviews+ OR TI interviews OR AB interviews OR MM health beliefs OR MH phenomenological research+ OR TI phenomenological research OR AB phenomenological research OR TI focus groups OR AB focus groups OR MH interviews+ OR TI interview* OR AB interview* OR MH health behavior+ OR TI lived experience* OR AB lived experience* OR TI parental attitudes OR AB parental attitudes
#3	MH asthma+ OR TI asthma* OR AB asthma* OR MH respiratory sounds OR TI respiratory sounds OR AB respiratory sounds OR MM Dyspnea OR MM Work of Breathing OR TI bronchiolitis OR AB bronchiolitis OR TI wheez* OR AB wheez* OR TI bronchospasm OR AB bronchospasm OR TI bronchoconstriction OR AB bronchoconstriction OR TI shortness of breath OR AB shortness of breath
#4	#1 AND #2 AND #3
Limit to 1972-2017, English language	

PsycINFO: 1+2+3 = 1,352 results

Search	Query
#1	caregiver$.ti,ab OR caregiver$.sh OR parent$.ti,ab OR parental attitudes.sh,ti,ab OR caregiver burden.tw OR caring behavio$.tw OR father.tw OR mother.tw OR famil*.ti,ab OR carer.ti,ab
#2	Qualitative stud$.ti,ab OR Exp Qualitative research OR lived experience.sh,ti,ab OR Interview$.ti,ab OR Attitude to health.tw OR Experience$.ti,ab OR Quality of life.ti,ab OR Health behavio$.ti,ab OR focus group$.tw OR phenomenol$.ti,ab OR ethnograph$.ti,ab OR feminist research.tw OR action research.tw
#3	Exp asthma OR Asthma$.mp,ti,ab OR Bronchiolitis.ti,ab OR respiratory tract disorders.sh,ti,ab OR Wheezing.mp OR Wheez$.ti,ab OR Disease management.sh OR Treatment barriers.ti,ab OR bronchial disorders.tw OR bronchospasm.tw OR bronchoconstriction.tw OR dyspn$.ti,ab OR breathlessness.tw
#4	#1 AND #2 AND #3
Limit to 1972-2017, English language	

Web of Science: 1+2+3 = 170 results

Search	Query
#1	TI=caregiver* TI=parent* TI=mother* TI=father* TI=carer* TI=famil*
#2	TI=qualitative* TI=interview* TI=experience* TI="quality of life" TI="life experience*" TI="lived experience*" TI=Ethnograph* TI=Phenomenol* TI="focus group*" TI="attitude to health" TI="feminist research" TI="action research"
#3	TI=asthma* TI=bronchiolitis TI=wheez* TI=bronchospasm TI=bronchoconstriction TI="bronchial spasm" TI="bronchial asthma*" TI="work of breathing" TI="childhood asthma" TI="chronic asthma" TI=breathless* TI=dyspn*
#4	#1 AND #2 AND #3
Limit to 1972-2017, English language	

Appendix II: Studies excluded after full text review

1. Alijani Renani H, Hajinejad F, Idani E, Ravanipour M. Children with asthma and their families' viewpoints on spiritual and psychological resources in adaptation with the disease. J Relig Health. 2014;53(4):1176–89.

   Reason for exclusion: Not parents experiences

2. Asher M, Price J. Childhood asthma: parents' views of professional advice. Community Practitioner. 1998;71(5):177–8.

   Reason for exclusion: Very limited parent voice

3. Barton CA, Sulaiman ND, Clarke DM, Abramson MJ. Caregivers' use of, and attitudes towards, written asthma action plans in North-West Melbourne. Prim Care Respir J. 2005;14(3):143–6.

   Reason for exclusion: Not parent experience - solely use of Asthma Action Plans

4. Bialostozky A, Barkin SL. Understanding sibilancias (wheezing) among Mexican American parents. J Asthma. 2012;49(4):366–71.

   Reason for exclusion: Children with and without asthma

5. Biksey T, Zickmund S, Wu F. Disparities in risk communication: a pilot study of asthmatic children, their parents, and home environments. J Natl Med Assoc. 2011;103(5):388–91.

   Reason for exclusion: Not parent experience - understanding of environmental risks

6. Buetow S, Adair V, Coster G, Hight M, Gribben B, Mitchell E. GP care for moderate to severe asthma in children: what do infrequently attending mothers disagree with and why? Fam Pract. 2003;20(2):155–61.

   Reason for exclusion: Not parent experience

7. Buetow S, Adair V, Coster G, Hight M, Gribben B, Mitchell E. Reasons for poor understanding of when and how to access GP care for childhood asthma in Auckland, New Zealand. Fam Pract. 2002;19(4):319–25.

   Reason for exclusion: Exclude expert views

8. Buford TA. Transfer of asthma management responsibility from parents to their school-age children. J Pediatr Nurs. 2004;19(1):3–12.

   Reason for exclusion: Exclude - children have comorbid conditions

9. Bulbul A, Jones CJ, Mukhopadhyay S, Smith HE. Parents' experiences of administering asthma medications to their children thematic analysis of online forum discussions and blog entries. Allergy. 2015;70:639–40.

   Reason for exclusion: Exclude - poster only

10. Buu MC, Carter L, Bruce JS, Baca EA, Greenberg B, Chamberlain LJ. Asthma, tobacco smoke and the indoor environment: a qualitative study of sheltered homeless families. J Asthma. 2014;51(2):142–8.

    Reason for exclusion: Shelter staff views

11. Callery P, Milnes L. Communication between nurses, children and their parents in asthma review consultations. J Clin Nurs. 2012;21:1641–50.

    Reason for exclusion: Exclude - asthma review consultations

12. Cane R, Pao C, McKenzie S. Understanding childhood asthma in focus groups: perspectives from mothers of different ethnic backgrounds. BMC Fam Pract. 2001;2:4.

    Reason for exclusion: Mothers did not have to have children with asthma

13. Carpenter LM, Lachance L, Wilkin M, Clark NM. Sustaining School-Based Asthma Interventions Through Policy and Practice Change. J School Health. 2013;83(12):859–66.

    Reason for exclusion: School based interventions - children to 19 yrs

14. Cheezum RR, Parker EA, Sampson NR, Lewis TC, O'Toole A, Patton J, et al. Nightwatch: Sleep Disruption of Caregivers of Children With Asthma in Detroit. J Asthma Allergy Educ. 2013;4(5):217–25.

    Reason for exclusion: Exclude - caregiver sleep

15. Chernoff RG, List DG, DeVet KA, Ireys HT. Maternal reports of raising children with chronic illnesses:the prevalence of positive thinking. Ambul Pediatr. 2001;1(2):104–7.

    Reason for exclusion: Multiple comorbidities

16. Chiang L. Exploring the health-related quality of life among children with moderate asthma. J Nurs Res (Taiwan Nurses Association). 2005;13(1):31–9.

    Reason for exclusion: Children's experiences

17. Cicutto L. Mothers of ill children experienced uncertainty before asthma was diagnosed in their children [commentary on Horner SD. Uncertainty in mothers' care for their ill children. J Adv Nurs 1997;26(4):658-63]. Evidence Based Nursing. 1998;1(3):92–92.

    Reason for exclusion: Commentary on another paper already included

18. Clark BA, Chalmers KI. Helping parents cope. Canadian Nurse. 2003;99(2):19–22.

    Reason for exclusion: Details outlined in a thesis by the same author

19. Clay D, Farris K, McCarthy AM, Kelly MW, Howarth R. Family perceptions of medication administration at school: errors, risk factors, and consequences. J Sch Nurs. 2008;24(2):95–102.

    Reason for exclusion: Quantitative

20. Coffey JS, Cloutier M, Oliver MM, Terrazos C. The Experience of Puerto Rican Families Who Bring Their Children to The Emergency Department for Asthma Care. Int J Qual Methods. 2012;11(5):883–4.

    Reason for exclusion: Exclude - this is a thesis - article included by same author with same conclusions

21. Dawson C. The lived experience of caregivers for children with asthma. Dissertation. Submitted to University of Albany, State University of New York; 2017.

    Reason for exclusion: Child comorbidities, developmental/mental health issues

22. Deaton AV. Adaptive noncompliance in paediatric asthma: the parent as expert. J Pediatr Psychol. 1985;10(1):1–14.

    Reason for exclusion: Exclude quantitative

23. Dellve L RK. Parents' coping with their child's asthma. Scan J Dis Res. 2000;2(2):100–13.

    Reason for exclusion: Children with asthma and allergy not separated

24. Desai PP, Rivera AT, Backes EM. Latino Caregiver Coping with Children's Chronic Health Conditions: An Integrative Literature Review. J Pediatr Healthcare. 2016;30(2):108–20.

    Reason for exclusion: Exclude - literature review

25. Duffy JF. Asthma: A phenomenological evaluation of family and child perspectives. Dissertation Abstracts International. 1982;42:4573.

    Reason for exclusion: Exclude - illness

26. Egginton JS, Textor L, Knoebel E, McWilliams D, Aleman M, Yawn B. Enhancing School Asthma Action Plans: Qualitative Results From Southeast Minnesota Beacon Stakeholder Groups. J Sch Health. 2013;83(12):885–95.

    Reason for exclusion: Not parent experience

27. Fereday J, MacDougall C, Spizzo M, Darbyshire P, Schiller W. "There's nothing I can't do--I just put my mind to anything and I can do it": a qualitative analysis of how children with chronic disease and their parents account for and manage physical activity. BMC Pediatr. 2009;9:1.

    Reason for exclusion: Not parent experience

28. Fiese BH, Wamboldt FS. Coherent accounts of coping with a chronic illness: convergences and divergences in family measurement using a narrative analysis. Family Process. 2003;42(4):439–51.

    Reason for exclusion: Exclude - quantitative

29. Gallo AM, Knafl KA. Parents' reports of "tricks of the trade" for managing childhood chronic illness. J Soc Pediatr Nurses. 1998;3(3):93–100.

    Reason for exclusion: Exclude - chronic illnesses

30. Garnett V, Smith J, Ormandy P. Child-Parent shared decision making about asthma management. Nurs Child Young People. 2016;28(4):16–22.

    Reason for exclusion: Not parent experience - shared decision-making

31. Gates L, Akabas S. Meeting the demands of work and responsibilities of caring for a child with asthma: Consequences for caregiver well-being. J Social Serv Res. 2012;38(5):656–71.

    Reason for exclusion: Exclude - quantitative

32. Gehring LL. Focusing on my child: weaving the web of asthma care. 2002. p. 248 p-248 p.

    Reason for exclusion: On page 87 talks about children with other chronic illnesses does not meet inclusion criteria

33. Gilchrist FJ, Brady M, Gallop K, Wild DJ, Tabberer M, Jacques L, et al. How do children and their caregivers perceive the benefits of inhaled asthma therapy? J Asthma. 2012;49(5):552–6.

    Reason for exclusion: Not parent experience - benefits of treatment change

34. Givens PL. A study of parents' perceptions of access to care for paediatric asthma. Dissertation Abstracts International: Section B: The Sciences and Engineering. 2010;70:7474.

    Reason for exclusion: Not parent experence

35. Grover C, Goel N, Chugh K, Gaur SN, Armour C, van Asperen PP, et al. Medication use in Indian children with asthma: the user's perspective. Respir. 2013;18(5):807–13.

    Reason for exclusion: Exclude - no parent voice

36. Hafetz J, Miller V. Child and parent perceptions of monitoring in chronic illness management: A qualitative study. Child Care Health Dev. 2010;36(5):655–62.

    Reason for exclusion: Exclude - chronic illnesses - does not single out asthma in parent voice

37. Halterman JS, Fagnano M, Conn KM, Lynch KA, DelBalso MA, Chin NP. Barriers to reducing ETS in the homes of inner-city children with asthma. J Asthma. 2007;44(2):83–8.

    Reason for exclusion: Exclude - knowledge of environmental tobacco smoke

38. Heyduck K, Bengel J, Farin-Glattacker E, Glattacker M. Adolescent and parental perceptions about asthma and asthma management: a dyadic qualitative analysis. Child Care Health Dev. 2015;41(6):1227–37.

    Reason for exclusion: Adolescents with pneumological or other chronic somatic or psychosomatic diseases

39. Hookham V. Family constellations in relation to asthma. J Asthma. 1985;22(2):99–114.

    Reason for exclusion: Exclude - parent voice not adequately represented

40. Horner SD. Catching the asthma: family caring for school-aged asthmatic children. 1992. p. 206 p-206 p.

    Reason for exclusion: Exclude thesis - Primary paper from this author included already

41. Houle CR. Towards a balanced view of asthma in adolescence: Understanding the quality and divergence of self- and proxy-reports from African Americans adolescents and their caregivers. Dissertation Abstracts International: Section B: The Sciences and Engineering. 2009;69:5347.

    Reason for exclusion: Exclude - agreement between adolescent report and parents report of asthma

42. Jones B, Ingham TR, Cram F, Dean S, Davies C. An indigenous approach to explore health-related experiences among Maori parents: the Pukapuka Hauora asthma study. BMC Public Health. 2013;13.

    Reason for exclusion: Exclude - research process rather than parent experience of asthma

43. Kelo M, Eriksson E, Eriksson I. Perceptions of patient education during hospital visit - described by school-age children with a chronic illness and their parents. Scan J Caring Sci. 2013;27(4):894–904.

    Reason for exclusion: Asthma and allergy - not able to separate

44. Kieckhefer GM, Ratcliffe M. What parents of children with asthma tell us. J Pediatr Healthcare. 2000;14(3):122–6.

    Reason for exclusion: Exclude children up to 19 years

45. Knestel A, Raymond KP, Fiese BH. Perceived caregiver barriers in the management of children's asthma: A qualitative study. Int J Psychol. 2008;43:499–499.

    Reason for exclusion: Poster

46. Koenig K, Chesla CA, Kennedy CM. Parents' perspectives of asthma crisis hospital management in infants and toddlers: an interpretive view through the lens of attachment theory. J Pediatr Nurs. 2003;18(4):233–43.

    Reason for exclusion: Thesis - primary paper included already

47. Kueny A, Berg J, Chowdhury Y, Anderson N. Poquito a poquito: How Latino families with children who have asthma make changes in their home. J Pediatr Healthcare. 2013;27(1):e1–11.

    Reason for exclusion: No - barriers to making changes in homes

48. Lapillonne A, Regnault A, Gournay V, Gouyon JB, Benmedjahed K, Anghelescu D, et al. Development of a questionnaire to assess the impact on parents of their infant's bronchiolitis hospitalisations. BMC Health Serv Res. 2013;13:272.

    Reason for exclusion: No quantitative

49. Laster N, Holsey CN, Shendell DG, McCarty FA, Celano M. Barriers to asthma management among urban families: Caregiver and child perspectives. J Asthma. 2009;46(7):731–9.

    Reason for exclusion: Children with asthma and comorbid psychosocial conditions. Findings not separated.

50. Lauritzen SO. Lay voices on allergic conditions in children: parents' narratives and the negotiation of a diagnosis. Social Science & Medicine. 2004;58(7):1299–308.

    Reason for exclusion: Exclude - allergic conditions - not specifically asthma

51. Littlejohn-Blake SM. Family patterns in African-American families who are coping with childhood asthma. Dissertation Abstracts International Section A: Humanities and Social Sciences. 1997;57:4947.

    Reason for exclusion: Family patterns not experiences - other comorbid conditions eg cerebral palsy

52. Lyte G, Milnes L, Keating P, Finke A. Review management for children with asthma in primary care: a qualitative case study. J Nurs Health Chronic Illn. 2007;16(2):123–32.

    Reason for exclusion: Not parent experience - primary care needs

53. Mammen J., Rhee H, Norton S., Butz AM. Perceptions and experiences underlying self-management and reporting of symptoms in teens with asthma. J Asthma. 2017;54(2):43–152.

    Reason for exclusion: Teens experiences only

54. Mammen JR, Rhee H, Norton SA, Butz AM. Perceptions and experiences underlying self-management and reporting of symptoms in teens with asthma. J Asthma. 2016;1–10.

    Reason for exclusion: Not parent experience

55. Martin M, Beebe J, Lopez L, Faux S. A Qualitative Exploration of Asthma Self-Management Beliefs and Practices in Puerto Rican Families. J Healthcare Poor Under. 2010;21(2):464–74.

    Reason for exclusion: Exclude - self management in youth

56. Martin MA, Floyd EC, Nixon SK, Villalpando S, Shalowitz M, Lynch E. Asthma in children with comorbid obesity: Intervention development in a high-risk urban community. Health Prom Pract. 2016;17(6):880–90.

    Reason for exclusion: Exclude - parent inclusion just based on overweight or obese child (doesnt have to be one with asthma)

57. McClelland M, Wenz C, Sood K, Yono A. Perceptions of paediatric asthma in African American underserved families using metaphorical analysis. J Spec Pediatr Nurse. 2013;18(4):342–53.

    Reason for exclusion: Parent voice not separated from child

58. Meng A, McConnell S. Decision-making in children with asthma and their parents. J Am Acad Nurse Pract. 2002;14(8):363–71.

    Reason for exclusion: Exclude - no parent voice

59. Miller VA, Miller VA. Parent-child collaborative decision making for the management of chronic illness: a qualitative analysis. Families, Systems & Health: J Collab Family HealthCare. 2009;27(3):249–66.

    Reason for exclusion: Exclude - collaborative decision making - chronic illnesses does not really separate asthma

60. Morawska A, Gregory C, Burgess S. Parental beliefs about behaviour problems of their asthmatic children and interventions to support parenting. J Child Healthcare. 2012;16(1):75–90.

    Reason for exclusion: Child comorbidities, developmental/mental health issues

61. Mudd SS, Ogborn CJ, Bollinger ME, Morphew T, Kub J, Lewis-Land C, et al. Parental decision making associated with paediatric emergency department use for asthma. Ann Allergy Asthma Immunol. 2016;117(5):490–4.

    Reason for exclusion: Exclude - quantitative

62. Munro S.J. Learning to Live with Uncertainty: Exploring Mothers' Perspectives and Experiences of Caring for a Child with Asthma. Reno: University of Nevada; 2005.

    Reason for exclusion: Exclude children over 18 also

63. Neufeld A, Harrison MJ, Hughes K, Stewart M. Non-supportive interactions in the experience of women family caregivers. Health Soc Care Community. 2007;15(6):530–41.

    Reason for exclusion: Exclude - does not separate asthma from diabetes

64. Ngo G, Kilgore DB, Tran JH, Galant SP. Using community-based participatory research to assess the asthma needs of Vietnamese American children. Prog Community Health Partnersh. 2014;8(4):453–64.

    Reason for exclusion: Not parent experience

65. Panzera AD, Schneider TK, Martinasek MP, Lindenberger JH, Couluris M, Bryant CA, et al. Adolescent Asthma Self-Management: Patient and Parent-Caregiver Perspectives on Using Social Media to Improve Care. J Sch Health. 2013;83(12):921–30.

    Reason for exclusion: Exclude - teens 13-19 years

66. Pelaez S, Lamontagne AJ, Collin J, Gauthier A, Grad RM, Blais L, et al. Patients' perspective of barriers and facilitators to taking long-term controller medication for asthma: a novel taxonomy. BMC Pulm Med. 2015;15:42.

    Reason for exclusion: Study includes patients with asthma as well as parents of children with asthma - does not really separate into two groups. Parent experience intertwined with other patient's experiences.

67. Peterson JW, Dobie S. Community's voice in managing childhood asthma: the assessment phase of research. J Healthcare Poor Underserved. 2005;16(4):747–59.

    Reason for exclusion: Exclude - limited parent voice

68. Pradel FG. The social environment and management skills of children with asthma. Dissertation Abstracts International: Section B: The Sciences and Engineering. 2000;60:3883.

    Reason for exclusion: Exclude - children's experiences

69. Rodehorst-Weber TK, Wilhelm SL, Stepans MBF, Tobacco R, delaPaz F. Screening Native American children for asthma: findings from focus group discussions. Issues in Comprehensive Paediatric Nursing. 2009;32(4):200–9.

    Reason for exclusion: Exclude - screening methods

70. Rydstrom I, Dalheim Englund A-C. Meeting Swedish healthcare system: Immigrant parents of children with asthma narrate. Clin Nurs Res. 2015;24(4):415–31.

    Reason for exclusion: Exclude Swedish health system

71. Sampson NR, Parker EA, Cheezum RR, Lewis TC, O'Toole A, Patton J, et al. A life course perspective on stress and health among caregivers of children with asthma in Detroit. Fam Comm Health. 2013;36(1):51–62.

    Reason for exclusion: Exclude - focuses on caregiver health

72. Sampson NR, Parker EA, Cheezum RR, Lewis TC, O'Toole A, Zuniga A, et al. "I wouldn't look at it as stress": Conceptualizations of caregiver stress among low-income families of children with asthma. J Healthcare Poor Under. 2013;24(1):275–88.

    Reason for exclusion: Exclude - caregiver stress

73. Samuels-Kalow M, Hardy E, Rhodes K, Mollen C. "Like a dialogue": Teach-back in the emergency department. Pat Educ Couns. 2016;99(4):549–54.

    Reason for exclusion: Exclude teach back

74. Schwartz NA, von Glascoe CA, Torres V, Ramos L, Soria-Delgado C. "Where they (live, work and) spray": pesticide exposure, childhood asthma and environmental justice among Mexican-American farmworkers. Health Place. 2015;32:83–92.

    Reason for exclusion: Exclude - environmental issues

75. Seare A, Jago R, Henderson J, Turner KM. Children's, parents' and health professionals' views on the management of childhood asthma: a qualitative study. Prim Care Respir Med. 2017;53.

    Reason for exclusion: Talks about parent child dyad but only presents child voice

76. Seeleman C, Stronks K, van Aalderen W, Bot ML. Deficiencies in culturally competent asthma care for ethnic minority children: a qualitative assessment among care providers. BMC Pediatr. 2012;12:47.

    Reason for exclusion: No care providers views

77. Shaw A, Thompson EA, Sharp D. Complementary therapy use by patients and parents of children with asthma and the implications for NHS care: a qualitative study. BMC Health Serv Res. 2006;6.

    Reason for exclusion: Exclude - complementary therapies - unsure of age of children

78. Shaw A, Thompson EA, Sharp DJ. Expectations of patients and parents of children with asthma regarding access to complementary therapy information and services via the NHS: a qualitative study. Health Expect. 2006;9(4):343–58.

    Reason for exclusion: Exclude - Comp Medicines - unclear parents of what age children

79. Silva MDB, Silva LR, Santos IMM. Maternal care in the management of child asthma: the contributions of transcultural nursing. Anna Nery Sch J Nurs / Escola Anna Nery Revista de Enfermagem. 2009;13(4):772–9.

    Reason for exclusion: Exclude - not English

80. Sodi T, Kgopa B. Coping strategies of mother carers of children living with chronic illness and disease in a rural South African community. J Psychol Africa. 2016;26(5):432–5.

    Reason for exclusion: Exclude - chronic illness does not separate asthma

81. Spagnola M, Fiese B. Preschoolers with asthma: narratives of family functioning predict behavior problems. Fam Process. 2010;49(1):74–91.

    Reason for exclusion: Exclude quantitative

82. Sterling YM, Peterson JW. Lessons learned from a longitudinal qualitative family systems study. Appl Nurs Res. 2005;18(1):44–9.

    Reason for exclusion: Not parent experience - explanatory modes underpinning decision making

83. Stevens E, Cullinan P, Colvile R. Urban air pollution and children's asthma: what do parents and health professionals think? Pediatr Pulmonol. 2004;37(6):530–6.

    Reason for exclusion: Exclude - pollution and asthma

84. Stewart M, King M, Blood R, Letourneau N, Masuda JR, Anderson S, et al. Health inequities experienced by Aboriginal children with respiratory conditions and their parents. CJNR: Can J Nurs Res. 2013;45(3):6–27.

    Reason for exclusion: Exclude - 6-19 year olds

85. Stewart M, Letourneau N, Masuda JR, Anderson S, Cicutto L, McGhan S, et al. Support Needs and Preferences of Young Adolescents With Asthma and Allergies: "Just No One Really Seems to Understand." J Pediatr Nurs. 2012;27(5):479–90.

    Reason for exclusion: Asthma and allergies - not able to separate

86. Stewart M, Letourneau N, Masuda JR, Anderson S, McGhan S. Online solutions to support needs and preferences of parents of children with asthma and allergies. J Fam Nurs. 2011;17(3):357–79.

    Reason for exclusion: Parent preferences not experiences

87. Stewart M, Masuda JR, Letourneau N, Anderson S, McGhan S. "I want to meet other kids like me": Support needs of children with asthma and allergies. Issues in Comp Pediatr Nurs. 2011;34(2):62–78.

    Reason for exclusion: Exclude - lack of parent voice

88. Sullivan CE. Cybersupport: empowering asthma caregivers. Pediatr Nurs. 2008;34(3):217–24.

    Reason for exclusion: Exclude - children had other health conditions

89. Thompson L, Diaz J, Jenny A, Diaz A, Bruce N, Balmes J. Nxwisen, ntzarrin or ntzo'lin? Mapping children's respiratory symptoms among indigenous populations in Guatemala. Soc Sci Med. 2007;65(7):1337–50.

    Reason for exclusion: Exclude - children without asthma also - understanding of terms

90. Timmermans S, Freidin B. Caretaking as articulation work: the effects of taking up responsibility for a child with asthma on labour force participation. Soc Sci Med. 2007;65(7):1351–63.

    Reason for exclusion: No - women's caretaking role

91. Timmermans S. Why modest geographic effects for asthma? Pharmaceutical treatment as neutralizing mechanism. Health (London). 2007;11(4):431–54.

    Reason for exclusion: Exclude - minimising effects of asthma

92. Tod AM, Nelson P, Cronin de Chavez A, Homer C, Powell-Hoyland V, Stocks A. Understanding influences and decisions of households with children with asthma regarding temperature and humidity in the home in winter: a qualitative study. BMJ Open. 2016;6(1):e009636.

    Reason for exclusion: Home temperature not parent experiences

93. Trollvik A, Severinsson E. Influence of an asthma education program on parents with children suffering from asthma. Nurs Health Sci. 2005;7(3):157–63.

    Reason for exclusion: Exclude - educational intervention

94. Tumiel-Berhalter L, Zayas LE. Lay experiences and concerns with asthma in an urban Hispanic community. J Natl Med Assoc. 2006;98(6):875–80.

    Reason for exclusion: Exclude - parents of children with asthma and also adults over 18 years. There are some quotes from parents but others I am unsure who they are from.

95. Van Sickle D, Morgan F, Wright AL. Qualitative study of the use of traditional healing by asthmatic Navajo families. Am Indian Alsk Native Ment Health Res. 2003;11(1):1–18.

    Reason for exclusion: Exclude - not children

96. Vasek P.S. What do Parents really know? A Qualitative Study to Assess Asthma Education. 2004.

    Reason for exclusion: Education focus not overall experience

97. Vincent SD, Toelle BG, Aroni RA, Jenkins CR, Reddel HK. Exasperations" of asthma: a qualitative study of patient language about worsening asthma. Med J Aust. 2006;184(9):451–4.

    Reason for exclusion: Exclude - not specifically parents

98. Wind S, Van Sickle D, Wright AL. Health, place and childhood asthma in southwest Alaska. Soc Sci Med. 2004;58(1):75–88.

    Reason for exclusion: Not parent experience - perception in comparison to other respiratory illnesses

99. Yinusa-Nyahkoon LS. Managing childhood asthma within the inner-city: The perspective of African-American parents. Dissertation Abstracts International: Section B: The Sciences and Engineering. 2009;70:240.

    Reason for exclusion: Exclude another article by same author with these results dissertation

100. Young B, Fitch GE, Dixon-Woods M, Lambert PC, Brooke AM. Parents' accounts of wheeze and asthma related symptoms: a qualitative study. Arch Dis Child. 2002;87(2):131–4.

    Reason for exclusion: Recognizing asthma and wheeze - rather than parents experiences of managing

101. de Souza NS, Neves ET, de Borba RIH. Family care for children with asthma: a descriptive study. Online Braz J Nurs. 2013;12:659–61.

Reason for exclusion: Contacted author for full text - sent - not English

Appendix III: Studies excluded after critical appraisal

1. Buford TA. School-age children with asthma and their parents: relationships with healthcare providers. Iss Comp Pediatr Nurs. 2005; 28(3):153-162

   Reason for exclusion: No clear question or objective stated. Participants voice not adequately presented. The interpretation of the results unclear.

2. Maltby HJ, Kristjanson L, Coleman ME. The parenting competency framework: Learning to be a parent of a child with asthma. Int J Nurs Pract. 2003; 9(6):368-373

   Reason for exclusion: No ethics approval

3. Bearison DJ, Minian N, Granowetter L. Medical management of asthma and folk medicine in a Hispanic community. J Pediatr Psychol. 2002; 27(4):385-92

   Reason for exclusion: Uncertainty on how research collected, analysed and interpreted

4. Ou Liang-Shiou, Peng Siao-Yun, Yu Ching-Yi, Huang Jing-Long, Lin Hsih-Fong, Hsu Chih-Chieh, Yeh Kuo-Wei, Chen Li-Chen, Mo Li-Li. A study on the stressors of primary caregivers of children with asthma. Health Soc Work. 2015; 40(3):e110-e116

   Reason for exclusion: Methodology and methods not well presented and no ethics approval stated

5. Peterson JW, Sterling YM, Stout JW. Explanatory models of asthma from African-American caregivers of children with asthma. J Asthma. 2002; 39(7):577-590

   Reason for exclusion: No statement of informed consent or ethics

6. Robinson EA. Parents' attitudes to self-medication by their asthmatic children. Brit J Nurs. 1994; 3(13):651-656

   Reason for exclusion: Poor methodological quality, no clear objective, very limited patient voice

7. Cuffwright M. Childhood asthma: influencing parent's perceptions of disease. Comm Pract. 1999; 72(2):25-26

   Reason for exclusion: Overall methodological quality poor

8. Grineski S. Coping with asthma in the central city: Parental experiences with children's healthcare. J Healthcare Poor Under. 2008; 19(1):227-236

   Reason for exclusion: No statement regarding informed consent or ethics

9. Handelman L, Rich M, Bridgemohan CF, Schneider L. Understanding paediatric inner-city asthma: an explanatory model approach. J Asthma. 2004; 41(2):167-77

   Reason for exclusion: The way data analysed and presented questionable

10. Jerrett MD, Costello EA. Gaining control: parents' experiences of accommodating children's asthma. Clin Nurs Res. 1996;5(3):294-308

    Reason for exclusion: No statement regarding ethical approval or informed consent

11. Jones SL, Weinberg M, Ehrlich RI, Roberts K. Knowledge, attitudes, and practices of parents of asthmatic children in Cape Town. J Asthma. 2000;37(6):519-28

    Reason for exclusion: No ethics or informed consent. Participant voice not adequately represented

12. Koenig K. Families discovering asthma in their high-risk infants and toddlers with severe persistent disease. J Fam Nurs. 2006;12(1):56-79

    Reason for exclusion: Full thesis included. No ethics statement / infomred consent. Only selected families included in the results. Methodological quality inconsistent with phenomenology

13. Mesters I, Pieterse M, Meertens R. Paediatric asthma, a qualitative and quantitative approach to needs assessment. Patient Educ Couns. 1991;17(1):23-34

    Reason for exclusion: No informed consent or ethics

14. Ostergaard MS. Childhood asthma: reasons for diagnostic delay and facilitation of early diagnosis--a qualitative study. Prim Care Respir J. 2005;14(1):25-30

    Reason for exclusion: Interpretation of results do not appear to align well with methodology. Conclusion do not always flow from findings.

15. Ostergaard MS. Childhood asthma: parents' perspective - a qualitative interview study. Family Practice. 1998;15(2):153-157

    Reason for exclusion: No statement of ethical approval or informed consent

16. Park ES, Martinson IM. Socioemotional experiences of Korean families with asthmatic children. J Fam Nurs. 1998;4(3):291-308

    Reason for exclusion: No ethical statement or informed consent obtained

17. Soo WF, Tan NC. The influence of caregivers' knowledge and understanding of asthma aetiology on domiciliary management of children with asthma. Singapore Med J. 2014;55(3):132-6

Reason for exclusion: Poor methodological quality. Poor description of methods and presentation of findings

18. Trnka S. Domestic experiments: familial regimes of coping with childhood asthma in New Zealand. Med Anthropol. 2014;33(6):546-60

    Reason for exclusion: No description of methodology or methods

19. Koenig K, Chesla CA. Asthma management among low-income Latino and African American families of infants and young children. Family Relations: An Inter J of App Fam Stud. 2004;53(1):58-67

    Reason for exclusion: Methods are not well described and the interpretation of results do not appear to align with the question. No ethics statement found

Appendix IV: Characteristics of Included studies

Study	Methods for data collection and analysis	Country	Phenomena of interest	Setting/context/culture	Participant characteristics and sample size	Description of main results
Mosnaim et al.[126]	Grounded theory. Focus groups (face-to-face). Semi-structured, open-ended questions. Thematic analysis.	Chicago, Illinois USA	To understand Hispanic families and their experience with children who have asthma.	Low income Spanish speaking immigrant Hispanic families. Focus groups completed between October and November 2003 in community centres and churches in Hispanic neighbourhoods. 14 female and 10 males.	n = 24 immigrant Hispanic families involved in the care of a child with asthma. 9 mothers, 6 grandparents and 9 fathers.	All the participants reported strong beliefs in using folk medicines. Barriers identified included language, culture, poverty, lack of health insurance, and poor living conditions. Results highlight the lack of asthma self-management skills, diagnostic uncertainty, and the use of folk medicine as factors that should be taken into consideration when tailoring interventions to improve asthma outcomes in this vulnerable population.
Cheng et al.[97]	Semi-structured face-to-face in-depth interviews.	Taiwan	Experiences of mothers of 7-11 year old children	Interviewed in hospital room. Mothers all married, four	n = 15 mothers of children with asthma. Children with	There were four themes that formed part of the mothers' experiences.

	Analysed using content analysis.		with asthma who were assisting their child's adaptation to school life.	educated to college level or higher. Five mothers not working. Fathers' average age was 38.9 years and nine were educated to college level or higher. All fathers were employed.	asthma consisted of eleven boys and four girls and had an average age of 8.3 years. Eight had been diagnosed with asthma before the age of five years. Eight children had received treatment for asthma.	Those were: 1. Being concerned about the child's adaptation to school life, 2. Improving attitudes and relieving symptoms, 3. Establishing the child's self-management abilities and 4. Bearing role strain and normalizing the life of a child.
Coffey et al.[100]	Hermeneutic phenomenological approach. Initial face-to-face in-depth interviews (45 mins). Second interviews conducted via telephone (30 mins). Thematic analysis.	Hartford, Connecticut USA	The aim of this study was to describe the lived experience of Puerto Rican families caring for their child's asthma and using the ED for asthma care.	Interviews conducted at Connecticut Children's Medical Centre in a private setting. Hispanic Puerto Rican 18 years of age or older. Ten women (nine mothers and one grandmother who was the child's legal guardian).	N = 10 women and one grandmother (who was child's legal guardian) Hispanic Puerto Rican 18 years of age or older of a child 6 months through 18 years diagnosed with asthma and had an ED visit for asthma care in the past year.	Six themes were generated from in-depth interviews with 10 Puerto-Rican caregivers: (1) The Folklore of Asthma, (2) Culture and the Medicine Woman, (3) In Awe of Asthma, (4) Praying to God, (5) The Decision–Time to Go, and (6) The ED Environment. The findings emphasize the necessity of establishing and maintaining a therapeutic partnership between primary care providers

						and families of children with asthma. The results may be used as a foundation for understanding motivations for seeking asthma care in the ED.
Dowell.[104]	Qualitative, descriptive design. Semi-structured face-to-face interviews 60-90 minutes duration. Data analyzed using content analysis techniques with aid of ATLAS.ti v 7 Scientific Software.	North Carolina County USA	To explore experiences, needs and functioning of low-income African American caregivers of children with asthma in order to better understand symptom management.	Home setting, McDonalds and the public library. Recruitment for study took place in two locations in a central North Carolina county: a child development center and an allergy and asthma clinic. Low income, African American mothers. All had at least a high school education, and nine mothers had 1-2 years of college education. Half were employed, a few were unemployed and receiving	N = 15 African American mothers or primary caregiver as legal guardian (eg grandmother) of a child aged 2 to 14 years who had been diagnosed with asthma within the past 5 years.	Three main themes were identified: managing the symptoms; cultural beliefs and values; and culturally competent healthcare provider. For the caregivers cultural disparity is not just about access to health services, but instead the healthcare providers' understanding of the complexity of symptoms management.

				subsidies and one mother reported no income. Mean age of mothers was 32.4 years.		
Borhani et al.[92]	Qualitative study. Unstructured, face-to-face (30-90 minute) in-depth interviews. The Graneheim and Lundman's qualitative content analysis method was used for analyzing the data.	Kerman, Iran	Exploring the experiences of mothers of an asthmatic child.	Asthma and Allergy Clinic - Besat Health Centre - Iran.	10 Iranian mothers of children with asthma. All married and living with their husbands. All had at least elementary level of education. Children were younger than school age and their asthma was not severe. Specialist diagnosis of asthma in children at least 6 months prior to study.	The analysis of the data showed five main themes including constant concern, feeling of having an unusual life, the need for help from others, feeling of guilt, and the desire to constantly monitor the child.
Berg et al.[90]	Qualitative exploratory approach. Ethnographic group and individual in-depth interviews. Thematic content analysis.	Inner city Los Angeles USA	Latino family experiences and needs in caring for a child with asthma	Community and home settings. Interviews conducted in Spanish. Low income - Latino parents. Predominantly Mexican,	n = 12 (7 mothers and 2 fathers) age range 28-51 yrs - Preschool children diagnosed with asthma before 5 years of age.	Several common themes emerged from the data: (a) fear, "I got scared"; (b) the acute care experience, "I was not told what to do, nothing"; (c) knowledge, "I did not know

				two born in El Salvador, one in Honduras and one in United States. Eight participants had immigrated recently within a 3 year period.		anything about asthma"; and (d) parent alternative strategies or strengths, "We want to do what is best...we need to be prepared".
Barton et al.[89]	Single semi-structured face-to-face in-depth interviews Thematic analysis aided by QSR NVivo	Northern and Western suburbs of Melbourne, Australia	To describe the experiences of Australian parents caring for children with asthma.	All but one interview was conducted in participant's home. Median household income for families was $30,000 to $50,000 and roughly equal numbers of caregivers had completed high school or a tertiary degree.	n = 21 caregivers - predominantly mothers of children aged 2-14 years with diagnosed asthma - on several occasions however both parents participated in the interview. Children experienced predominantly mild to moderate episodic asthma.	Six themes emerged from the interviews: emotions and behaviours, coping strategies, disruption to activities, health and treatment beliefs, problems with asthma management, and relationships with doctors. Parents' experiences and health beliefs impacted on their management of asthma. These may act as barriers to optimal asthma care in some families. The overriding theme to emerge was 'it gets easier'. It got easier with time because the children could

						communicate more effectively, and were better able to take care of themselves, and their asthma became less severe or less of a problem
Arcoleo et al.[48]	Semi-structured in-depth interviews with mothers. Phenomenological thematic analysis using NVIVO 9.	Phoenix, Arizona USA	Mothers experiences of living with a child with asthma. Their understanding of the nature of asthma and how their cultural beliefs influence asthma management.	Two school-based health clinics. Mexican mothers. Over half (11/20) rated their standard of living as "just getting by" or "poor".	n=20 Mexican mothers of a child 5-17 years old diagnosed with asthma. 11/20 reported their child's asthma to be well-controlled.	Mothers expressed a symptomatic perception of asthma and limited understanding of the disease. Most believe the disease is present only when their child is symptomatic. Many are surprised and puzzled by the unpredictability of their child's asthma attacks, which they report as sometimes "silent". The inconsistency of triggers also leads to frustration and worry, which may reflect their concerns around daily controller medication use and preference for alternative illness management

						strategies. Our clinical encounters should be refocused to better understand the context of these families' lives and the cultural lens through which they view their child's asthma.
Dickinson and Dignan.[102]	Exploratory descriptive study informed by grounded theory. Face-to-face - One hour long open-ended interviews conducted over a 3 month period. Field notes were also taken to record participant's behaviour during the interview. Data was analysed using the constant comparative method of analysis as described by Glaser	New Zealand	Experience of a caregiver in relation to the management of their child aged two to five years during an acute asthma episode.	Mothers 24-40 years – self reported 'European New Zealanders'. English as primary language. Three were employed in either part-time or full-time paid employment. Three families had a family history of asthma, and two of the mothers had older children also affected by the disease. There were 5 pre-schoolers with asthma age 2-4 years and had been	n = 5 caregivers with a child between 2-5 years who had had a recent acute asthma episode not requiring hospital admission. Children diagnosed as having asthma between 15-30 months of age. All on regular preventer medication. Four had been admitted to hospital in the last 12 months.	The study reveals that mothers perceive that they are responsible for the management of their pre-school child during an acute asthma episode, a process they described as 'managing it'. This process involves mother in 'working on treatment', 'making the call', 'watching' and 'calming', while the husband/partner, family, friends and health professionals are 'supporting treatment'. This study suggests that nurses and doctors need to move away from

	(1978).			diagnosed as having asthma between 15 months and 30 months of age. All the pres-schoolers were on regular preventer medication.		the current paternalistic view of healthcare delivery in acute settings and embrace the concepts of support and partnership in the care of the preschool child with asthma and their family.
Archibald et al. [86]	Interpretive descriptive study using semi-structured interviews. Iterative data collection and analysis using NViVO.	Canada - large Canadian urban centre	To gain insight into how parents understand their asthma-related information needs and identify lingering information deficits relevant to childhood asthma.	Two asthma clinics and one paediatric emergency department in a large Canadian urban centre. One clinic located in a lower-income area with a larger number of immigrants. A Paediatric ED and a second clinic on the opposite end of the city. Diverse income brackets and socio-economic status.	n = 20 families including 20 mothers and one father of 23 children with asthma. Child had any form of asthma (eg mild episodic or severe persistent). Data classified by "time since diagnosis" - inexperienced (2.5 years or less), moderately experienced 2.5-5 years) and experienced (5 years or more).	Participants knowledge did not always reflect time since diagnosis, and information needs and deficits persisted for years. Parents often reported receiving little or no education about asthma and its management. An asthma management information hierarchy was identified, starting with the most foundational, recognising severity; followed by acute management; prevention versus crisis orientation; and

						knowing "about" asthma. In the absence of adequate and accurate education, parents' beliefs about the nature of asthma as an acute rather than chronic condition shaped their asthma management decisions and information-seeking behaviors. Information deficits were affected by interactions with health-care providers. These parents' pervasive unmet information needs and deficits highlight the need for comprehensive, problem-oriented asthma education.
Barrett et al.[88]	Face-to-face interviews with primary caregivers of children with asthma Qualitative phenomenological study with thematic	Tuscaloosa, Alabama USA	Experiences of rural families caring for children with asthma	Home setting. Rural location. Low socio-economic status.	Six primary caregivers - Five mothers (three African American and two Caucasian) One Father (African American).	Parental knowledge about asthma and asthma management strategies was quite good. The cost of asthma regimens and school policies

	analysis				Children aged 6-12 yrs (mean 6.7 yrs). Duration of asthma from 5 years to 11 years (mean 6.2 years).	about medications were major barriers to better control. Other management strategies were directed at maintaining normality of family life.
Chen et al.[96]	Exploratory and descriptive research methods. Individual qualitative in-depth semi-structured interviews using open-ended questions. Interviews were analyzed using content analysis. Interviews were conducted in private locations and lasted 30-40 minutes.	Taiwan	This study explores the experiences of primary caregivers in providing care to children with asthma.	Recruitment via allergy clinics of two medical centers and one regional hospital in northern Taiwan. Interviews were conducted in private locations. Mean age of participants 40.9. 70.6% mothers, 5.9% fathers, 23.5% grandmothers). Seven had high school education, 11 were currently employed. Mean age of children with asthma was 6.65 years. 35.3% of	N= 17 primary caregivers of children between 5 and 11 years old who had been diagnosed with asthma more than 1 year before the study and had no other uncontrolled chronic health problems.	The findings are described in three themes covering 10 categories. These themes and categories include feelings of uncertainty during illness (disease as perception related, lack of information), feelings of chaos and instability (worry, fear, frustration, helplessness, physical distress), and social tension and family conflict (disorientation of daily activity and burden of care, economic burden, family tensions and disagreements). Negative experiences with

				children had severe asthma and 64.7% had moderately severe asthma.		asthma care and the unpredictability of the disease outcomes impair the ability of caregivers to adapt successfully to their caregiving role and encourage perceptions that they cannot cope with this illness. Better understanding of the caregiver experience may assist healthcare providers to better target support to these caregivers so that they are better able to care for children with asthma.
Boyle et al.[93]	One focus group was conducted with parents of children who had been identified with asthma or breathing problems. Semi-structured interview guide consisting of	Southeastern United States	This study explored beliefs about asthma and asthma management among parents in an African American school.	Focus groups were conducted during 1997-1998 school year. African American participants. All associated with an elementary school located in a primarily low-income	n = 4 mothers aged 25-31 years participated in the parents' focus group.	Parents described complex lifestyles and the challenges of asthma management.

	open-ended questions. Data analysed by content analysis; segments of information were categorized into groups that were later abstracted into themes.			residential area. Focus groups were conducted in the library of the elementary school.		
Bokhour et al.[91]	Qualitative study using semi-structured interviews. Grounded theory analysis identified recurrent themes.	Boston USA	Exploring patterns of parents’ reported behaviors regarding giving children medication, and how these behaviors were interconnected with explanatory models and other features of family life.	Parents were recruited from three socio-economically and ethnically diverse sites: an inner-city academic medical center, a neighborhood health center, and a multi-specialty clinician group. African-American, Latino and white parents.	N= 37 African-American, Latino and white parents of children 5-12 years with persistent asthma. Children had persistent asthma in the last year and were prescribed controller medications, defined as inhaled anti-inflammatories, inhaled cromones, and oral leukotriene modifiers.	Three types of non-concordance were identified: Unintentional – parents believed they were following recommendations Unplanned – parents reported intending to give controller medications but could not. Intentional – parents stated giving medication was the wrong course of action. Analysis revealed two explanatory models of asthma: chronic – parents believed their child always had asthma; and intermittent – parents believed

						asthma was a problem their child sometimes developed.
Jonsson et al.[116]	Semi-structured focus group interviews were performed. 60-90 minutes in duration. Open-ended questions. Two with parents of children 2-12 years . Data were qualitatively analyzed using Systematic Text Condensation.	Stockholm, Sweden	To describe the experiences of living with asthma among parents of young children with asthma.	Child Outpatient Clinic. 7 females and 4 males.	N = 11 parents (7 mothers and 4 fathers) of children aged 2-12 years with a doctor's diagnosis of asthma since at least 2 years. Children with on daily treated with inhaled corticosteroids.	Three themes relevant to the participants' experiences of living with asthma were presented; strategies, frustrations and expectations. Parents emphasized frustration regarding not being believed, lack of understanding, feelings of loneliness or anxiety. One identified expectation was that the participants wanted to be met with competence and understanding in asthma care from health professionals. Another expectation expressed among parents was that teachers in nursery and primary schools should have more knowledge

						and understanding on how to care for children with asthma. Developing a partnership between patients and healthcare professionals could be a successful way to improve the care of patients with asthma.
Klok et al.[119]	Six semi-structured focus groups using open-ended questions, 2 hours in duration. Verbatim transcripts were analysed with standard qualitative research methods. Thematic analysis	The Netherlands	This study aimed to explore how differences in asthma care (primary versus specialist care) influence parents' perceptions about asthma, its treatment and how they qualify the relationship with their healthcare providers.	Primary care practices or paediatric asthma clinic (specialist care). Caucasian – most from (upper) middle class backgrounds.	N = 44 parents of asthmatic children aged 2-12 years. Mean age of children was 5.7 years ranging from 2-12 years. Fourteen children under 5 years had primarily viral-induced wheeze exacerbations. Children 5 years and over had mild to moderate persistent asthma; the large majority were atopic.	Parents decided deliberately whether ongoing ICS use was useful for their child. This decision was based on their perceptions about illness and medication. In primary care, this issue was hardly ever discussed with the healthcare provider because regular scheduled follow-up was unusual. In specialist care, regular scheduled follow-up was usual, and parental perceptions about illness and medication were discussed and

						modified when needed. Parent-reported adherence was lower in primary care than in specialist care. This study illustrates how strongly parental perceptions of illness and medication influence adherence to healthcare providers' advice and that such perceptions can be modified within a strong doctor-patient partnership, improving adherence.
Dixon-Woods et al.[103]	Semi-structured interviews. Data analysed using constant comparative method. Analysis was assisted by use of QSR NUD*IST computer software.	Leicester UK	To investigate the views of children, young people and their parents on primary care services for childhood asthma.	16 mothers, 3 mothers and fathers together and one father.	N = 20 families (16 mothers, 3 mothers and fathers together and one father) of children aged 8-16 years. The majority (17) had moderate asthma and (3) had very mild asthma.	Parents emphasized outcomes, quality, organization and access to healthcare as important and drew attention to the complex and challenging nature of the professional-parent relationship. Parents had several roles, seeing themselves as

						carers and advocates as well as users of health services.
Finnvold .[36]	Interpretive perspective Semi-structured in-depth interviews 5 face to face and 5 via telephone Focus group with 4 participants Thematic analysis	Norway - two counties in south east of Norway and one northern county. Focus group participants recruited from capital region.	Parental experiences of an asthmatic child's diagnostic process.	Home setting, via telephone. Conference room for focus group. Data collected in 1999.	n=14 parents of children between 3 and 9 years old. All were women, but in one case both the father and mother were interviewed.	The pre-diagnosis phase is often recalled as a period of frustration and uncertainty for parents. Results show that instead of accepting the authority of the professional, parents eventually acquire knowledge elsewhere about the diagnosis and the healthcare system, and act according to that knowledge. As a fundamental uncertainty appears involved in the diagnostic process, parents dealing with this uncertainty use a number of strategies to gain control of the process of alleviating their child's disease.
Hudson et al.[114]	Face-to-face, semi-structured interviews. Interpretive thematic	United Kingdom	To explore the experiences of parents living with a child with	Interviews were carried out in families' homes with South Asian	n = 49 (29 mothers; 15 fathers and 5 secondary carers) of children aged	Healthcare systems have a responsibility to develop services that are sensitive and appropriate

	analysis using NVivo.		asthma.	(Indian, Pakistani and Bangladeshi origin) parents and carers.	between 5 and 12 years old with asthma .	to the needs of their communities. In South Asian communities, further efforts are required to raise awareness of symptoms and effectively communicate how, when and where to seek help for children. There is a need for improved diagnosis and consistent effectively communicate information, especially regarding medication. Parents made several suggestions for improving services: presentations about asthma at easily accessible community venues; an advice centre or telephone helpline to answer queries; opportunities for sharing experiences with other families; having information provided in South

						Asian languages, longer GP appointments; extended use of asthma nurses; and better education for healthcare professionals to ensure consistency of care and advice.
Nichol et al.[129]	Semi-structured interviews face-to-face. Interviews lasted between 20 and 50 minutes. Data analysis was thematic.	Bristol UK	Exploration of families' experience of asthma, the homeopathic package and study participation.	8 families were interviewed at their homes and 1 family was interviewed at the homeopathic hospital.	N = 9 families of children aged 7-14 years (3 girls and 6 boys) with asthma. Mothers were the main parental participants.	Key themes were identified: the complexities of asthma and asthma management; the potential for homeopathy to improve asthma management.
Arroyo and Becker.[87].	Semi-structured interview in focus group format. Thematic analysis.	Urban Midwestern Chicago, USA	Understanding parental concerns prior to holding an educational session and to determine how to best design and market an asthma education program that parents would want to attempt.	Focus group held in youth centre. 4 female and 1 male participant. All participants obtained a high school education, with one having some college education.	N = 5 parents or caregivers of a child who attended the local youth centre who had been diagnosed with asthma or had asthma-like symptoms, child age between 1 and 18 years and ability to communicate	Five major themes: environmental triggers, asthma self-management, emotional response to emergency situations as well as confusion about the actions of medications and their proper administration. Most children experienced tobacco smoke

					in English..	exposure at home. Designing asthma programs that address these common themes may help asthma educators engage caregivers in asthma education and result in better asthma control for their children.
Horner.[39]	Three in-depth interviews each lasting 60-90 minutes were conducted in the families' homes. Data Analysis to identify substantive codes.	United States	To explore how families with school-aged children diagnosed with asthma incorporate asthma care into their daily lives.	12 families – 7 from a rural area and 5 from a densely populated urban centre of a southern state. The 12 families had 15 children with asthma ranging from 6-18 years. Three single-parent families, one extended family and eight nuclear families: 12 mothers, 6 fathers and 1 great-aunt. Three families were of African descent and nine families	N = 12 families (12 mothers, 6 fathers and 1 great-aunt) with 15 children with asthma ranging in ages from 6-18 years.	Exploration of families' experiences with asthma in school-aged children revealed the work of parents and children as they sought to Catch the Asthma Before it Got Out of Hand. The process of Catching the Asthma consisted of the overlapping phases of learning the ropes, dealing with asthma, and coming to terms with asthma. Asthma episodes were a central focus of family life while families were engaged in learning the

				were of European descent.		ropes of asthma management. Over time, as families became more adept at recognizing presumptive signs of asthma and potential triggers for asthma attacks and began dealing with asthma in an efficacious manner, asthma moved from the center of families' attention to a more peripheral position. Throughout the process of Catching the Asthma, the families began coming to terms with asthma, and, as the children matured, the primary responsibility for daily management of asthma was shifted from parents to children.
Horner.[113]	Three rounds of face-to-face in-depth interviews, each lasting 60-90	Texas, USA	Exploration of the mothers' experience as they cared for	12 families with 15 children with asthma ranging in age from 6 to	N = 12 families with children with asthma range from 6 to 18 years.	Mothers revealed that the pre-diagnosis phase of their children's illness was an overwhelming

	minutes, conducted in the families' homes.		their young children during illness episodes, prior to a diagnosis of asthma in the children.	18 years. Three were single-parent families, one extended family and eight nuclear families. Three of the families were of African descent and the other nine families were of European descent.		time for them. Groping in the dark is the core variable that reflects (a) the harrowing experiences of sleepless nights while mothers watched their children struggle to breathe (b) the wearing toll incurred while helping their children through seemingly unending illnesses, and (c) their increasingly intensified search for answers to resolve their children's health crisis.
Grover et al.[111]	Semi-structured in-depth qualitative interviews using open-ended questions. Some of the interviews were conducted over the telephone. Thematic analysis.	Sydney, Australia	This study aimed to carry out an in-depth exploration of the views of parents/carers on medication use.	26 parents/carers interviewed between November 2011 and April 2012. 22 mothers, 2 fathers and 2 caregivers. 96% of fathers and 65% of mothers were working full time.	N = 26 Parents/carer of a child between 7 and 12 years of age with a diagnosis of asthma and using a preventer medication for at least 3 months in the last 12 months with no other comorbid chronic illness.	Parental or carer issues included lack of clear understanding of how medications worked, as well as administration difficulties, cost constrains, and beliefs about medications contrary to quality use. There seems to be a lack of depth in terms of what parents understand about their child's

						asthma. Effective communication about medication usage, especially the inclusion of the child in the consultation to empower them to be involved in their own asthma care, may be the answer.
Meah et al.[125]	Open-ended, face-to-face, conversational-style interviews. Interviews were carried out in participants' homes. Qualitative analysis of the data was carried out using Framework.	North-west England	To explore self-management experiences of 7-12 year olds and their parent/carer.	North-west of England. Inner city and suburban areas. Varying cultural backgrounds – Bangladeshi, Pakistani, White and Black Caribbean backgrounds. Data were collected over a 13 month period during 2004/2005.	N = 18 Parent/carers of children 7-12 years. Thirteen children were prescribed regular preventive therapy of inhaled steroids and five children were also prescribed add on therapy indicating more severe asthma. Mean length of time since diagnosis was 6.5 years. Children were from varying cultural backgrounds including	Parents' accounts revealed a keenly felt tension between giving children opportunities to take responsibility for their own asthma management and fear of the (potentially life threatening) consequences of failure to prevent or manage a serious asthma attack – highlighting the absolute nature of parental responsibility. Parent – particularly mothers – are caught between the dilemma of preparing their children for independence

					Bangladeshi, Pakistani and White and Black Caribbean background.	and equipping them with the skills to make autonomous healthcare decisions, whilst simultaneously unable to escape the moral expectation to confirm to good, responsible motherhood.
Koenig.[1 20]	Face-to-face interviews from 1 to 5 times in their homes over periods that varied from 3 – 22 months following hospitalisations of their child. Interviews lasted 1.5 to 2 hours.	Northeastern United States	To describe low-income parents' perspectives on the challenges of managing asthma in their children younger than 3 years.	Low-income, single mothers, African American or Latino and Medicaid eligible. Interviews conducted in their homes. Children had been hospitalized for wheezing or asthma in northeastern United States from November 2002 to July 2003.	N = 5 families of children younger than 3 years of age, diagnosed with asthma or on daily inhaled or oral steroids in addition to albuterol and had no other chronic illnesses. Families were all low-income, African American or Latino and headed by single mothers.	The parents, all single mothers, struggled to manage asthma in crowded conditions, with limited transportation for frequently needed emergency care, and in face of the complicating needs of other children and family members. Not knowing then knowing the diagnosis, and provider availability and lack of availability were two dichotomous challenges mothers faced when managing asthma in their very young children.
Newbou	Semi-	United	Partnership	Recruitment	n = 43	In this study,

Id et al.[128]	structured face-to-face interviews, structured and open questions conducted in participants' own homes with parents of young people aged 8-15 years with asthma recruited through GP surgeries. Data analysed using thematic analysis using NUD*IST.	Kingdom	s between young people and their parents in the management of asthma. How responsibilities for medication are shared between young people and their parents and to identify factors leading to the transfer of responsibilities for medication from parents to young person.	through GP surgeries. Four health authority areas selected with different levels of deprivation. 38 mothers, 1 father and 4 mothers and fathers interviewed jointly of 27 male and 16 female children mean age 10.5 years.	parents (38 mothers, 1 father and 4 mothers and fathers interviewed jointly) of 43 children (27 boys and 16 girls) mean age 10.5 years with asthma.	young people and parents emphasized working together with only limited instances of differing views. This research identified the life events and social activities of the young person which were associated with transfer of responsibilities for medication from the parent to the young person. The young people and parents reported that health professionals rarely discussed issues surrounding transfer of responsibility, despite national guidance which recommends that health professionals assist young people to take on increased responsibility for their own lives. Health professionals should be aware of factors that may lead to the

						transfer of responsibility from the parent to the young person and be prepared to offer timely advice and support to both young people and their parents.
Jones et al.[115]	Semi-structured interviews with 10 parents of children with asthma. All participants were interviewed either while their child was hospitalized or within four days of discharge from hospital. Interviews took place in either their child's private room in hospital or their home and ranged from 15 to 60 minutes. Data analysis undertaken using Boytzis (1998) version of thematic	New Zealand	The aim of this study was to explore parent's sense of self-efficacy and the experiences that impact on sense of self-efficacy in relation to the management of their child's chronic respiratory disease.	Participants were recruited from one of two paediatric wards in a tertiary teaching and research hospital in New Zealand. Recruitment and data collection occurred between August 2010 and January 2011. Three quarters of the parents were Pakeha/European and remainder Maori, New Zealanders and Samoan.	N = 10 parents of children with asthma aged from under two to sixteen years with asthma.	The findings in this study suggest living with, and managing, a child's chronic respiratory condition creates a strong sense of responsibility for one parent within the family. This impacts negatively on both parents' sense of self-efficacy, through the burden of responsibility for the primary caregiver and through a lack of confidence to contribute more fully for the secondary caregiver. It is proposed that in order for parents to maintain self-efficacy in their care giving role, health professionals

	analysis.					need an understanding of how best to support them with their responsibility of care. Future research into the strategies that can assist parents to manage the negative aspects of responsibility and enhance partnerships in care are recommended as valuable in working towards addressing the issues raised by parents in this study.
Palmer.[131]	Initial interviews were semi-structured face-to-face interviews using a grounded theory approach. Follow-up interviews were conducted by telephone. A diary was kept to record field notes regarding	Pittsburgh, USA	To examine family caregiver perspectives and experiences of having a school-age child with asthma.	10 caregivers of varied racial backgrounds (6 black and 4 white). All caregivers were women and 2 of the 10 were grandmothers caring for school-age grandchildren. All children attended urban schools and ranged in age from 6 years	n = 10 caregivers (parent or guardian) of a child age 6-11 years with a diagnosis of asthma made by a physician at least 1 year prior to the study. Children with medical conditions such as seizures, attention deficit	A theory of the process of becoming a vigilant caregiver was generated. The process of vigilance is three-fold, consisting of a diagnosis phase followed by a battling phase and finally a resolution phase that uses various strategies to minimise the impact of asthma on the child and family.

	observation of family behaviors after the interviews.			1 month to 11 years 9 months. There were 6 girls and 5 boys (one family had two children with asthma) Wide variety of social status, age groups and family types .	disorders, any chronic illness were excluded.	
Van Sickle and Wright.[144]	One hour face-to-face ethnographic interviews were conducted. Thematic analysis using NUD*IST software.	Shiprock , New Mexico	To examine how medication-taking and the use of healthcare services were influenced by perceptions of the disease and beliefs about medications among Navajo families.	Interviews were conducted between June 1997 and August 1998 with 22 Navajo families with asthmatic children. Interviews were conducted in either the family home or at an office location at Dine College.	N = 22 Navajo families of 29 asthmatic children between 3 and 16 years. Median age 7 years. 55.2% of the children were male.	Most respondents perceived asthma as the transient experience of symptoms in someone who was chronically vulnerable to breathing problems. The majority (97%) of these asthmatics reported using bronchodilators, although only 34% reported current use of antiinflamatory medications. Although controller medications were distinguished from rescue medications, they were thought to have the same effect on the

						lungs. Many families were concerned about becoming dependent on the medicines and attempted to “wean” the asthmatic from the drugs. A large proportion (80%) of children had assumed responsibility for their own medication taking. Parents often referred to previous attacks requiring treatment in the emergency department when deciding whether to initiate medication or seek medical attention, often resulting in a delay of treatment. Nebulized treatments delivered in the emergency department were perceived to be the strongest therapy available. As a result, visits to the emergency department were common (79%), as were hospital admissions

						(57%).
Klok et al.[118]	Qualitative study – face-to-face, semi-structured, in-depth interviews lasting approximately 1 hour. Grounded theory methodology. Data analysis using standard methodology for qualitative studies.	Zwolle, The Netherlands	Explore factors that contribute to persistent non-adherence to inhaled corticosteroids in children ranging between 2 and 12 years of age receiving comprehensive asthma care, with adherence assessed objectively.	Interviews in homes of parents. Middle-class Caucasian population of parents.	N = Twenty children's parents (mean age 5.9 years) were interviewed. Children were diagnosed with asthma by a paediatrician and using ICS.	Distinctive patterns of modifiable barriers to adherence emerged, including a novel finding of parents misjudging their child's ability to manage the daily use of medication by him/herself. Persistent non-adherence appeared to be caused by a number of maintaining factors. Most noticeable factors were unawareness of non-adherence by both parents and healthcare providers, a lack of parental drive to achieve high adherence and ineffective parental problem-solving behaviour. All of the parents reported that they had been recommended to provide daily ICS to their child. Even though some parents reduced the

						dose, all expressed the intention to use ICS regularly in order to achieve good asthma control in their child.
Englund et al.[105]	Unstructured face-to-face interviews using broad open-ended questions 30-60 minutes in duration. Data analysis using a phenomenological-hermeneutic approach, interpretation of narratives and into themes.	Sweden	To describe what it means to be parents of a child with asthma.	Mothers and fathers were interviewed. 3 of the mothers and fathers were married to each other. Two of the mothers and one of the fathers were single parents. The remaining mothers (n = 7) and fathers (n = 8) were married or cohabitants with people who did not participate in the study. Twenty lived in houses in rural areas, and four lived in blocks of flats in a municipality. One single mother and one father were	N = 12 mothers and 12 fathers of children aged 6 to 16 years of aged with documented moderate or severe asthma.	Results revealed that parents were living a strenuous life and their actions involved both protecting and liberating. Parents also reported feelings of sadness and acceptance. In most cases, mothers acted in a protecting manner and expressed feelings of sadness; fathers acted in a liberating manner and expressed feelings of acceptance.

				unemployed. The other parents were professionals, with varying work schedules. 17 interviews were completed in family homes and 7 elsewhere based on parents wishes.		
Mansour et al.[124]	Parents were recruited from 4 schools located in low-income, urban areas with high rates of asthma hospitalisationss. Focus groups involving parents of children 5 to 12 years old with asthma were conducted using a standardized questionnaire. Data was analyzed to extract common themes using	United States	The purpose of this study was to identify barriers to the treatment of asthma among urban, minority children as perceived by parents.	Parents or legal guardians were recruited from 4 public elementary schools located in inner-city All parents described their racial background as black. Parents' average age was 36.8 years, 92% were females, 7% were non-married, and 38% had less than a high school education. Forty-five	Parents or guardians of a child with physician diagnosed asthma between 5 and 12 years. Children had experienced asthma symptoms in the last 24 months, were non-white with no other chronic medical illnesses.	The most frequent types of barriers identified by parents were patient or family characteristics (43%), followed by environmental (28%), healthcare providers (18%) and healthcare system (11%). Parents were specifically concerned about the use, safety and long-term complications of medications, the impact of limitation of exercise on their child's quality of life, and their own quality of life.

	SPSS.			percent of children had intermittent or mild asthma and 55% had moderate to severe asthma.		
Riera et al.[136]	Using a grounded theory approach, semi-structured, one-to-one, in-depth Spanish-language interviews and a follow up focus group. Iterative data analysis and the constant comparative method. Concepts grouped into themes.	New Haven, Connecticut. United States	To explore the caregivers' perceptions and experiences with asthma health communication.	Data was collected from September 2011 to May 2012. 31% of population Hispanic or Latino. 2012 5-year average median household income was $38,482 compared to $69,519 in Connecticut as a whole. Latino asthma healthcaregivers with LEP, mothers, grandmothers, father and an aunt from Puerto Rico, Colombia, Mexico, Dominician Republic, Ecuador and Cuba. Interviews took place at	N = 20 limited English proficiency (LEP) Latino asthma healthcaregivers providing regular asthma care for children 2 to 12 years old.	LEP caregivers encountered significant asthma burdens related to emotional stress, observed physical changes, and communication barriers. Language-discordant communication and the use of ad hoc interpreters were common. This finding is complex, and was influenced by perceptions of interpreter availability, delays in care, feelings of mistrust toward others, and individual emotional responses. Language-concordant education and suitable action plans were valued and

				either a local nonprofit Latino advocacy organization or the caregiver's home. Mean age of child with asthma was 7 years.		desired.
Rose and Garwick .[137]	Family caregivers were interviewed in their own homes. Semi-structured, face-to-face, in-depth interviews lasting 90 minutes. Data analyzed using content analysis strategies.	Minneapolis USA	To identify barriers to effective management of childhood asthma as perceived by urban American Indian family caregivers.	14 mothers, 1 aunt and 1 grandmother aged between 21 and 44 years. Educational level ranged from junior high school to vocational or technical college education. The majority of the children (n = 12) lived in a single-parent or aunt or grandparent-headed household; 4 lived in a two-parent household. Family household size ranged from 2-7 members and the family income	n = 16 American Indian adult family caregiver (over age 16 years) who had the primary responsibility for managing the care of a child (aged 3-12 years) with a chronic illness (asthma).	Five categories of barriers were identified: provider (individual and system), condition-related, family caregiver, socioeconomic, and environmental

				ranged from less than $10,000 to $29,999 per year. Nine children were male and seven were female aged between 3 and 12 years. Age at diagnosis ranged from 6 months to 9 years and all had lived with asthma for at least 1 year		
Garro et al.[109]	Seven Focus groups lasting 60-90 minutes. Open-ended core topics were used in the first half of each FG session, and more focused core topics were used in the latter half of each session. Thematic analysis using NVivo 8.0.	Providence, Rhode Island USA	To identify the expectations that caregivers have during the diagnostic process and to provide guidance to clinicians on how to incorporate these expectations in caregiver education.	Seven focus groups with 38 participants were conducted between February and August of 2010. Caregivers were recruited from asthma education classes held in the community and from an ED of an urban tertiary care hospital. Population 49% white, 36% Latino,	38 caregivers of children 1-6 years old diagnosed with asthma by a clinician in the preceding 12 months.	Caregiver expectations during the asthma diagnostic process included: 1. Provision of a diagnostic strategy 2. Acknowledgment of caregiver advocacy 3. Addressing caregiver's beliefs about treatment with asthma medications before a diagnosis was confirmed, and 4. Discussing asthma specialist involvement in the diagnosis.

				and 15% African American. Forty percent of the families are below the federal poverty line.		Higher perceived severity of a child's illness made caregiver expectations more difficult to meet.
Newbould et al.[127]	Face-to-face, semi-structured interviews using open questions were conducted with parents in their own homes. Interviews took on average 28 minutes. Qualitative analytical procedures were used and the identification of themes. NUD*IST was used to assist with data management.	South East England	To examine the experiences and concerns of parents regarding the management of medication for asthma whilst at school.	38 mothers. 40 self-identified as from a white ethnic group. 37 owned their own homes. Contrasting areas in South East England.	N = 43 parents of young people aged between 8-12 years with asthma.	Parents expressed concern regarding the awareness and levels of support available to their sons/daughters, in particular if a crisis should develop. In order to ensure optimal care, there is a need for the development of protocols tailored to the needs of young people with different conditions. These should preferably be devised in partnership between the young person, their parents and the school to ensure that the flexibility and support required for optimal management are offered.
Peterso	One-on-one,	USA	Parental	Interviews	n = 18	Eight main

n-Sweeney et al.[37]	face-to-face, semi-structured qualitative interviews using open ended questions. Interviews were in-depth and lasted between 1 and 1.5 hours. Data were analyzed by clustering and identifying themes.		experiences with their children with asthma, specifically their beliefs, knowledge, and attitudes about asthma management, including medication use.	took place in the participant's homes. Diverse racial and socioeconomic backgrounds and represented the spectrum of illness severity.	mothers of children and adolescents aged 2-18 years with diagnosed asthma.	themes within the domain of asthma management and medication use were identified. "I know my child", "trial and error", "partnership", "need for education", "negotiating responsibility", "hassles with medication administration", "preferences", and "the benefits outweigh the risks of side effects".
Peeler et al.[133]	Descriptive phenomenological approach. One-to-one semi structured interviews lasting up to one hour. In-depth discussion with open-ended questions. Data analysis guided by Colaizzi's seven-step approach - statements extracted, formulated	Queensland, Australia	Experiences of parents who had a child admitted to hospital for severe bronchiolitis requiring oxygen therapy.	Data was collected over a 12 month period. Interviews conducted at their home following the child's discharge. Caucasian parents, one single and half had more than one child. This was their first experience of having a child admitted to hospital with an illness. Six children	n = 12 mothers of children aged between two to six months when diagnosed.	Mothers feared for their child's life. Being unable to control the situation they were left feeling fearful, bewildered, useless and helpless, questioning their mothering skills because they were unable to perform their usual caring role.

	meanings, grouped meanings, developed themes.			admitted to intensive care, with remainder cared for in high dependency unit - most spent less than 48 hours in these units.		
Watson et al.[150]	Semi-structured interviews lasting approximately 1 hour. All participants were then invited to a 2-day asthma camp held in July 2011. 1 sharing circle and 1 focus group with 17 caregivers both lasting approximately 1 hour. Open-ended questions were used. Data analyzed using thematic analysis.	Nova Scotia, Canada	To identify asthma-related support needs and intervention preferences.	During May and June 2011 17 Mi'kmaq (Aboriginal) families in Cape Breton, Novia Scotia. Low socio-economic status group.	n = 17 Mi'kmaq English speaking caregivers of 21 youths aged 8 to 12 years with caregiver reported asthma or spirometry diagnosis of asthma and the use of any asthma medication in the last year.	The study yielded 4 key findings: 1) asthma triggers included household mold, indoor smoking, pets, season change, strenuous exercise, extreme cold, and humidity 2) social and educational support is lacking in Mi'kmaq communities despite a strong desire for these services 3) cultural, linguistic and geographic barriers to accessing support exist; and 4) family members are primary support resources.
Crosland et al.[101]	In-depth semi-structured	Inner city Newcast	To explore parents' perceptions	Socio-economically disadvantage	N = 32 parents of children with	All parents were aware of some of the risks their

	qualitative interviews were carried out as part of a larger study evaluating the impact on families of a pilot intervention to eradicate dust mite load in the homes of children aged 4 to 16 years with asthma. Interviews were audiotaped, transcribed verbatim and analysed using thematic analysis.	le England.	of environmental household risks to their child's asthma and to identify the strategies they adopt in relation to these perceived risks.	d urban community in North East of England. A total of 30 interviews were carried out with parents three months after they had the intervention installed (one parent had two children enrolled in the study). All of the parents lived in the same inner city area of Newcastle. In some families, one parent was present at interview (22 mothers and two fathers), while in the remaining six interviews both parents were present and contributed.	asthma aged 4 to 16 years and living in a socio-economically disadvantaged urban community in the North East of England.	children faced at home. Some appeared to know more than others and coping styles varied. A typology of three groups of parents was identified: those who actively seek advice and adopt clear preventative strategies (preventers); those who minimise the risks and only react when things go wrong (reactors); and those who engage in compensatory activities in an attempt to trade-off between harms and benefits (compensators). The unifying themes underpinning these different styles are that all parents are motivated to maintain normal family life but that they adopt different strategies to achieve this.

Gibson-Scipio and Krouse.[110]	Focus group session using open-ended questions in a private room at a local restaurant/gaming centre. 90 minutes in duration. Data analysis to identify themes.	Detroit USA	To identify the asthma management goals, beliefs and concerns of primarily African American urban caregivers of teens with asthma.	14 caregivers – 8 mothers, 3 fathers, 2 Aunts and 1 Grandparent. 8 African American 4 Caucasian and 2 Other. 1 Married, 6 Single, 2 Divorced, 2 Separated, 3 living with partner. 8 income of less than $40,000 per year and 6 on more than $40,000 per year.	N = 14 caregivers of urban African American adolescents aged 14-18 years with asthma diagnosed by a healthcare provider such as a physician, physician assistant or nurse practitioner.	Caregivers identified goals that related to supporting their teens' progress toward independent asthma self-management. They described significant concerns related to the teens' ability to implement asthma self-management, especially in school settings. Caregivers also revealed beliefs that represented knowledge deficits related to asthma medications and factors that improved or worsened asthma. Most caregivers identified grave concerns about school policies regarding asthma medication administration and the lack of knowledge and support provided by teachers and staff for their teen.
Santati	In-depth	Thailand	What	Interviews	N = 10	Participants in

et al.[139]	interviews using open-ended questions lasting 1 to 1.5 hours. Follow-up interviews conducted by telephone. Field notes were kept throughout data collection process. Data analysis by using the constant comparative method of grounded theory.		asthma means to Thai parents, how asthma symptoms impact on each family's life and how parents come to manage asthma attack prevention properly.	took place at the asthma clinic at the hospital parents used for treatment. All parents were mothers. They had experience in asthma attack management for more than 1 year. Parents' ages ranged from 37 to 50 years. Education levels ranged from 11 to 15 years. Children were between 1 and 6 years of age when diagnosed with asthma with the length of time since diagnosis ranging from 4 to 8 years. Children had mild intermittent, moderate and severe asthma.	parents of 11 children with asthma (diagnosed by a physician) aged 5 to 14 years.	this study experienced six phases from the beginning of symptom presentation until they found their own way to take control over asthma attack. These six phases were searching out, seeking help, trying out and making change, dealing with change, never giving up, and finding ways to take control. These findings are useful for nurses who seek to understand parents' experiences in taking care of asthmatic children, in order to develop strategies and to plan interventions that are suitable to help Thai families who have children with asthma improve the quality of their asthma care.
Samuel	Semi-	Philadel	The goal of	Parents of	N = 31	Participants

s-Kalow et al.[56]	structured, open-ended, in-depth qualitative interview study in ED. Grounded theory approach. Data analysis using thematic analysis.	phia, USA	this study was to characterize parent perceptions of needs and preferences regarding the ED discharge process by health literacy and identify ideas for process improvement.	paediatric patients recruited from a neighboring tertiary care paediatric ED with an annual volume of over 90,000 patients. 31 paediatric parents, 48% were limited literacy, 85% were black or African American and 81% had public insurance. 39% completed high school, 45% completed some colllege and 16% completed college or higher degree.	parents of paediatric patients (child aged 11 or under) being treated for asthma in the ED with planned discharge home. Parents of children with complex healthcare needs were excluded.	across literacy groups and settings identified multiple actionable areas for improvement in the ED discharge process. These included the use of simplified/lay language, increased visual learning and demonstration, and the desire for complete information. Individuals with limited literacy may particularly benefit from increased attention to consistency.
MacDonald.[123]	Ethnographic study. Participant observation and face-to-face in-depth interviews. Five mothers were interviewed on two	Canada	To describe the meaning childhood asthma had to mothers of afflicted children in order to assist healthcare	Mothers ranging in age from 26-42 years.	N = 5 mothers were interviewed on two separate occasions and 3 mothers were interviewed once for a total of 13	The overall theme that emerged from the data was that of “Mastering Uncertainty”. The mothers expressed their experiences with mastering uncertainty in

	separate occasions and three mothers were interviewed once in their own homes. Data analysis to identify themes.		professionals in providing a more holistic approach to care.		interviews. Mothers ranged in age from 26-42 years and had a child with asthma aged between 3 and 10 years.	terms of self by describing "Internal Self" and "Actions" during a "Passage of Time". The theme of uncertainty that emerged from the data is not unique to mothers of children with asthma. Chronic uncertainty has been found to be one of the greatest stressors of mothers of children diagnosed with a life-threatening disease.
Rydstrom et al.[138]	Face-to-face, 30-60 minute duration In-depth interviews, most conducted in homes of informants. Qualitative research design inspired by grounded theory. Data analysis by constant comparison method.	Sweden	The aim of this study is to illuminate what happens to family relationships when a child in the family has asthma, as experienced by mothers, by identifying what influences and characteriz	Swedish speaking mothers. Mothers selected by an allergy nurse in a hospital in a medium-sized town in southwest Sweden. Three of the mothers were single parents, and fourteen lived with the biological	N= 17 Swedish speaking mothers of a child aged between 6 and 16 years who had documented moderate or severe asthma.	The core category that developed was being governed by disease-engendered uncertainty. The category mothers' availability was seen in two dimensions. The first dimension, mothers' being available for the child with asthma, created two subcategories: 1.

			es the family relations.	father. In three families the child with asthma was the only child. The other families (n=14) had 2 or 3 children, including the child with asthma.		Control and 2. Tight bonds. The second dimension, mothers' being less available for other family members, also created two subcateogries: 3. Being forsaken and 4. Lack of understanding.
Ungar et al.[141]	Semi-structured, face-to-face, in-depth interviews. Thematic analysis.	Canada	To explore how purchasing children's asthma medications influence houshold purchasing behavior, standard of living, and perceived quality of life in low-income families without medication insurance.	Low-income (household income less than U.S $45,000 per annum) and no drug plan. Interviews conducted between June 2002 and February 2003. Half of the sample were immigrants to Canada and originated from Europe, Carribean/West Indie and Asia. Reasonably well educated, 30% were at or below poverty line. 13 mothers, 4 fathers participated	N = 17 (13 mothers and 4 fathers) of children aged 1 to 18 years with clinically diagnosed asthma, use of asthma medications in the last year, household income less than US $45,000 per annum and no drug plan.	Because asthma management was a high priority, foregone expenditures included paying for other family members' health needs, essentials (clothing, food, better housing) and nonessentials (recreation, vacations) and long-term investments such as their child's future education and their retirement. Respondents believed quality of life was negatively affected.

				in interviews.		
Trollvik and Severinsson.[140]	In-depth, semi-structured interviews lasting 1-1.5 hrs in parents homes and at the hospital. Phenomenological content analysis. Coded into themes and subthemes.	Norway	To describe nine parents' everyday experiences of living with a child suffering from asthma. To illuminate the parents' experiences of encounters with healthcare professionals.	Nine parents of five children with moderate to severe asthma in the 2-6 year age group. Four couples and one single parent. Parents had different backgrounds and were strategically selected: short/long time since participating in Asthma Education Program, rural/non-rural area, other children (siblings) with or without asthma, and different occupational backgrounds.	n = 9 parents of five children with moderate to severe asthma in the 2-6 year age group.	Four main themes emerged: feelings of uncertainty, helplessness and guilt; the need for support and help from healthcare professionals; adaptation to everyday life; and the development of coping strategies. In addition, two subthemes: trying out and seeking information, eerged. Trying out was found to be an important strategy for parents in managing the illness. In encounters with healthcare professionals, parents felt that they were not respected and that their competence was questioned. In conclusion, this study emphasizes the importance of a mutual dialogue between healthcare professionals and

						parents to enable the parents to develop the competence necessary to care for their child.
Shaw and, Oneal.[51]	Grounded theory. Qualitative. Face-to-face interviews in participants' homes. Interviews lasted approximately 60 minutes. Thematic analysis.	USA	To identify predominant categories involved in the process leading up to a hospitalisations and/or an ED visit, categories arising during the hospital experience, as well as those occurring postdischarge of children (0-18 years) who had recently experienced an acute asthma attack requiring hospitalisations or an ED observation.	13 parents/guardians (10 families) of 10 children. Family income ranged from less than \$20,000 per year to greater than \$60,000 per year (mean income of \$36,000 per year). Parent eduction ranged from general education diploma to a 4-year college degree. Two parents held general education diplomas, two had graduated from high school, six had some college education and three	N = 13 parents/guardians (10 families) who had a child with asthma (aged 0-18 years).	Four categories were identified as factors affecting the process of living on the edge of athma. Predominant categories included balancing, losing control, seeking control, and transforming. Categories depict how family members take various actions that lead to outcomes dependent upon the contextual variables and the uniqueness within each family. There is no order to the four categories as they are all continuous and overlap and intertwine throughtout this process. Depending upon how families viewed asthma, they either strive

				had obtained bachelor of arts degrees.		to control the chronic disease, or they view asthma as an acute event only, with the perception that control cannot be obtained.
van Dellen et al.[143]	Qualitative, focus group interviews taking about 2 hours. Semi-structured interview procedure and field notes were taken. Thematic analysis.	Amsterdam, The Netherlands	To explore and compare explanatory modes in aetiology of the condition, onset of symptoms, course of illness and treatment of mothers from Moroccan, Turkish, Surinamese and Dutch backgrounds. To gain an insight into the groups' beliefs about causes, consequences, symptoms and the self-management of asthma.	Dutch, Turkish, Surinamese, Moroccan mothers. Household incomes and socioeconomic status of the three migrant groups are lower than that of the ethnic Dutch population. Educational level of most of the mothers was low: 43% had never attended school or had primary education only.	N = 28 mothers of 32 children aged 7-7 years diagnosed with asthma by a paediatrician. Mothers were Dutch, Turkish, Surinamese and Moroccan.	Study findings show that mothers, regardless of ethnicity and age, have their own explanatory models. Overall, there is a great deal of uncertainty related to the causes, consequences, problems, and symptos of asthma and its treatment. It also seems that many concerns and feelings of discofort are the result of lack of knowledge. For instance, the fact that asthma is not seen as a chronic disease requiring daily intake of an inhaled corticosteroid, but rather as an acute phenomenon

						triggered by various factors, may be very relevant for clinical practice. This particular belief might suggest an explanation for non-adherent behaviour. A thorough understanding of the mothers' beliefs regarding the illness and its treatment is an important aspect in the management of asthma. Gaining an understanding of these beliefs will provide a foundation for a solid clinician-patient/family partnership in asthma care.
Valerio et al.[142]	Qualitative, focus groups. Semi-structured questions. Thematic analysis using Nudist 5.	Michigan USA	Parental caregiver perspectives on barriers to asthma care in the Medicaid system.	Four focus groups held between December 2001 and January 2002. 35 women and 1 man age range of 25-35 years. Majority of participants were African American	N = 36 parental caregivers of children 6-16 years with a diagnosis of asthma currently or previously enrolled in the Michigan Medicaid Health Management System.	Major themes identified included caregiver emotions, caregiver/patient knowledge, environmental issues, school/daycare support, Medicaid health-care system issues, the fole of medical providers

				(64%) and 31% were married. Annual income range of < $10,000 with only five participants with income > $30,000/yr. Median level of education for participants was 13 years. Children had a median age of 10 years.	Parents of children with additional chronic medical conditions such as diabetes, sickle-cell anemia, or lung-related conditions were excluded from the study.	and emerging adolescence. Parents demonstrated asthma awareness but were not confident in their role as the child's disease manager. A specific gap was seen in the caregiver's level of self-efficacy to control exposure to asthma triggers, monitor the child's symptoms, and modify medications based on asthma symptoms.
Walker.[147]	Exploratory qualitative study. Face-to-face, audio-taped, semi-structured interviews. Data analysis of themes.	Texas, USA	To explore minority caregivers' perceptions of their children's emotional responses to asthma and to compared minority caregivers' perceptions of boys' emotional responses to asthma with minority	Four caregivers of male children (two were African American and two were Latinos) and four caregivers of female children (two were African American and two were Latina). Interviews conducted in homes, expect for	N = 8 caregivers (4 African American and 4 Latina) of children with asthma. 7 mothers and 1 grandmother.	Major themes and subthemes were identified with content analysis. Sons were reported as quiet when experiencing asthma. Daughters were described as being verbal, sorried, excited. A question from the study was whether the children's responses were related to caregivers' (a)

			caregivers' perceptions of girls' emotional responses for asthma.	one interview that took place in a café. Interviews took place between July 27, 2011 and January 6, 2012. Mean age of children 9.75 years.		actions, (b) responses to asthma, and/or (c) race/ethnicity.
Yinusa-Nyahkoon et al.[153]	Face-to-face, semi-structured interviews took place in parents homes or at their children's healthcare site. Follow-up interviews were conducted 1 year later. Data analyzed using constant comparision analysis following a grounded theory approach.	Boston, Massachusetts USA	Social forces underlying ecological barriers and what African American parents living in the inner city do to manage their children's asthma amidst these challenges.	African American parents – 18 mothers, 1 father. Mothers were married and had at least a high school education. Over half of the participants lived above poverty level. Study was conducted over 2 years excluding summer months when asthma flares are least common.	N = 19 economically diverse African American parents of children aged 5-12 years, diagnosed with persistent asthma. 11 parents participated in a follow-up interview 1 year later.	Parents identified four adaptive routines they use to manage their children's asthma: 1. Give young children with asthma responsibility for medication use; 2. Monitor the availability of the school nurse; 3. Manage air quality; and 4. Frequently clean the home. These routines are described as adaptive because parents navigate ecological barriers and social forces within their daily context to manage their children's asthma.
Bellin et al.[50]	Focus groups (face-to-face)	USA	To examine how low-	Low income-caregivers of	N = 13 caregivers of	Five themes emerged in the

	lasting approximately 90 minutes. Data analysed using thematic analysis.		income, inner-city parents experience asthma caregiving.	children aged 7-12 years. Mean age 33.9 years, 92.3% were the biological mother, 84.6% were single, 69.2% impoverished (annual household income less than or equal to $30,000). Children mean age 7.8 years were African American, 92.3% enrolled in Medicaid and averaged 1.3 ED visits over the prior 3 months, 61.5% resided in homes with at least one smoker and nearly all 84.6% experienced activity limitation due to asthma. Focus groups conducted between July and October 2015.	African American children aged 7-12 years with asthma. 12 mothers and 1 father mean age 33.9 years.	analysis: intensive caregiving role, complex and shared asthma management responsibility, parental beliefs and structural barriers to guideline-based care, lack of control over environmental triggers, and parent advocacy to improve child asthma care and outcomes. Caregivers managing a child with high-risk asthma in the context of poverty indicate the need for ongoing asthma education, increased sensitivity to the complexity of home asthma management, and family-centered interventions that enhance communication and collaboration between caregivers and providers.
Wales	Face-to-face	Sydney,	To major	Interviews	N = 7 parents	The parents were

et al.[146]	interviews, open ended questions. Interviews lasted 1-2 hours. Data analysed using a thematic approach.	Australia	aim of this study was to explore the transfer of responsibility for care, the issues that arise from shifts in control of management and how this impacts on adherence to treatments, by exploring the ideas and beliefs of parents and school-aged children with chronic illness.	conducted at outpatient clinic at a tertiary children's hospital.	of children aged 6-12 years with asthma.	very frank about the issues they felt supported or hindered their child's ability to adhere to treatment. There was little astonishment around the issues that were identified and are well documented in the literature. These included the nature of the illness, how visible the disease was to others, the demands treatment placed on the family and child, the difficulties associated with judging the child's ability to assume treatment responsibilities, family functioning and their need for support, understanding of the illness or health beliefs about treatment, and the quality of their relationships with healthcare professionals.
Williams et al.[151]	Qualitative study using	Scotland	To explore the reasons	Recruitment through six	N = 38 parents of	The lower level of activity among

	in-depth interviews. Interviews lasted approximately 1.5 hours. Constant comparison analysis using NVivo.		for low physical activity levels among children with asthma and to identify strategies to improve activity.	GP practices and a paediatric respiratory unit in Tayside, Scotland. Interviews took place in the family home.	children aged 6-14 years with moderate to severe asthma were interviewed. Two parents participated in eight interviews, while 22 interviews involved one parent (typically mothers).	children with asthma was supported by a climate of fear among parents and teachers about what was safe and possible for the child. Restrictions were imposed because of perceived dangers of exercising in the presence of 'triggers'. Physical activity was regarded as a threat to be managed rather than something beneficial. Teachers found it difficult to distinguish between children who were physically incapable of exercise due to asthma and those who were unmotivated. GPs were unknowingly drawn into the controversy by children and parents who cite medical advice to sanction exemption from exercise.
Callery	Qualitative	Urban	To gain	Recruitment	25 carers of	Carers reported

et al.[38]	study using open-ended conversational style interviews. Carers were interviewed separately to children. Thematic analysis using NUDIST.	areas of Greater Manchester UK	insights into the beliefs of a group of 25 young people aged nine to sixteen years old and their carers about asthma and its management.	via a hospital and two primary care practices. Interviews in family home. Generally deprived urban areas of Greater Manchester.	young people aged nine to sixteen years old with asthma. Carers were usually the mother but included fathers and grandparents. The young people had been diagnosed with asthma for at least one year in an urban and generally deprived community. Most had moderate asthma.	assessing asthma symptoms through observed effects on the child and other family members, including emotions and behaviours that disrupted family life. Carers' assessment of asthma severity through the absence of acute attacks is consistent with managing asthma as intermittent acute episodes.
Cashin et al.[95]	Phenomenological study. Open-ended interviews lasting 50-100 minutes. Thematic analysis of narrative text.	Canada	Lived experience of fathers who have children with asthma	Recruited from outpatient asthma service at a local hospital. Anglophone Caucasians of Western European descent. Fathers aged from 39-46 years all married and living with their wife. Four held university	n = 8 fathers with children aged between 7 and 11 years who had been diagnosed with asthma. They were first diagnosed with asthma when they were between 2.5 years and 8 years old. At the time of	Five themes were identified: feeling relief in knowing the diagnosis, learning the ropes, being vigilant, living with concern, and being comfortable with asthma and management.

				degrees and four had completed at least 6 months of post-secondary education. Three fathers were employed in the professional sector, three were in the non-professional sector, and two were unemployed.	the interviews, the children had been diagnosed for a period of 2 to 6 years.	
Kealoha .[117]	Descriptive qualitative approach. Four focus groups. Open-ended questions. Directed content analysis using NVivo.	Hawaii	The purpose of this study is to explore contemporary Native Hawaiian parents' perspective and experience of caring for their children with asthma in the context of uncertainty	Native Hawaiian parents. The focus groups were held in two locations close to the participants' community of residence between November 2011 and January 2012. Three focus groups were held in Windward O'ahu and one focus group was conducted in Honolulu.	N = 10 Parents (father or mother) of Native Hawaiian ancestry. Parents were over 18 years of age with a child aged from birth to 18 years of age with parent reported asthma for more than one year duration.	Nurses are in a strategic position to alleviate Native Hawaiian parents' experience of uncertainty regarding asthma care. Nurses will find the application of the UIT (Uncertainty in Illness Theory) constructive when working with Native Hawaiian parents because their unique perspectives and experiences can be better assessed and understood. As

						nurses become more knowledgeable about indigenous viewpoints including cultural values and preferences, they will be able to assist Native Hawaiian parents in a familiar and acceptable manner. Future implications for research, nursing practice, and policy have been provided.
Reece et al.[135]	Cross-sectional qualitative study. Individual 30 minute exploratory interviews. Template analytic technique was used to analyze the data.	Northeast United States	To explore how SE Asian families view childhood asthma.	SE Asian families living in the United States for an average of 17.5 years. Ten families spoke Khmer or both Khmer and English, one spoke Laotian and English and one spoke English. Interviews took place in a clinic room in participant's preferred language (Khmer or English).	N = 12 SE Asian parents of a child aged 2-10 years with a diagnosis of asthma, plus the answer of "yes" to at least four symptoms consistent with an asthma diagnosis.	Families predominantly followed current asthma practice guidelines. Families described the severity and impact of asthma as intense. They identified barriers to care as difficulty getting appointments and unavailable providers and noted the need for education and frequent healthcare visits as facilitators to care. Nurses are encouraged to ask families in their care how

						they explain their children's asthma, thus facilitating more culturally competent care and increased ability to meet the family's needs.
Raymond et al.[134]	Face to face semi-structured qualitative interviews. Open-ended questions. Thematic content analysis.	Illinois USA	To determine which daily routines caregivers found most helpful in managing their child's asthma and to determine whether these strategies were related to children's asthma severity.	Interviews were held in a laboratory setting (a research home adjacent to a university). 94% mothers, 3.7% fathers and 2.3% grandmothers. Caregiver reported child race was 53% non-Hispanic White, 31% African-American, 0.5% Asian-American and 3% Hispanic, 12.5% other (typically mixed ethnicity). Thirty percent of the mothers reported having high school	Primary caregivers of children between ages 5 and 12 years with a diagnosis of asthma (of at least 1 year) as indicated by physician notes in medical record and by a spirometric test. Children were prescribed daily asthma controller medication for at least 6 months and had no other chronic medical conditions.	Six primary household strategies were identified: Reactive, Planning ahead, Social, Emotional, Avoiding triggers and Cleaning. In general, strategies offered by caregivers did not differ by socioeconomic status. Caregivers who endorsed Avoiding Triggers as effective strategies had children with better lung functioning. Caregivers who endorsed Planning Ahead or Emotional strategies had children with better asthma-related quality of life. These household strategies hold

				education or less. Disease severity was relatively equally distributed (mild 22%, mild persistent 30%, moderate persistent 37% and severe 11%). Socioeconomic status ranged from 8.0 to 66.0 (Hollingshead index) – median 38.58.		promise for reducing paediatric asthma symptoms and improving child quality of life.
Chiang et al.[98]	Face-to-face in-depth interviewing in participants' homes. 1-2 hours in duration. Content analysis.	Taiwan – 2 counties Taipei County and Taoyuan County	The lived experience of parents caring for asthmatic children in two hospitals by qualitative method.	Two hospitals in northern Taiwan, one in Taipei County, with residents of higher SES and the other is located in Taoyuan County, with people of lower SES. 16 parents (8 in each area). One father and eleven mothers aged between 34 and 41 years with more	n = 16 parents of children aged 3-14 years with physician-diagnosed asthma for at least three months without major organ disease or mental disease.	Six major themes about the influencing factors of self-management were deduced from the interview data: lack of understanding and dislike of the asthma label, less self-perceived severity, lack of understanding about asthma medication, lack of confidence in environmental controls,,

				than one year's experience of caring for an asthmatic child. Ten had college educational background, and the others had a high school educational background.		financial burden of anti-mite products, and doubt about effectiveness. Three major barriers to self-management behaviors of parents in the Taoyuan area were inconsistent use of alternative treatments, overdependence on medical service, and lack of use of peak flow meter. Parents with asthmatic children living in the Taoyuan area had poorer self-management behaviors than those in the Taipei area, and SES was one of the determining factors. The health beliefs of Taoyuan parents included many misconceptions.
Freidin and Timmermans.[107]	Open-ended, in-depth qualitative interviews. Interviews averaged 1 hour. Analyzed in grounded	Two USA communities	To account for the various reasons that lead caregivers to opt for complementary and	Participants homes. Ethnically and economically diverse group. 20 Latina, 25 non-Hispanic	N = 50 primary caregivers of school-age children (ages 6 to 12) diagnosed with asthma.	In our study, we found the use of complementary and alternative medicine was related to several factors: mothers' experience with biomedical

	theory tradition using ATLAS.ti Version 5.0.		alternative asthma treatments and the treatment patterns that these decisions shape.	White, 2 multi-ethnic background, 2 African immigrants and 1 African America. Fifteen of them were first-generation immigrants. 30 reported that it was difficult to make ends meet financially, one was homeless at time of the study, 2 had been homeless in the recent past, 3 received disability benefits, several were in welfare-to-work programs, and most others who were working had working-class jobs such as waitress or cashier. The remaining 20 respondents held or had held middle-	In 45 families, mothers reported that their children had mild, controllable asthma, but in 5 families the children's asthma was life threatening. In 49 of the 50 families, the mother self-identified as the primary informal caretaker.	treatments, the healthcare provider's response to concerns expressed about prescribed medications, familiarity with alternatives to conventional treatments and their use in social networks of care, and mothers' own understanding of the efficacy and safety of these alternatives.

				class or professional jobs, such as teacher, nurse or information specialist.		
Patrick.[132]	Qualitative descriptive approach using unstructured interviews. Because of geographic constraints, many of the interviews took place over the telephone. All interviews took place in a mutually agreeable place to both parties or via telephone depending on the participant’s preference. These interviews were scheduled for 60 minutes. Thematic analysis.	Alaska	The purpose of this study is to describe the experience of parenting a child who has asthma from the perspective of the mother.	Ten participants were interviewed over a two-month period of time. All were mothers of children who had asthma. Participants' ages ranged from 22 to 54 years. Their children's ages ranged from 22 months to 17 years. Most mothers had one child with asthma however, one mother had three children with asthma and two mothers had two children with asthma. Level of education o f the mothers ranged from high school completion to	N – 10 women age 18 and older who spoke English and were parenting a child with asthma were considered appropriate informants for this study. Their children ranged in age from six months to 18 years; all had lived with the mother since infancy. Level of severity of asthma ranged from mild intermittent to moderate persistent, using the Expert Panel Report II Guidelines for Managing Asthma (NIH, 1997b).	Four major categories of meaning emerged from participants' descriptions of the parenting experience. These categories are Caring for ill Child, Learning to Manage, Doing What It Takes, and Coming to Terms with Asthma.

				doctorate degrees. Occupations of the participants ranged from “stay at home moms” to registered nurses. Ages of the children, when diagnosed with asthma, ranged from four months to fourteen years. With the exception of two children, all had co-existing conditions, the most prevalent being allergies and eczema.		
Clark.[99]	An exploratory, descriptive study was conducted using face-to-face semistructured tape-recorded interviews. Data were analyzed using	Canada	The goal of this study was to explore and describe the process of managing the preschool child’s asthma from the parent’s	A convenience sample of parents who visited one of two paediatricians in one clinic were recruited. Fifteen interviews lasted on average one	N = 17 parents, fifteen mothers and two fathers of fifteen preschool children. Parents of preschool children (defined as 1-6 years of age)	Parents’ descriptions of their experiences revealed that their process of “Integrating Asthma into Daily Life” involved three phases: Ascribing Meaning, Learning to Manage, and Incorporating the

	qualitative data analysis procedures. Constant camparative data analysis technique. The interviews took place in the participant's homes and 3 in the researcher's office. One interview took place in a rural setting, although more participants came from rural homes. The rest of the homes were in a variety of socioeconomic areas in the urban setting. Data were also collected by using field notes following the interviews about interactions, or observations noted during the interview		perspective.	hour, but ranged from 30 minutes to one and one half hours, and were completed over a 10 month period. Mothers ranged in age from 21 years to 41 years of age and fathers ranged in age from 21 to 45 years. There were five single mothers interviewed, all others were two parent families, but most fathers did not participate in the actual interviews. Sixty-six percent of mothers held less than a University education. The families had an average of one other child, with numbers ranging from zero to three.	diagnosed with asthma by a physician. Parents able to speak and read English. Purposive sampling was used to interview parents of children from the full spectrum of severity of their child's asthma.	Disease.

	with the parents. The data were then transferred into Nudist (Qualitative Solutions & Research Pty. Ltd., 1994), a qualitative software program.			At the time of interviews, nine mothers were homemakers, one was going to school full time, three worked outside the home full time, and two worked out of the home part time. Sixty-six percent of family incomes were under $40,000 per year. The asthmatic child ranged in age from one to six years. The average age was 2.9 years. The children had been diagnosed with asthma at the age of 3 months to 4 years of age. Parents had been managing a child with asthma for an average of 1.8 years.		

				The sample contained four children with mild asthma, six with moderate and five with severe.		
Fleming .[106]	Separate semi-structured interviews (40) with the children and carers in their own homes were carried out within one month after the observed clinic appointment. All interviews were tape-recorded. Carer interviews lasted from 31 to 99 minutes, with the majority over an hour long. Data analysis of transcribed audiotapes and fieldnotes used a constant comparative approach	UK	To examine the experience of asthma for children and their carers within their everyday lives and how family decision making processes might impact on the management of childhood asthma at home and on involvement of families in the hospital clinic.	The setting was a specialist children's outpatients' clinic in a tertiary referral centre for childhood asthma situated in Central London. The first four clinic observations and interviews with the children and carers carried out in January to February 2006. The age range of the carers was 36 to 52 years (mean 41.6 years). Two carers had a different racial background,	N = 20 carers and 20 children (aged 7 to 11 years) with asthma were interviewed, as well as 14 clinic staff. The exclusion criteria were: children with a new diagnosis of asthma of less than a year; children who have other long-term illnesses (except eczema and allergic rhinitis); children with food allergy as well as asthma; children who live a long distance away (more than two	Children with asthma and their carers actively construct meanings about having and managing asthma and these meanings are likely to impact on how they self-manage and make decisions about asthma care. Carers' experiences of looking after children with a chronic illness also resulted in a redefining of their identities and biographies. Their perception of their children as 'normal' or 'different' had an impact on social interaction within the family social world and interactions with others.

	within grounded theory. ATLAS.ti5 computer software was used to review and code data to aid the identification of topic categories and themes.			the rest of the carers were from a white background.	hours travel time). Nineteen mothers and one father took part in the interviews. There were eight mothers with asthma in this study. All had been diagnosed with asthma by a doctor. Five mothers had asthma since childhood. The other three mothers had asthma diagnosed within the last four years and they did not take steroid inhalers but took Ventolin as needed to relieve symptoms.	
Koenig.[121]	Each family was interviewed three times. Interviews took place in the family's home and lasted	California, USA	This interpretive investigation examined how low income Latino and African-American	Eight families were Latino, two were African-American and in one family the father was African-	Eleven families were recruited by identifying Latino and African-American children between 12	Families coped with caregiving responsibility, family stressors, and multiple daily hassles related to poverty. Although asthma immersed

	between 1 1 / 2 and 2 hours. The intent of the first interview was to allow the parents to describe how they understood 'the problem of asthma' before narratives of situations and events regarding management were elicited. The second and third interviews were designed as semi-structured interviews that would elicit parents' narratives about recent stressful incidents that had arisen in the caring for and parenting of their child with asthma. Between the first and second interviews and the second and		parents of children hospitalized for asthma or reactive airway disease understood and managed asthma in their 12 month to 4 year-old children with severe persistent asthma.	American and the mother Latina. In three families the parents were married. In one family the parents lived in a common-law relationship. Seven mothers were single. In three families, the parents lived with the maternal grandmother of the child and other extended family members. Only three parents were older than 30. Ten of the eleven families had been first time parents as teenagers. Six children were girls and five were boys. At the time of the first interview, six children ranged in age from 14 to 24 months and	m onths and 4 years of age who had been hospitalized due to asthma or reactive airway disease at Valley Children's Hospital in Fresno, California in the months from November 1996 to April 1997. The children had been diagnosed with either reactive airway disease or asthma for at least 6 months. Children whose illness management was complicated by other chronic illnesses and /or disability were excluded from the study. By the parents' reports seven	parents and children in world defining fear, parents relied less on professional providers than on themselves in making assessments and taking steps to access care. Four distinct patterns of self-agency for managing asthma were found. Parents with determined self-agency managed asthma with the goal of selfsufficiency. Feeling overwhelmed when symptoms flared into crisis, parents practicing discontinuous self-agency relinquished care to professionals. Parents who practiced flexible self-agency devised varied strategies to treat crises and access care, while sharing responsibility with professionals whom they did not fully trust.

	third interviews, each family agreed to be observed twice in their home. The process of thematic analysis proceeded by reading each case as a whole, to search for specific themes, and in detail, to determine if the theme was supported on all levels by the text.			five children were between 27 and 37 months. With the exception of one family where the mother and father both worked full time in institutional jobs that brought them benefits but combined income of less than $25,000 per year, the families in this study were disadvantaged by extreme poverty and by being ethnically diverse. All but one family relied on free medical care.	children were first diagnosed with asthma at the age of 2 to 3 months. Two children were diagnosed at age 7 to 8 months, one at 12 months, and one at 21 months.	Two single mothers practiced self-agency disrupted by more critical life concerns. Asthma management was important only during, and immediately following, crisis. Frightened for their child's life during severe breathing crisis, parents experienced hospital management as additionally traumatizing for their child. Since most felt their daily management practices were disrespected and misunderstood by crisis care providers, parents dreaded future hospitalisationss and worked to avoid emergency visits.
Palmer.[130]	Ten caregivers were interviewed, some more than once, for a total of	Pittsburgh USA	The purpose of this study was to examine family perspective	Urban location of Pittsburgh. The area's urban population contained a	N = 10 Parent or guardian of a child age 6 to 11 years with a diagnosis of asthma	From the results of this study, the investigator generated a grounded theory of the process of becoming a

	15 semi-structured interviews. The length of the initial interview was approximately 40 to 60 minutes and all initial interviews were face-to-face. Length of follow-up interviews varied according to the nature of the questions involved and took an average of 10 to 20 minutes each to complete. Follow-up interviews were conducted by telephone. Interviews took place in a variety of comfortable settings chosen by the participants. Data analysis via thematic analysis.		s and experiences of having a school-age child with asthma.	mix of Black and White population groups. The sample for this study consisted o f 10 caregivers of mixed racial backgrounds. There were 6 Black and 4 White caregivers. All caregivers were women and 2 of the 10 were grandmothers caring for a school-age grandchild. One family interview included a grandmother who also helps to care for the child but is not the primary caretaker. Seven of the caregivers worked at least part-time outside of the home. All o f the children in the study attended urban schools. The	made by a physician at least 1 year prior to the study; diagnosis was consistent with the NHLBI (1997) definition of asthma; participant spoke and understood English. The diagnosis had to be made at least 1 year prior to the study so that participants would not be unfamiliar with the condition and would have had time to integrate the asthma into their lives. Participants were excluded from the study if they did not meet the inclusion criteria or if the child had a medical diagnosis or condition that	vigilant caregiver. The process was three-fold and began with the diagnosis of asthma. The diagnosis phase was characterized by a crisis period followed immediately by a period of insufficient knowledge on the part of the caregivers and high expectations from healthcare personnel. Following diagnosis, the caregivers described ongoing battles and conflicts they encountered. Conflicts included such foci as the lack of a firm or satisfactory diagnosis, frustration and conflicts with healthcare providers, issues related to a lack of support, work-related conflicts, school conflicts, and familial disagreements or conflicts. These battles led to the third phase which

				children's ages ranged from 6 years 1 month to 11 years 9 months with an average age of 9 years and 3 months. There were 6 girls and 5 boys in the study (one family had two children with asthma). The asthma was present in all of the children an average of 6 years with the range being 2 years and 3 months to 11 years. Interestingly, 7 of the 11 children in the study performed peak flow monitoring as part of their asthma management plan.	may have confounded the results of the study. Examples o f confounding medical conditions include seizures, attention deficit disorders, any chronic illness, or any illness that required children to be on medications that may alter their behavior (other than their asthma medications).	involved the utilization o f various strategies by the families such as acquiring knowledge, teaching, and taking control in order to minimise the impact of asthma on the health of the child and the family. Families experienced a wide variety of emotional reactions to the child's asthma including anger, frustration, denial, hope, and pride. Caregivers sometimes became vigilantes in order to manage or resolve conflicts by breaking or bending rules that prohibited optimal management of their children's asthma. This theory of vigilance has utility for healthcare workers seeking to understand the families' experiences with asthma. Knowledge of

						where families are in the process of becoming vigilant may assist nurses in the development and planning of interventions to improve the quality of care for these families.
Wagner and Steefel.[145]	A qualitative methods design was accomplished using semi-structured interviews. Open ended questions. Information coded using NVivo, textual analysis combined into categories and assembled into themes.	Newark, New Jersey USA	Parents' beliefs regarding asthma management and use of Asthma Action Plans.	Low income African American caregivers of children with asthma, having a household income of less than $35,000 annually and some high school education.	n = 9 female caregivers (heads of household), either mother (7) or grandmother (2) to the child with asthma. Children ranged in age from 3 to 15 years.	Self-determination was found to be a fundamental goal of asthma management; however, three themes emerged as barriers and facilitators to this goal: challenges in the urban environment, preference of familial methods, and access to medical care. Conclusions: Findings from this study regarding minority caregivers' beliefs regarding difficulty navigating the healthcare system coupled with insurance instability, leading to use of Emergency

						Departments, are consistent with past research. Although caregivers expressed belief in use of prescribed medications as indicated on AAPs, familial methods, found to provide a sense of control over asthma, were preferred.
Carrillo et al.[94]	Mixed methods study including focus group discussions. Focus groups followed a semi-structured format. Focus groups lasted around one hour. Thematic analysis.	Texas, USA	To assess the impact of asthma in the quality of life of Hispanic children and their families and to identify barriers and challenges to asthma management as perceived by parents of children diagnosed with asthma.	Hispanic families. 69% of focus group respondents had less than high school education and 85% reported being married or in a cohabiting union. All children had health insurance.	n = 15 low income Hispanic parents of asthmatic children aged 5-12 years participated in 3 focus groups. 14 focus group participants were female and 1 male. Mean age 40.1 years.	Key themes emerged from focus groups: Lack of asthma knowledge, the burden of disease for asthmatic children and their families, and the importance of asthma education and self-management behaviors for asthma control.
Yamada et al.[152]	A descriptive exploratory qualitative study conducted	Alberta, Canada	Parents were asked about barriers and enablers to	Parents of children with asthma were recruited from primary	n = 11 parents with a child with asthma aged between 1	Interviews with parents identified nine TDF (Theoretical Domains

	between Sept and Dec 2015. Interviews were conducted in person where possible, or over the telephone. Interviews took approx. 14 minutes. Interviews were transcribed verbatim, de-identified, and analysed using NVivo10 qualitative software. Content analysis was used to analyse the interview data.		managing and adhering with their child's asthma treatment plan.	care practices across Alberta.	and 18 years, who attended a primary care practice for the treatment of their child's asthma and spoke and understood English.	Framework) domains that influenced the target behaviour: Knowledge, skills, beliefs about capabilities, social/professional role and identity, beliefs about consequences, environmental context and resources, behavioural regulation, social influences and emotions. Conclusion: Barriers and enablers perceived by parents that influenced asthma management will inform the optimization of the Primary Care Asthma Paediatric Pathway prior to its evaluation.
Lakhanpaul et al.[122]	Qualitative methodology. Semi-structured interviews. Data analysed using interpretive	UK	To explore perceptions and experiences of asthma and asthma management in British South	South Asian ethno-religious groups: Indian Gujurati Hindu; Indian Gujarati Muslim;	n = 49 South Asian parents (29 mothers and 15 fathers) and 5 secondary carers (4 females and	Barriers to optimal asthma management exist at the individual family, community and healthcare system levels. Culturally

	thematic analysis facilitated by NVivo.		Asian and White British families, to identify barriers to optimal asthma management and to inform culturally appropriate interventions to improve management.	Pakistani Muslim; Bangladeshi Muslim; Indian Punjabi Sikh and Indian Punjabi Hindu and White British families with children aged 4-12 with diagnosed asthma.	1 male) of children aged 5-12 years with diagnosed asthma. n = 17 White British parents (13 mothers and 4 fathers) of children aged between 5 and 11 years with diagnosed asthma.	sensitive, holistic and collaboratively designed interventions are needed. Improved communication support for families with lower proficiency in English is required. Healthcare professionals need to ensure that families receive an asthma plan and make greater effort to check families' understandings of asthma triggers, use of medications, assessment of asthma severity and accessing help.
Hook.[112]	Qualitative study using ethnographic approaches. Data were collected using face-to-face, in-depth semi-structured interviews. Open-ended informal interviews.	San Antonio, Texas	This study sought to understand and interpret the local meaning of caring for a young child (4 to 5 years old) diagnosed with persistent	Families were recruited between April 2016 and March 2017. Low socioeconomic urban sector of San Antonio, Texas. 75% of families/care	n = 12 families/care givers of children aged 4-5 years diagnosed with persistent asthma	Two overarching themes emerged within the dataset, uncertainty and distress. Families were worried about the next asthma event and how they would respond. The families were worried about

	Thematic analysis using NVivo 11 software.		asthma.	givers were Hispanic and 25% were Black Non Hispanic. 33% had less than high school education, 25% were high school graduates or had a GED certificate; 40% had some education past high school and 8% (1 caregiver) had a bachelor's degree. Family income less than $49,143 per year.		cigarette smoking but recognized that they did not have much control over cigarette exposure. The findings suggest the continued development of outcome-based research to assess the experience of the illness and treatment within the "local world" of the patient because culture does matter in clinical care.
Abdullah Al Aloola et al.[85]	Semi-structured in-depth, face-to-face interviews were conducted. Thematically organised using a latent content analysis.	Saudi Arabia	The needs and preferences of parents in relation to the asthma education and policies that affect the management of children's asthma at school, and	Interview were conducted privately (outside school grounds) between November 2015 and February 2016. Ethnic grouping: Saudi Arabian parents.	n = 19 Saudi Arabian parents (9 mothers and 10 fathers) of children between 7 and 12 years with asthma diagnosed by a health professional.	Six themes emerged from the interviews and were grouped into three major categories: General asthma management issues; school based asthma management issues; and communication dissatisfaction. Participants

			identify parents' perceptions, expectations, concerns and beliefs about school based asthma care.	95% of parents interviewed both had a university degree and 5% had a high school degree. 69% of parents both worked full-time, 26% had fathers only working full time and 5% had only the mother working full time.		expressed concern at schools' social and physical environments and a lack of confidence in the ability of schools to manage their child's asthma, especially when their child was ill. Most of the participants advocated for staff training and school community engagement to improve the management of asthma in Saudi primary schools. Conclusion: This research clearly describes a need for school-based asthma support, including asthma-related policies, procedures and education on asthma and first aid in Saudi primary schools.
Waters et al.[149]	Participatory action research approach, we conducted focus groups and individual interviews.	Washington DC	Parents and guardians of African American and Hispanic children's experience	The focus groups were conducted at Children's National Health System, and the individual interviews	N =15 African American and N=15 Hispanic parents or legal guardians of children aged 4-12 years	The findings were organized around four central strands of inquiry that informed the development of the stress management

	The focus groups and interviews followed a semi-structured protocol. A total of four focus groups were conducted, two with African American parents and two with Hispanic parents. Data Analysis via content analysis and thematic analysis using Dedoose (software program for managing qualitative data).		s of managing asthma and stress. To understand the perceptions of stress and stressors and inform the development of a stress management intervention targeted at parent caregivers of children with asthma.	were conducted at the hospital, parents' homes, or by phone, depending on parents' preferences. The focus groups and interviews required 90–120 min to complete. Participants ranged in age from 24-55 years (m = 37.5) and were largely mothers (90%). Children were aged from 4-14 years (m = 7.4) and had an average of 1.2 urgent care visits in the preceding 12 months. Disadvantaged African American and Hispanic. All of the Hispanic parents indicated El Salvador, Guatemala, or Mexico as their	with persistent asthma, public insurance and absence of a chronic medical condition other than asthma.	intervention, (a) parents' experiences of stress, both related to asthma and other external factors, (b) strategies parent employed to cope with stress, (c) intervention preferences, and (d) the cultural similarities and differences between African American and Hispanic parents' experiences.

				countries of origin or ancestry.		
Garcia.[108]	Face-to-face, open-ended questions, semi-structured interviews. Interviews at informant's or researcher's home or another location where privacy could be assured. Interviews lasted approximately 1 hour. Data analyzed for common themes. Content analysis.	USA	To explore and describe the phenomenon of the experience of having a child with asthma as perceived by mothers of children with asthma.	Large metropolitan area of approximately 3 million people in southwestern United States. All informants were at least 21 years of age. Informants ranged in age from 27-53 years with children aged between 19 months to 17 years. Three mothers had two children with asthma, and seven of the mothers had one child with asthma. All were Caucasian and married. Six were employed outside the home, three were self-described homemakers, and one helped with her	N = 10 mothers with children aged between 19 months and 17 years with asthma.	A core category, uncertainty, and four process-oriented categories: vigilance, searching for answers, taking charge, and finding a balance emerged. Findings indicated mothers need to be included as integral members of the healthcare team. A timely diagnosis of asthma with understanding, appropriate education, and provision of resources would decrease uncertainty and improve mothers' ability to manage effectively.

				husband's business. Most were college educated, with some having completed graduate work.		
Wallace .[148]	Parent/guardian perceptions of the barriers and facilitators of healthcare access for their child's asthma care were collected through semi-structured telephone interviews. Interviews took between 30-45 minutes, including responses to quality of life and asthma symptom surveys. Parent (or guardians) were interviewed via telephone. The	Denver, Colorado USA	The purpose of this exploratory, descriptive study was to identify factors that facilitate or impede the use of healthcare resources by urban children with asthma.	32 mothers, 1 father, 1 female guardian. The majority of participants identified themselves as Hispanic (53%), followed by non-Hispanic African-Americans (26%) and non-Hispanic Caucasians (21%). The majority of participants stated that they had completed high school or at least some college (56%). Most (59%) parents reported an annual household income of	N = 34 parents/guardians of children, aged 5-12 years, who sought asthma care in one metropolitan healthcare setting between August 2003 and August 2004. Interviews were conducted between November 2004 and February, 2005.	Both parent and healthcare professional participants identified a number of factors influencing children's access to asthma services, including parental beliefs, family organization, service organization, and insurance-related factors. Utilization data analyses identified that age and race-related factors influence access to care. As children age, they had a reduced risk of having emergent/urgent visits and those who are Hispanic were less likely to have insurance. Insurance status

	conversations were guided by a semi-structured interview. Data analysis via thematic analysis.			$20,000 or less and most (62%) identified themselves as single parents. The majority of the children of parents interviewed had Medicaid insurance (62%). The mean age of these children was 8.79 years. 27% of parents stated that a healthcare provider had informed them that their child was, or may be, overweight. In addition, of 26 parents asked, 14 (54%) stated that their child with asthma is exposed to tobacco smoke.		was shown to influence access to care in that those who were uninsured were less likely to access allergy specialty services. In addition, those with Medicaid insurance also experience more insurance type changes. Insurance type changes were associated with a greater number of asthma related visits to all settings. Finally, a negative association was then found between asthma-related emergent/urgent care and primary care visits. Among the many implications resulting from this study's findings was the seemingly strong influence clinical service organization and relationships between parents and providers have upon healthcare access patterns.

						Implications for nursing and recommendations for further research were also discussed.

Appendix V: List of Study Findings with Illustrations

(1) Barrett JC, Gallien E, Dunkin J, Ryan L. Managing asthma within the context of the rural family. Public Health Nursing. 2001;18(6):385-91.	
Finding	Experiences with asthma (U)
Illustration	Caregivers described the process of learning their child's symptoms of asthma. The symptoms and reactions always involved a cough, tightening of the chest, wheezing, and difficulty in breathing. Pg 387
Finding	Parents talked about where they sought care for their child (U)
Illustration	All parents used the emergency department when the symptoms escalated or when the primary physician’s office was closed. Three parents described how stressful going to the emergency department was for both them and their child. Four parents had a primary physician that they went to for mild symptoms. Pg 387.
Finding	Day-to-day management of asthma (C)
Illustration	All parents talked about trying to keep the child’s indoor environment as clean as possible by washing bed linens, dusting, vacuuming, and keeping stuffed animals out of their child’s room. All six parents were using the mattress and pillow covers given to them in the original study and commented on how that had helped their child’s nighttime asthma. Two parents had eliminated carpets and rugs from their home. The remaining four parents discussed the use of Acaracide or baking soda on the carpet before vacuuming. Two parents had eliminated clutter in the home. Two parents had replaced the curtains in the home with blinds. Three parents had some sort of filter system in the home. Pg 387
Finding	All parents described efforts made to lessen asthma triggers in the home or to decrease the child's chance of an asthma exacerbation (U)
Illustration	These included keeping the child indoors on rainy days, giving preventative medication before exercise or sports activities, and elimination of perfume or cologne from household toiletries. Pg 387
Finding	Effective intervention was the use of the hypoallergenic mattress and pillow covers (U)
Illustration	"And I think probably the thing that made the most difference for him was putting his pillow, hypoallergenic cover on there. That made an immediate difference, in my opinion." Pg 388
Finding	The struggle between obtaining the cooperation of family members in needed interventions particularly limitation of smoking, while maintaining good family relationships (U)
Illustration	"the allergy doctor said she didn’t want my sister smoking in the house anymore. So my sister goes to the kitchen now and turns on the fan, but it still bothers my son. We just give him his breathing treatment and hope we don’t have to go to the emergency room." Pg 388
Finding	School prohibitions about children carrying medication with them (U)
Illustration	"If someone was having an asthma attack and they needed their inhaler right then, I don’t think it’s such a good idea to have it at the other end of the school and have to get

	permission, and sometimes it's a student in the office, and not a person who can get the medicine, and that sort of thing. It's unfortunate because it ends up hurting the kids." Pg 388
Finding	Cost of the recommended therapies (U)
Illustration	"….that the emergency room doctor told her to get a "breathing machine". She knew this was good advice, but she could not afford it." Pg 388
Finding	Conflict about family pets (U)
Illustration	"Well, I was told to pull the carpet up all over and get rid of the dog, but I just – I don't think that has enough of – I mean – it doesn't trigger it that much. Now if they was worse – a lot worse – then, yes, we probably would have done something like that, but we just didn't feel like they was severe enough to go to that extent." Pg 388.
Finding	Parents named many sources of information about asthma, both professional and lay, and generally were confident about the adequacy of their knowledge (C)
Illustration	One representative parent said that as long as you know you are doing the right thing, then you do not have to worry. The doctor or nurse is going to come and tell you, and if you cannot get a nurse, somebody who already has asthma is going to help you out. They will show you what to do and what not to do. Pg 388
Finding	Effective interventions (U)
Illustration	Parents reported that keeping the indoor environment clean and dry prevented problems. Two parents discussed the value of prophylactic medications. Two parents talked about avoiding foods to which their child was allergic. Two parents discussed controlling their child's exposure to outdoor irritants. Pg 388
Finding	Caregivers described the process of identifying what triggers their attack (U)
Illustration	Included triggers were consistently pollens, mold, cigarette smoke, dust, exercise, and cold, damp weather. Pg 387
(2) Arcoleo K, Zayas LE, Hawthorne A, Begay R. Illness representations and cultural practices play a role in patient-centered care in childhood asthma: experiences of Mexican mothers. Journal of Asthma. 2015;52(7):699-706.	
Finding	The primary symptom mothers reported were shortness of breath, choking, coughing, chest tightness, wheezing, sneezing, restlessness, fatigue, and/or fainting (U)
Illustration	"asthma causes them to be unable to breathe. They feel like they are choking...that is what I think asthma is...the chest closes up tightly....he feels like fainting..." p702
Finding	Mothers described their child's asthma as an illness that is unpredictable, dangerous, deceiving, and potentially life-threatening (U)
Illustration	" ...it's a frightening illness because he can be literally fine in the morning and severely ill by the evening. It comes very quickly..." p702.
Finding	Little knowledge about asthma (U)
Illustration	"to tell you the truth I didn't know what asthma was, and in Mexico they don't speak much about asthma". Pg 702
Finding	Hereditary explanation provided justification for mothers who had relatives with asthma (U)
Illustration	"because my mom had it, and I do too, and now my kids, I think that it is a hereditary problem." Pg 702.
Finding	Severity was also determined by whether they could adequately treat their child at home

	or if they needed to go to the doctor of emergency room (U)
Illustration	"[my child] doesn't have advanced asthma and is not bad because I've only taken her to the hospital 3-4 times in four years." Pg 703
Finding	Those who did not give their child controller medications as prescribed explained they only used it when the child had symptoms (U)
Illustration	"He uses the spray medication only when he gets asthma, not if he doesn't have it....if he uses it daily it will not work when his asthma is very bad...[doctor] recommends using it daily even if he has no symptoms because later he could get worse..." Pg 703
Finding	Mothers worried about their child becoming addicted (U)
Illustration	"...sometimes they become addicted [to medication] and they have to give them stronger medication...I'm afraid to give them medication because later on they would have no effect because they become addicted." Pg 703
Finding	Concerns about their child taking too much medication (U)
Illustration	"If he's going to use 'Singulair' then why give him 'Zyrtec' at the same time? And why use 'Albuterol' and then 'Advair' too and the shots for the allergies, for a kid that's 10 years old. I understand it's for his health, but it's a lot for a 10 year old child...like an old man, he takes three types of inhalers, three types of pills, and shots for his allergies...." Pg 703
Finding	Long-term effects of asthma medication use were also a concern (U)
Illustration	"..secondary effects...you don't know what's going to happen...giving them too much medication...it might give her cancer...or stomach ulcers..." Pg 704
Finding	Lack of accurate, consistent information (U)
Illustration	"...I've also done some research, spoken to different doctors, nurses, providers...The frustrating part is that, depending on who you speak to you get a different answer. There's no consensus...[for] best treatments for asthma...." Pg 702
Finding	A few mothers did report receiving the information they needed (U)
Illustration	"I ask the doctor[s], 'why does this happen?' ...and they've informed me there are stages, and how it is, and her case, how to calm her down...it helps, the information...it has been very important, he's answered a lot of questions." Pg 702
Finding	Some mothers believed their child could eventually outgrow their asthma (U)
Illustration	"[the doctor] told us that when he turned seven years old it could go away...that if by [then] it didn't go away he would have it for the rest of his life..." Pg 704.
Finding	Fear, worry and even desperation they experienced in caring for a child with asthma (U)
Illustration	"It worries me that someday I'm not there...when he has a sleep-over at a friend's house...he gets an asthma attack...and the family doesn't know what to do in that moment". Pg 704
Finding	Limitations on the child's activities and family lifestyle (U)
Illustration	"It is hard to take because there are things he cannot do....there are a lot of things we cannot do with him, he cannot go to some places...because he could get asthma there." Pg 704
Finding	Adapted to caring for and living with a child with asthma (U)
Illustration	"...at first I was worried, then while time went by we've learned how to control it so that it's normal...we're making it part of our lives so it's not traumatic and we have options..." Pg 704

Finding	Another mother blamed her exposure to chemicals (U)
Illustration	"....I was pregnant....dyed my hair a lot....the chemicals to dye hair have a very strong smell...[the chemicals] affected them because they have very low defenses, they are so little, what the mother breathes, smells, feels the baby feels." Pg 703
Finding	Physical activity as a trigger for asthma (U)
Illustration	"When he runs a lot he can't breathe well and....feels pain in his chest and has to use his inhaler fast...it's not constant, only when he runs." Pg 703.
Finding	Severity was also classified by the extent of their child's activity limitations (C)
Illustration	"It's a horrible illness for them...to have all of these things prohibited so it doesn't cause them asthma..." Pg 703
Finding	Use of the "machine" (nebulizer) was indicative of more severe illness (C)
Illustration	"....the doctor decided to not give it to her in the machine....she had a strong reaction.....and with the inhaler she had no reaction...it's asthma but not a strong asthma." Pg 703
Finding	Environmental exposures support the humoral balance theory of disease (U)
Illustration	"He gets asthma more when the weather gets cold. He does not get it when the weather is hot." Pg 703
Finding	Lay sources of asthma knowledge included: personal experience, relatives and friends, and the media (U)
Illustration	"....other people who have children with asthma tell me, and sometimes I ask for information." Pg 702
Finding	Lay knowledge also changed with caregiving over time (U)
Illustration	"...knowledge about asthma changes as you live the experiences of asthma with your children." Pg 702
Finding	Knowledge derived from HCPs about asthma was limited for many mothers (U)
Illustration	"before [daughter] developed asthma I wasn't well informed about [it]....Now that I've been going to the clinic I still don't know that much..." Pg 702
Finding	Child's asthma was due to her use of antibiotics during pregnancy (C)
Illustration	"...when I was eight months pregnant I got a cough...[it] was getting more intense....The doctor said I was going to need an inhaler...it was provoking bronchitis..." Pg 702
Finding	Other mothers believed that environmental exposures caused their child's asthma (U)
Illustration	"when we lived in apartments with carpet that would make him have more frequent attacks...when we step on it the dust comes up and that causes my kids to generate more asthma." Pg 703
Finding	Cold foods or liquids were also identified as asthma triggers (U)
Illustration	"When he constantly eats...ice cream or very cold drinks, sometimes that brings on the cough...and that starts triggering the asthma." Pg 703
Finding	Mothers perceived illness severity by their child's symptoms, frequency and duration of symptoms (U)
Illustration	"if after the third time he's getting worse...meaning the shortness of breath or wheezing gets worse, that's when I'm supposed to take him to the hospital immediately." Pg 703
Finding	Episodic nature of asthma based on seasons (U)
Illustration	"....they can be fine from January through August and when August ends I know that it will come...." Pg 702

Finding	Some mothers learned about asthma from internet sources (U)
Illustration	"If I know a bit more it's because I look it up in the internet or other resources, not because [doctors] have given me the information." Pg 702
Finding	Challenges they all face when trying to identify causes of their child's asthma (C)
Illustration	"...there's so many factors that we can't agree on what triggers or what causes asthma, it varies from child to child." Pg 703
Finding	Almost all mothers reported that asthma is a dangerous disease because the child could die if not treated quickly (U)
Illustration	"when you mention the word asthma people don't think of it as a severe illness but it can turn into something fatal or pretty tragic if it's not addressed quickly." Pg 703
Finding	Mothers reported using controller medications daily as prescribed by their HCP (U)
Illustration	"Until now he hasn't had an attack....because I give him the medication that the doctor recommended daily...I give it to him daily and I don't skip a day." Pg 704
Finding	Most mothers believed there is no cure for asthma (U)
Illustration	"It's an illness that doesn't go away completely....it gets better but never goes away. You have to learn to live with it," Pg 704
Finding	Another mother believed her son's asthma will abate when (C)
Illustration	"....his immune system can take it....until he's strong enough to get rid of it....I don't see this as a chronic illness anymore." Pg 704
Finding	Mothers who spoke of a cure referred to natural remedies that are commonly used in Mexico (U)
Illustration	"....the star flower is good....he said you can be cured of asthma forever...." Pg 704
Finding	Mothers and family members were also very worried that their child could die from an asthma attack (U)
Illustration	"My child's having a severe episode and...it's severe enough where I'm racing against time to get him to the hospital....that would be any parent's severe fear...where it's kind of a life-death situation...." Pg 704
Finding	Feelings of desperation or hopelessness (U)
Illustration	"Desperate...I felt impotent of not knowing what to do, to not know how to control it...I wanted for her to not feel anything and...to be well." Pg 704
Finding	Not telling her daughter or her siblings about their daughter's asthma diagnosis because she did not want to worry them (U)
Illustration	"I don't know if it's bad that I haven't told her what she has exactly, since she hasn't had it that strong I try to not worry her." Pg 704
Finding	Hereditary explanations provided justification for mothers who had relatives with asthma but puzzled others who did not (U)
Illustration	"I don't know if it is also genetic...because in my son's case nobody in my family suffers from asthma....." Pg 702
Finding	Mothers were asked what they believed caused their child's asthma (U)
Illustration	One other thought that one of her children had 'infected' a younger sibling with asthma, but the doctor told her that "...maybe it's hereditary but not contagious." Pg 702
Finding	A few mothers described asthma in clinical terms; as an inflammatory condition of the respiratory system (U)
Illustration	"asthma is a physical problem that has to do with the respiratory airways," and another

	said that 'it is an obstruction of the ducts." Pg 702
Finding	Environmental exposures caused their child's asthma (C)
Illustration	"City children get sick with asthma more even though country children are in closer contact with animals. They have stronger immune systems. However in the city there is more pollution. The doctor said my child did not have a [strong] immune system. He needs to play with dirt. He got better [when] in contact with dirt." Pg 703
Finding	Others who expressed hope for a cure referred to spiritual intervention (U)
Illustration	"I tell him that God will cure him...we need to ask God to take care of you and to cure you, and he does it, I teach him to pray." Pg 704
(3) Mosnaim G, Kohrman C, Sharp LK, Wolf ME, Sadowski LS, Ramos L, et al. Coping with asthma in immigrant Hispanic families: a focus group study. Annals of Allergy Asthma & Immunology. 2006 Oct;97(4):477-83.	
Finding	Hispanic mothers of children with asthma say that they often have to deal with a crisis situation on their own (U)
Illustration	"[My son] hit the ball and made a home run and tried to get to the base but when he got there he had an attack....They offered to call an ambulance but I said no because they were going to charge me for the ambulance and I didn't have any money. I grabbed the car and went to the hospital with the boy and the little girl and the other one....I called my husband's work...but they (would not) pass the phone to him....I needed his help....I have other sisters but they live very far away and I do everything all by myself....(When we got home from the hospital and my husband got home from work) my son was already better....I called the school and told the teacher and the nurse (and he went to school the next day)." Pg 479
Finding	Fathers state that they play an active role in caring for their child experiencing an episode of acute asthma (C)
Illustration	"My son was 2 and a half when they discovered he had asthma...[My 2 children, wife, and I] all went in the car.....to Cook County Hospital....[My wife stayed with him all week at the hospital], she slept there every night...and I took my son to work with me....I went to visit every afternoon when I got off work." Pg 480
Finding	Grandparents are very involved in taking care of their grandchildren's asthma and the proximity of living arrangements is a significant factor in the type of role they play (U)
Illustration	"One day at 10pm at night my daughter-in-law knocked on my door. She lived in the apartment upstairs.....She told me to take the child...he wasn't breathing very much....I put alcohol and Vick's on his chest and I rubbed his back....He started to wake up and recover a little...My son didn't have a car and asked me to take my daughter-in-law to the hospital...My son stayed with the other boy because he was asleep and someone needed to stay with him." Pg 480
Finding	Mothers, fathers, and grandparents all demonstrated strong beliefs in the use of folk medicines and natural remedies to treat asthma (U)
Illustration	"I also had asthma symptoms, and they went away with possum oil." Pg 480
Finding	Religious belief also plays a role (U)
Illustration	"Listening to this lady who had faith in the oil and the onion that healed her child....She has faith in this and believed that this healed him. Faith moves mountains and I have faith in Jesus Christ and this is who helped my grand-daughter. He is the main doctor.

	He listens to our prayers and looks after out needs." Pg 480
Finding	Mothers unanimously stated that there is a lack of an adequate social support system for immigrant mothers of a child with asthma (C)
Illustration	"I think that it is very difficult to ask people for help here. People think that when you come here, you know it all." Pg 480
Finding	Families live in fear (U)
Illustration	"....moment comes and the person is stuck and doesn't know what to do, they can die.....[we don't have] information.....[we don't know] what to do in the right moment, to help the person so that they don't die." Pg 480
Finding	One mother described a desperate situation in which her son almost died of an asthma attack because they had no transportation to take him to the hospital (C)
Illustration	"My son was approximately 4 years old...It was like 12am when he got sick, and I told my husband we had to go to the hospital.....We didn't have a car. We were thinking about going on the CTA [Chicago Transit Authority]. We were waiting quite a while and the bus didn't come by and a man passed by and told us the bus didn't pass at night. We wanted to call the police, but there wasn't any public telephone either or a taxi and nobody to give us a ride. We didn't know what to do, so we started walking until we saw a police officer....I was almost crying and he took us to the hospital." Pg 480
Finding	Another mother depicted how her son was sick all of the time and her baby daughter was hospitalized largely owing to their poor living conditions (U)
Illustration	"When we arrived...we came to one of the worst basements....didn't have insulation....had black walls...[My son] started to sneeze and sneeze and then he was getting weary and I didn't know what it was....When I took him the doctor told me he was at risk of asthma. He asked me where I lived and when I told him he told me that I had to move from there because my son would develop asthma." Pg 481.
Finding	Family members felt confused and expressed that physicians did not give them a clear diagnosis (U)
Illustration	"[The doctors] didn't tell me that he had asthma....told me he had symptoms of asthma," and I father said, "I don't think that my daughter has asthma, but she has respiratory problems..." Pg 481
Finding	Respondents all indicated that they needed more help understanding the disease and knowing what to do (U)
Illustration	"The [the physicians] give you medicine and that's it. They never give you information [about asthma]." Pg 481
Finding	Fathers expressed their desire to be more involved in taking care of their child's asthma. They would like more information about managing their child's asthma at the time of the emergency department visit (C)
Illustration	"They never give you information [about asthma]." Pg 480
(4) Boyle JS, Baker R, Kemp VH. School-Based Asthma: A Study in an African American Elementary School. Journal of Transcultural Nursing. 2004 Jul;15(3):195-206.	
Finding	The first concern centered on the school experience. Parents emphasized the limitations of physical activity and the importance of medication (U)
Illustration	"I told them he had asthma, and that he can't participate in gym or something like that. He can participate in certain things but there are certain things he can't participate in,

	like running and jumping because he gets so excited to where he can't hardly breathe. Then I tell them that he has to keep his book bag outside or keep his pump in his pockets just in case he should need it. I ask them to keep a close eye on him." Pg 200
Finding	Parents felt they could sense the teachers' uneasiness of not quite knowing what to do or how to respond. (C)
Illustration	"I just tell them to call me if there is anything wrong." Pg 200
Finding	Parents described episodes of illness during which they had been frightened because their children were very ill (U)
Illustration	"Yes, I was really scared. At first, I didn't really feel scared because when she was young, I was all right with it because I thought I knew what was going on, but one time she got really sick, fast, and in the middle of the night. And she was just hot…hot…hot, and the temperature wouldn't go away and she was just like she was going out of it. I was like, Oh Lord, she's fixing to go. I was so scared. I took her to the emergency room and they gave her some kind of breathing treatment and it helped out. But I don't want to go through that again. They get sick, I mean, they really do get sick." Pg 201
Finding	children's colds and coughs during the winter were always prolonged by asthma (U)
Illustration	"They just get colds and can't get rid of them." Pg 201
Finding	Parents worried if their children wanted to participate in the school's sports program (U)
Illustration	"He gets up in the morning with a baseball glove in his hand. You can't tell them no, you got to let them do it." Pg 201
Finding	Parents described the extra cleaning that they performed, washing window blinds, cleaning carpets, and trying in all possible ways to eliminate dust, pollen and other pollutants (U)
Illustration	One mother said the extra cleaning was the worse thing about having a child with asthma because she was constantly dusting, sweeping, and trying to keep the house clean. They used humidifiers to keep the air moist, and doors and windows were closed, even in the summer weather. Pg 201
Finding	Parents reported that they believed they had access to satisfactory medical care, and they appeared to be comfortable with their physician and the care their children received (C)
Illustration	"I don't care who's there as long as they can tell me what's wrong with my baby and give me something for him. I've had to go to the emergency room in the middle of the night and it don't make no difference what doctor I see as long as they can help me and tell me what to do." Pg 201
Finding	Difficulties in preventing other family members from overreacting to the children's asthma (U)
Illustration	"My aunt called me yesterday and said that she was real scared because I had let my little boy go out of town for the weekend with his daddy. She said she was real scared because he'd been coughing for three weeks and that medicine don't seem to be helping. I told her it's helping for what it is for. It's not to help him stop coughing. It is to help him loosen up his chest. And she said, "Well I don't know about that, I'm just worried to death." I tried to tell her, but it don't do not good." Pg 201
Finding	Parents relied on their own mothers for help with the children, especially when a child was ill. Yet, sometimes this caused additional problems (C)

Illustration	"Sometimes its just more trouble than it's worth." Pg 202
Finding	Teaching the child about asthma (U)
Illustration	Parents described the necessity of helping children learn to monitor their asthma and learn how and when to take medication appropriately. Pg 200
Finding	Mothers developed skills to discern when their child was becoming ill (U)
Illustration	Mothers could tell by changes in activity level, decreased appetite, the need for additional sleep, or just "the way the child looked." Pg 201
(5) Finnvold JE. In their own words: early childhood asthma and parents' experiences of the diagnostic process. Scandinavian journal of caring sciences. 2010 Jun;24(2):299-306.	
Finding	The uncertainty expressed by several was caused by not being able to understand the origin of their child's suffering, and the physician's limited capability to diagnose the problem (U)
Illustration	"…just like in a dream when you are running and running, and never reaching anywhere. You are sort of in a vacuum, and don't know what is really happening, but know that something is really wrong, but cannot explain it to the doctor, or the doctor cannot sort it out either." Pg 302
Finding	Both negative as well as positive evaluations of their encounters with health professionals (U)
Illustration	"The consultation that we had was with the doctor only. I thought he was great. He had plenty of time for me. I think he used over an hour on me every time, and I felt that I was not thrown out. It is completely different down at the local health centre; they only give you about 10 minutes, and then you get kicked out….Now I go to the hospital, twice a year, for check-ups. In the beginning, it was every third month….At the hospital, they take you very seriously." Pg 302
Finding	Seeking out alternative sources of care (U)
Illustration	"It was when we changed doctors that things fell into place. It was in fact a general practitioner, who was really nice." Pg 303
Finding	The ability to acquire knowledge about their local healthcare facilities was evident in the interviews. The parents often used this information in a strategic manner to achieve access to healthcare facilities (U)
Illustration	"If it is acute, you can get in there, but if they sign you up for an appointment, you have to wait for 3 months; but if it is something urgent, it can take a week, and if it is very urgent, I have learned how to get in the same day. I just push on through, and tell them that I don't want to put up with it any longer….or else I call the emergency at three a clock, at that time the emergency takes over, and I know that at three they take you in no matter what…" Pg 303
Finding	Conscious about the words and expressions that she used in the conversation with the doctor (U)
Illustration	"…two days later his condition became worse, and I called again, or was it my sister that told me to call…..when we arrived, the doctor said that he had to be admitted to the hospital…we might have said the right things, and that is very important, that you know what to say…we were talking about inhalation devices, but really, we didn't have a clue…it is too bad that you have to get the words right, but I also think it is very

	important." Pg 303
(6) Barton C, Sulaiman N, Clarke D, Abramson M. Experiences of Australian parents caring for children with asthma: It gets easier. Chronic illness. 2005 Dec;1(4):303-14.	
Finding	They worried that an asthma attack could happen at any time, and especially that they would not be available when the child had an asthma attack. Some parents were extremely reluctant to allow their child to be away from their supervision at all (U)
Illustration	"He's into this sleepover thing now and he just loves to have sleepovers and he wants to stay at all his friends' house but I prefer them to come here and have his friends sleep here and then he says 'why don't I ever get to sleep over, they all come to my house?'….And he does get offers to go and stay over but firstly, it's too much responsibility on the parents, like here you are here's my child for the night now there's all his medication and there's the needle if he has peanuts and here's the Ventolin and this is how much dosage you need to give, it's very daunting on parents and I see the look in their face and I just think is it worth it?" Pg 306
Finding	Asthma attacks were more frequent during the night and early hours of the morning. This led to sleepness nights and fatigue on the following day (U)
Illustration	Caregiver: "No, actually, I bring him into bed with me. So, it's [nebulizer] in the bedroom. I try not to wake him right up, not that, it wouldn't matter with him, he'd go back to sleep anyway. But mostly, if he's really bad I'll put him into bed with me afterwards because I'm not going to just, we're at opposite ends of the house, and I'm not going to leave him on his own." Interviewer: "Do you get any sleep those nights?" Care-giver: "Not really, no. Not when you're sitting and listening to a kid that can't breathe. But I mean, my husband gets booted out too, because I can't we don't all fit into the bed together [laughs]." Pg 307
Finding	Experienced managers of asthma reported that initially they would go to the ED all the time, but when they were more confident, they would 'try to ride it out' at home. (C)
Illustration	"She was sick for about 3-4 days, but she hasn't deteriorated….Like if I could see that it wasn't helping her then I would go to the doctor. But if I know that, you've got to ride it through and it will get better, because everyday it was getting a bit better and then towards the end it just stopped by itself." Pg 307
Finding	Care-givers reported that asthma often left them feeling frustrated (U)
Illustration	They were frustrated when managing asthma, and wondering what medication the doctor would try next. The felt frustrated with their children when they had asthma, and with having to cancel social appointments or organize time off work. Some also reported frustration when trying to get a diagnosis of asthma and to be taken seriously by healthcare professionals. Pg306
Finding	During asthma attacks, parents often reported feeling scared or panicked (C)
Illustration	Not knowing enough about asthma, and fear that the child might die. Pg 306-307
Finding	Uncertainty about how an asthma exacerbation would develop (U)
Illustration	Uncertainty about how an asthma exacerbation would develop was a significant source of distress, as was not knowing enough about asthma, and fear that the child might die. Pg 306
Finding	Caring for a child with asthma 'gets easier' (U)
Illustration	"When he was two and a half….I thought what am I doing and he used to get me down, I

	used to be so depressed because I used to think how am I going to cope when he gets bigger. In actual fact it's a bit better. I'm finding him because he can talk to me and tell me and express what he's feeling, I find that it's better. It was worse when he was younger and if I ever talk to people who have children with asthma I'd say that it's really hard when they're young because you don't know what they're feeling or what to do, it's a terrible feeling." Pg 308
Finding	Parents described a number of strategies that they used for coping with asthma, such as accepting it (resigned acceptance), social support and, less often, positive reappraisal and religion (U)
Illustration	Resigned acceptance including statements such as 'dealing with it' or 'just part of being a parent.' Most felt that there was nothing they could do about their child having asthma; they just needed to accept it, and get on with the job of managing asthma. Pg 308
Finding	Caring for a child with asthma often involved considerable disruption to the work of both the primary carers and their partners. Their children's health was more important than their work (U)
Illustration	"I had this really horrible Principal who wasn't very understanding and one time I said to him 'I just don't care', I said, 'my family comes first' and I said, 'I don't need this job if you can't give me time off.' Because he started to make an issue about, 'you can't take time off for your children, you can only have time off if you're sick'. And I thought 'well if I don't get paid for it I don't care'. My children. That is the most important thing in my life, you know my family. But at the other school they were quite good. I moved school." Pg 308-309
Finding	The interviews revealed a number of health and treatment beliefs that influenced caregivers' use of asthma medications (U)
Illustration	The primary belief identified was that the 'child is just normal.' A number of caregivers did not like using asthma medications, particularly when their child was 'well'. This was especially so for preventer medications, although attitudes varied. While some parents were quite positive about asthma medications, others tolerated them, feeling that they were necessary. Preventers were looked on unfavourably, because they need to be used all the time and they contain steroids. Some caregivers had concerns about the risk of side-effects resulting from long-term use. The primary concern was for the child's weight or growth, but caregivers were also concerned about their child feeling tired and lacking energy, and behaviour problems. Some parents also felt uncomfortable about their child using reliever medications, due to physiological and behavioural effects such as shaking and hyperactivity. Pg 309
Finding	Even with subsidized medications and doctors' fees (bulk-billing), many families struggled to find the money needed to replenish medications on a fortnightly or monthly basis (U)
Illustration	Nonetheless, all of the parents reported that their child's health was the most important consideration and that, if necessary, they would go without something else in order to pay for a medication prescription. Pg 309
Finding	Caregivers were generally happy with the level of care that they received from their GP and/or paediatrician (U)
Illustration	Many parents reported travelling long distances, outside of their own towns or suburbs,

	in order to maintain a relationship with their GP. Pg 309
Finding	Support from partners and immediate family was highly valued, on both an emotional and a practical level (C)
Illustration	Partners, extended family or friends would care for other children if the child with asthma was admitted to hospital. They would often accompany the primary caregiver to hospital or take turns spending time on the wards. Pg 308
Finding	Being able to transfer responsibility to health professionals meant that they would no longer be responsible for the child's care which was comforting (U)
Illustration	"Once you're there [at the ED], you're relieved because you know it's not your responsibility anymore. They've got to fix him, you don't have to anymore." Pg 308
Finding	Some care-givers felt that they could tell when an asthma attack was beginning, and would watch it develop (C)
Illustration	"What goes through my head? Oh, here we go again [laughing]. Pg 307
Finding	The decision to seek emergency care at a hospital was not taken lightly (U)
Illustration	Care-givers would judge how the child was presenting. That is, how often did they need reliever medication, what were their symptoms, how was the child feeling, how did they look (e.g. 'pasty', tired, exhausted). Most parents then reported that 'they just knew' when the child needed to be taken to hospital, or if they could continue to be managed at home. If in doubt, care-givers would seek professional help from a GP or the hospital ED. Pg 307
Finding	Intermittent use of medications (U)
Illustration	She hasn't really used her every night ones, because she doesn't feel she has to unless she gets sick, and she has been advised by her doctor anyway so, while she is sick, even if she got better she has to keep using it for another month." Pg 310
Finding	Three areas in which asthma disrupted or complicated activities: family holidays, the child's school camps and care-givers' work (U)
Illustration	Going away on holiday involved 'getting the kit together' and making sure the child had his or her inhalers. It involved checking that hotels were not dusty or mouldy, and for some parents, it involved getting a letter from their respiratory specialist, to give to hospital staff if needed. Pg 308
Finding	Good use of medications (U)
Illustration	"He's just got used to it, it's just part of his daily life, he doesn't really, he knows, he will get himself ready for bed and he comes out and he knows what he has got to have, he knows that it's part of his routine." Pg 310
Finding	Some care-givers modified instructions from their healthcare provider in order to reduce the amount of medication that their child was taking, especially when their child was well (U)
Illustration	"The Ventolin has really cut down since Seretide. It took a few weeks though to kick in and what not, but I found even now that I'm starting to miss the evening with the preventative whereas I never used to, it's only been the last 6 weeks or something." Pg 310
Finding	Asthma goes in bursts: does so the use of medications (U)
Illustration	"In the winter months, we did have him on Becotide, not last year, the year before he was on Becotide for the whole of the year and, and then he was on the Ventolin

	whenever he needed it, but then what we found was last year we took him off for summer....what I've been told to do is when he gets a cold to put him on it for two weeks. And then take him off." Pg 310
(7) Cheng SC, Chen YC, Liou YM, Wang KW, Mu PF. Mothers' experience with 1st-3rd-grade children with asthma assisting their child's adaptation of school life in Taiwan. Journal of clinical nursing. 2010 Jul;19(13-14):1960-8.	
Finding	Mothers often worry whether their children will have sudden asthma symptoms that will endanger their lives, they also worry about whether teachers have the ability to handle such a situation. They instruct their child to call the family immediately if symptoms persist (U)
Illustration	"I would pay special attention to my child's symptoms. I would become very worried if my child had symptoms. I taught him to call home if there is anything wrong, on the other hand, my child knows when to call. Until now there have been no incidents." Pg 1964
Finding	Mothers would worry that the allergy symptoms might have an effect on children's peer relationships and learning (U)
Illustration	"I only care about his interpersonal relationships. As for scratching his itchy skin, this started when he was little. I told him that he should not do that at school because people at school will think he has problems." Pg 1964
Finding	Mothers talked with the teachers in advance about their child's condition and encouraged the children to take care of themselves (U)
Illustration	"I was happy to communicate with the teachers. The teachers are patient and easy to talk to. I was happy to meet the teachers. My child is naughty and I worry that he may not have a teacher who is patient. We do not want him to be treated differently because we can take care of him very well at home by ourselves and we do not want to bother the teacher." Pg 1964
Finding	Mothers worry about the long-term and possible harmful effects of asthma medications (U)
Illustration	"I feel I am powerless because patients need to take medication even if medical science is highly advanced. There are side effects when taking medication such as damage to the organs. Given the possibility that her medication may harm her, I feel that I do not know what to do." Pg 1964
Finding	They try alternative treatment and hyposensitisation treatment to improve child's health (U)
Illustration	"She was not able to concentrate and did not like to talk before the (hyposensitisation) treatment. After the treatment, she became cheerful, 'alive' and willing to communicate with other people. The treatment was helpful and improved her interpersonal relationships." Pg 1965
Finding	To strengthen a child's protection, the mothers adjusted their child's diet (U)
Illustration	"As to diet, we do not want him to eat shellfish. Iced water is also a definite no-no. Before he was six years old in kindergarten, he wanted to have cold food when he saw what people were eating. Every time he would eat such items, he would cough. Then he learned the lesson." Pg 1965
Finding	To avoid factors that induced asthma, mothers prohibited children with asthma from

	doing sports (U)
Illustration	"When she started to have asthma in elementary school, I reminded her not to run, laugh or jump in school. I think running made her breathe heavily. After she went to elementary school and started to have symptoms, I told her not to go sports classes". Pg 1965
Finding	As to the environmental management, mothers would keep their home clean, dry the bedding, mop the floors, keep the children away from dust, burning incense and paint odours because these easily induced asthma (U)
Illustration	"The way to avoid his asthma is to wipe clean the room, the closets and floors using bleach. The air conditioner has an allergen filter and since I wipe it very often, our home is basically clean." Pg 1965
Finding	Mothers would teach their children to identify the symptoms of discomfort and asthma, to understand the importance of medication and to know when to take medication (U)
Illustration	"I often tell him how to use the medicine. Now, he is more active in taking his medication on his own because I tell him and also because I have trained him to do it. When he goes to school, we cannot care for him, therefore we tell him to take it by himself. Now, he also sometimes takes medication at night by himself." Pg 1965
Finding	Mothers do not wish their children to use asthma as an excuse to refuse to do something or as a way of obtaining special treatment (U)
Illustration	"I use a normal attitude to treat him. Since his asthma is not severe, I worry that he may use it as an excuse and refuse to do things such as cleaning. Nevertheless, I remind him that he must wear a mask whenever there is dust in the air." Pg 1966
Finding	Mothers undergo extreme stress while taking care of their children. They have experienced exhaustion during the management of the child's asthma (U)
Illustration	"I feel so tired because we have a child with this condition at home. It is like he will never recover by taking medication. We feel powerless and helpless, at midnight, he coughs and cannot sleep. He often gets up at midnight and consequently has low energy during the day." Pg 1966
(8) Nichol J, Thompson EA, Shaw A. Health professionals' and families' understanding of the role of individualised homeopathy in asthma management for children requiring secondary care: Qualitative findings from a mixed methods feasibility study. European Journal of Integrative Medicine. 2013 Oct;5(5):418-26.	
Finding	Parents were highly conscious of the impact of asthma on the whole family (C)
Illustration	"It is a bit of a nightmare. It really is a bit of a nightmare." 421
Finding	Social impact of asthma on their child, in terms of peer relations (U)
Illustration	"She's the only one with the asthma at her little school, it's only such a tiny little school…So what, you know, it's just the stigma, isn't it, it's just the standing out." Pg 421
Finding	Children were perceived to resist medications (U)
Illustration	"There are times when he uses his inhalers as, almost like a weapon…..I'm not doing this I've had enough of this and I don't want to do it." Pg 421
Finding	Conventional medication helped to control the asthma, at least to an extent, most of the time (C)
Illustration	"It keeps it at a level." Pg 421

Finding	Possible long-term effects of newer medication on her daughter's lungs (U)
Illustration	A mother who was a pharmacist commented that her daughter had been taking medication since she was very young and wondered about possible long-term effects of newer medications on her daughter's lungs – "these things haven't been around all that long." Pg 421
Finding	After experiencing homeopathy plus usual care package, six of the nine families thought that there had been an improvement in the child's asthma symptoms (U)
Illustration	Families reported favourable changes in breathing, running and sports which they were inclined to attribute, more or less strongly, to the homeopathic remedies. Pg 423
Finding	Comments about service delivery within usual care were generally favourable, especially in relation to the children's hospital (C)
Illustration	Described by one parent as 'absolutely brilliant.' Pg 421
Finding	Parents expressed confidence in the consultants and appreciated the contact with the respiratory nurses (C)
Illustration	They felt that the hospital was there for them when they needed it. Parents valued explanations about what the different medications are designed to achieve and appreciated the increasing use of language that stresses 'management' as a realistic goal for severe asthma. Pg 422
Finding	Homeopathic treatment was also perceived to have brought about broader quality of life benefits for some of the children (U)
Illustration	According to a mother, the child 'has come out of herself, is now in the school netball team and has increased her school attendance. Pg 423
(9) Coffey J, Cloutier M, Meadows-Oliver M, Terrazos C. Puerto Rican Families' Experiences of Asthma and Use of the Emergency Department for Asthma Care. Journal of Paediatric Healthcare. 2012 Sep-Oct;26(5):356-63.	
Finding	Extent of asthma in their family history. (U)
Illustration	"Down from my grandparents, down from my father, my brother, myself, my two daughters, my sister and my cousin. When I was younger I was hospitalized for asthma, and my grandmother was hospitalized with asthma too." Pg 359
Finding	Use of traditional healing with regard to treating and caring for their child with asthma (U)
Illustration	The first mother interviewed talked about her great grandmother and the use of herbal treatments: "…she used to always be creative with ginger (jengibre) and made tea out of ginger and some other green leaves from Puerto Rico." Pg 359
Finding	Mothers who discussed use of herbs denied their use and deferred to the doctor for asthma treatments (U)
Illustration	stating that her son uses "….just the medicines the doctors give him." Pg 359
Finding	Fear and awe of asthma (U)
Illustration	"Scary because I feel like OK, there is nothing else I can do. It is out of my hands when it comes to breathing. You [are] scared for them because you know asthma can kill." Pg 359
Finding	Many mothers turned to prayer as part of their asthma care routine before and during their ED visits (U)
Illustration	"I pray like there is no tomorrow at night. Oh God help me…I just pray because I [am] scared." Pg 360

Finding	Asthma symptoms drove these mothers to make the decision to go to the ED (U)
Illustration	"If I can control it in my house, fine. If I can't I bring them to the emergency room." Pg 360
Finding	Emotions expressed by mothers about their ED experience (C)
Illustration	"….the hospital workers are very good for the children….[they give care] with a lot of love." Pg 360
Finding	Emotions expressed by mothers about their ED experience - The volume of people in the waiting room (U)
Illustration	"I gotta say this. The last time I went to the ED, it was packed. When I mean packed, I mean packed." Pg 361
Finding	Emotions expressed by mothers about their ED experience - Noise levels (U)
Illustration	"There was noise. Over there in the waiting [room], yeah lots of noise…." Pg 361
(10)Dowell JA. Experiences, Functioning and Needs of Low-Income African American Mothers of Children With Asthma. Journal of Paediatric Nursing-Nursing Care of Children & Families. 2015 Nov-Dec;30(6):842-9	
Finding	Management of symptoms for their child with asthma in a "moment-by-moment" fashion. (C)
Illustration	"I'm just dealing with it at the moment you know, and I know as the seasons change it's still going to act up, so. My biggest thing; stay by the phone you know or keep my doctor on call you know." Pg 845
Finding	Having to make quick decisions about whether to take her child to the primary care physician. (C)
Illustration	"One bad experience with him when he had asthma was when he had a real bad cold. And boy, we went to the emergency room, I took him to the emergency room because we lived in Randolph county and that doctor didn't open on Fridays so it was on a Thursday night, so he was sick; so he I ended up going to the emergency room. And we stayed in the emergency room until Friday morning so he didn't go to school. And they had to put him on oxygen because he couldn't breathe." Pg 845
Finding	Mothers often rely on others to assist in the management of asthma symptoms (U)
Illustration	"…Pretty much I have to make sure everybody is aware in my circle, aware of what's going on." Pg 845
Finding	"Taking control" was extremely important for the caregivers, especially with symptom management (U)
Illustration	"I must have control over my home because there is no one else….I just try to educate myself as much as I can on asthma so anything that I have around him or anything that may be in our house that could trigger him to have an asthma attack that I don't know about I try to make myself more aware of it." Pg 846
Finding	Mothers repeated throughout the interview the importance of "knowing their child". (U)
Illustration	"So most of the time, she just says it but if she's laying around and really not talking that much because she likes to talk, if I know she's not doing then I know something is wrong so…that's about it, that's how I really can tell because her whole, she's just a happy person all around like she's so sweet." Pg 846
Finding	These mothers' greatest concern was fear, "loss of the child" (U)
Illustration	"I don't want to see my baby die in his sleep because he can't breathe…I usually let him

	sleep with me but I’m scared that it might happen while he’s sleeping one day." Pg 846
Finding	These mothers' greatest concern was fear, "inability of the child to participate in sports" (C)
Illustration	"It won’t be something that will stop her from being able to play sports or interact with other kids….so whether he has to be restricted or whether he’s going to start you know playing football." Pg 846
Finding	Constant fear and anxiety even affected their own health (U)
Illustration	"Yes…um…my second child, yes I was depressed I was on depression pills…and I was stressed for over I think like what I think for like probably a month yes….’cause I was going through a lot." Pg 846
Finding	"Generational faith" - faith of these mothers passed down from one generation to another (U)
Illustration	"My aunt….instilling in us that you can do it there’s no such thing as you can’t do it. In the summertime they go from the hip hop, from vacation Bible school to instill in you yes you can do it. You get this blessing, yes you can do it." Pg 846
Finding	Cultural influences such as church (U)
Illustration	"…my brother was preaching..she had an asthma attack…so everybody started praying, they started praying…". Pg 846
Finding	Desire for culturally competent healthcare providers, including personally knowing the mother and her child. (U)
Illustration	"Yeah-uh, Everybody in there, they’re family I consider them being the, the receptionist some of them are a little older than me so I consider them as a you know, a mother figure because I can see, I talk to them and their one doctor is younger than me but the rest of them are a little older than me and I can sit down and talk to them and you know more about when they tell me something’s wrong when I just have to ask more questions to get a better understanding of it. They get it, because they’re parents too so you know they’re always-these guys, they love what they do…they are-the sweet, they talk to you like they know you personally you know." Pg 846
Finding	Mothers wanted to feel that the healthcare provider was listening to them (U)
Illustration	"He actually understands our cultural needs very well, he knows that different people, people are different and react different ways, you can’t treat everybody the same. So he takes his time and listens to us very well." Pg 847
Finding	Cultural influences such as community were an important part of day-to-day living (U)
Illustration	"Like but...I deal with it you know? I have back up family, if I have to leave work, go get them sometimes I have to take them to primary care. But my grandmother, she has always been there, that's my rock you know if I call and say my kids need anything or you know they need some medicine, she's there, her and her husband." Pg 846
Finding	Day-to-day experiences drove their ability to cope and intervene with their child's asthma symptoms, and they described having to be aware and flexible every moment (C)
Illustration	"...it's not really different than the other, one day at a time, that's how I think about it. You can take it one day at a time, don't rush it and live a year from now but you just....I don't want him to go through that so, I really want to nip it in the bud so to speak." Pg 845
Finding	Any healthcare provider was expected to have the skills to engage individuals in a

	conversation about health (C)
Illustration	"Help me and I can help my kids. Give me step plans and goals. And then they'll ask me before I ask them is there anything else that we can check on her, and if I say yeah they'll do it for me." Pg 846

(11) Archibald MM, Caine V, Ali S, Hartling L, Scott SD. What is left unsaid: An interpretive description of the information needs of parents of children with asthma. Research in nursing & health. 2015 Feb;38(1):19-28.

Finding	Parents had difficulty interpreting the meaning and severity of asthma symptoms (U)
Illustration	"We weren't really informed of the severity of her condition….we brought her home and said well we'll rest her, it's nothing….until the doctor said, you know, we need to get her uh, to get her to the hospital right away." Pg 22
Finding	Parents lacked confidence in their ability to manage acute exacerbations. They described not knowing what to do during an asthma attack, panicking in the moment, not having the inhaler on-hand (U)
Illustration	"I'd probably just panic and take her to the emergency….like I don't have a clue." Pg 23 "I don't know, I don't have his Ventolin...I'm a panicker." Pg 23
Finding	Parents reported that at some point since diagnosis they had not known when or how to properly use an inhaler (U)
Illustration	"They say, here's a pump, here's a chamber, she needs to take, you know four times a day of whatever it is, um, but on one actually stops to show you how to use it. " Pg 23
Finding	Healthcare Professionals used different inhaler techniques (U)
Illustration	Parents were confused because "every practitioner does it differently." Pg 23
Finding	Parents who did not know what to do in case of an asthma exacerbation generally did not know how to prevent exacerbations either (C)
Illustration	"Basically emergency stuff, that's what we had been doing….that worked out well because you know when stuff like that happens they take you in right away, so we didn't have to stress out about waiting to see the doctor." Pg 23.
Finding	Some parents were aware of particular asthma triggers but did not prevent exposure to allergens or irritants, believing that a physical barrier, like a door, offered sufficient protection (C)
Illustration	"I do have a lot, quite a few animals. I raise animals….but nothing in the room with them….nothing sleeps with them in bed. " Pg 23
Finding	Some parents who were aware of triggers to asthma exacerbations offered rationalizations for not eliminating them or identified incomplete efforts (U)
Illustration	"Smoking can make it worse, I know….I never smoke in my house ever. Um, I have to quit smoking in my vehicle." Pg 23
Finding	Many parents said they often "forgot" aspects of their children's asthma management, such as to take rescue inhalers with them on walks (U)
Illustration	"We went for a walk, uh a long walk, it was like three hours out in the park….near the end, we're slowing down, 'cause he just wasn't keeping up anymore….I guess in that sense I should have had his inhaler, because it might have probably helped him. But I'm really not smart to plan ahead." Pg 23
Finding	Consistently administering daily preventative medications such as inhaled corticosteroids was even more challenging for parents and particularly so during periods

	of symptoms remission (U)
Illustration	"They were meant to be supposedly on the daily medications….then they'd go through a time where they were symptom-free…you're meant to carry on and we get carried away with life and the asthma inhalers have fallen under beds." Pg 24
Finding	Many parents were unable to describe what many HCPs consider basic asthma knowledge (U)
Illustration	"I don't even know what asthma is or side effects, I have no idea". Pg 24
Finding	Parents reported receiving little to no education at the time of diagnosis or during subsequent visits to the ED (U)
Illustration	"He never explained to us what the medications do, what the side effects were….it was just here, give this medication to her." Pg 24
Finding	Parents who had received referrals to asthma clinics commented on the impact or quality of the education received (U)
Illustration	"Until we came to the children's asthma clinic after those bad attacks we didn't know much. They just said it was bad….we didn't understand how it worked until the asthma clinical showed us the models where you can see the difference." Pg 24
Finding	Parents felt that they would have benefited from hands-on learning with HCPs (C)
Illustration	"They gave her...these inhalers which we didn't know how to use." Pg 23
Finding	Need for procedural knowledge about asthma care (e.g. how to use an inhaler) (C)
Illustration	"I need to be comfortable with myself to know at least what is going on with him...and what can help him."
Finding	They sought information only when they identified a gap (C)
Illustration	"I don't really look up information...everything I need to know I can find it if I need to find it, I just don't really know everything I need to know." Pg 24
Finding	The reported lack of education by HCPs hampered parents' ability to identify their information deficits (U)
Illustration	"I can't even articulate what I think I should know right now...or what I would like some help with." Pg 24
Finding	Some parents became aware that they needed to direct their interactions with HCPs or specifically ask for more information (U)
Illustration	"I have to do a lot of thinking before we come to make sure that I have all my questions ready to go." Pg 24
Finding	Parents rationalized their lack of prevention or planning by referring to a child as being tough or a trooper (U)
Illustration	"Well we haven't done that because....she's just a spry little girl and um, she's also very tough." Pg 23
Finding	Misconceptions about asthma were prevalent and at times reinforced by HCPs (U)
Illustration	Many parents viewed asthma as an acute condition, and approximately half believed that their children would grow out of asthma, a misconception reinforced through interactions with HCPs who were not asthma specialists. Pg 24
(12) Dickinson AR, Dignam D. Managing it: A mother's perspective of managing a pre-school child's acute asthma episode. Journal of Child Healthcare. 2002 Mar;6(1):7-18.	
Finding	Mothers negotiated with health professionals to get the best treatment plan for their child. In some instances this meant that recommended medical treatment be deferred in

	response to the mother's expert knowledge about her child (U)
Illustration	"He (the doctor) says well I think we should (give a nebulizer)", and I will say "no, not this time….If he needs it really on the point of going either way, he will get it." Pg 10
Finding	'Timing' the response to treatment (U)
Illustration	"Then I get to a point where I sort of look at him and think, that last lot of Ventolin two hours ago, you're worse or back to what you were two hours ago. I kind of use the two-hour mark when I think of it." Pg 10
Finding	Weaning the child off the added medication given to manage the asthma attack. It is an uncertain and stressful time: (U)
Illustration	"you know there is this constant thing…..Now, shall I wean her down to one today, or shall I leave it till tomorrow? I tend to get a bit 'ansy' about whether today's the day to drop to one; or if she coughs, Oh, we better have three today, I find I tend to be a bit panicky." Pg 11
Finding	The process of 'Making the Call'. This was the decision-making process mothers went through to decide when a phone contact or visit to a health professional was needed (U)
Illustration	"I find personally the call is really hard to make, regarding has she reached that point where I need more help. I find it a really hard thing to determine and I often think, Oh, I've left her too long. I find it really hard to sort of say at this point, this is enough, we go now." Pg 11
Finding	'making the call' was something that the mothers felt was their primary responsibility (U)
Illustration	"so I think if I find it (the call) hard, there is no way I could ask anyone else to make it." Pg 11
Finding	An essential part of a doctor or nurse's role was to 'confirm the call' made by the mother and offer reassurance and affirmation that the mother was indeed 'managing it' (U)
Illustration	"I am quite happy about my doctor because the first time I had to give it (Betnesol), this is what happened: I gave him Betnesol. I gave it at home. I have given it in the morning, and he (the doctor) said, "well, you've done just the right thing." You just need someone to say that to you, to reassure you exactly about what you need to do." Pg 12
Finding	Vigilantly 'watching' the child during the acute asthma episode (U)
Illustration	"I find that when she has asthma I usually go to sleep in her bed with her because I am scared that I might not hear something if I go to bed." Pg 12
Finding	Mothers not only 'calming the child' but also keeping themselves calm (U)
Illustration	"to a certain extent you can put fear into it. If you're showing fear, they are going to pick up on it for sure, so I have tried to be resolutely calm." Pg13
Finding	Mothers described the fear and panic of watching their child have an asthma attack, but all felt that an important part of 'managing it' was remaining sufficiently calm in order to avoid upsetting the child and potentially making the asthma worse (U)
Illustration	"Yes, I get quite frightened, and I think I find I get extremely stressed actually. Particularly by the time we get to the hospital it is invariably crisis point for me. I'll be sitting there and it is always 100 degrees; and I'm sitting there and I'm hot, and I can just feel like my heart rate is up and I feel stressed, and I'll be sitting there trying to read a story, and I will read the same page twice because I'm thinking, come on, come on, because you always wait for a while." Pg 13
Finding	One of the more stressful and difficult aspects of 'managing it', described by the

	mothers, was the process of 'making the call'. It was extremely important for mothers that they could justify their choice even if, as one mother described, this choice may have resulted in the child's death (U)
Illustration	"And rightly or wrongly I could have justified that to myself. I think now looking back I would say, no, I didn't do all that I could have...But I didn't do that, so up until recently I could justify [child] dying. That's terrible isn't it?" Pg 11
(13)Arroyo J, Becker EA. A Needs Assessment for the Delivery of Asthma Education to Parents of Young Children. Respiratory Care Education Annual. 2014;23:34-44.	
Finding	Mold and dust in her living conditions made her child susceptible to asthma symptoms (U)
Illustration	"So I'm in a basement apartment, which could be also hazardous. Because there's probably mold and you know dust and um a um the mess and stuff like that, so, I know that's that could be uh, so I tried a kinda you know wipe and dust as often as possible." Pg 36
Finding	Tobacco exposure was another major concern (U)
Illustration	"I think because we stayed in the household with my mom and she's a smoker". "Yea that's how my parents was. My parents was smoking and then they try to do it in another room." Pg 36
Finding	Another preventative measure was use of a smoking jacket (U)
Illustration	"…I wear smoking jacket. So if I was out to smoke I wear a jacket. I don't really interact with [child's name] as much but I wear a jacket because there such a thing as third-hand smoke. So the third-hand smoke will come off of my clothing, but if I have my jacket on it will less likely be on my clothing it on the jacket." Pg 36
Finding	Albuterol was frequently misused (U)
Illustration	"The only thing I really know is the um albuterol If I don't have that, no then I would be kind of lost in not know what would be the next step." "we would like to know what cause the episode so we can keep the child away from it so we're not constantly giving the child albuterol." Pg 37
Finding	Lack of confidence and knowledge among participants regarding how to properly manage their child's asthma (U)
Illustration	"Um I think I get nervous, scared, cause my son had an attack and I panic. I think I was panicking more than he was (laughing), so my first reaction was emergency room". Pg 37
Finding	Many did not feel comfortable with leaving their child with someone who was not a family member (U)
Illustration	"uh sometimes. Depends on whose house he with and who you with" [comfortable with] Well mainly just my, my immediate family". Pg 37
Finding	The asthma action plan was thought to be too generic (U)
Illustration	"they all reads the same…yea I don't think it's more individualize, I would like for it to be more individualize per child because whereas like her child has asthma but his trigger is not as bad as her child's trigger." Pg 37
Finding	The asthma action plan was not understood (U)
Illustration	"Yea cause it is kinda confusing like you were saying they have the red the yellow and then the green." Pg 37

Finding	Parental recommendations for managing asthma (C)
Illustration	"I try to dust a lot, keep a lot of things wiped down, far as door knobs and her answering my phone. The knobs on the sink, the toilets, you know the little things that I she'll touch and got the most nastiest germs that can trigger her asthma. That's what I try to keep clean at home. And a lot of Lysol spray." Pg 37
Finding	Fear and anxiety were the most common emotions participants felt during asthma emergencies (U)
Illustration	"But um my concern would be like the um risk of their child dying from it, you know. Because your child's coughing and if you can't calm them down, and what can you do like in the event of an emergency?" Pg 38
Finding	A sense of helplessness was expressed among participants unable to make their child feel better (C)
Illustration	"Well, I'm a single mom. And, it kinda gets lonely when you by yourself on the hospital and your baby got tubes an-and stuff sticking in her. I mean you wish you were there and your baby was sitting outside the bed. Like you to take the pain for her, but you can't." Pg 38
Finding	Some participants did not use a spacer (U)
Illustration	"I don't know, I – I guess he said outgrew that baby thing as he use to call it. Because like that's how I use to administrate the medicine to my daughter. Through the chamber." Pg 39
Finding	Responsibility to administer albuterol was given to child (U)
Illustration	"And she's a big girl. Like, like literally she'll go, go take your blue medicine. She'll go. Twist and squeeze it, and squeeze it back in the in the mask, and put the mask on, turn the machine on." Pg 39
Finding	Others used a spacer but found it to be expensive even though they had insurance (U)
Illustration	"And a chamber is kinda expensive thing if you have private insurance. The chamber is like $85, I wanna say." Pg 39
Finding	Misconception regarding when to use an inhaled corticosteroid and when to use a beta2-agonist (C)
Illustration	"So most o- of the Advair as well as the um Albuterol would be twice day too." Pg 39
Finding	Possible side-effects of inhaled corticosteroids was a concern (U)
Illustration	"Oh, (laugh) I would just be concerned about the long-term side effects of medicating a child overall. Like, a child as young as [child's name], he's four so, he's going to be on Advair for God knows how long." "And I just would be uh worried about the medication not working you know cause then he can become immune to it…." Pg 39
Finding	Participants had no preference for who provides informational sessions about asthma. Participants wanted a person who will be engaging and knowledgeable to deliver asthma education (C)
Illustration	"…doctors are really dry, you still wouldn't understand the importance of asthma, so it doesn't matter as long as they're engaging." Pg 40
Finding	Some participants did not mind having informational sessions on Saturdays, the majority preferred weekdays after work or early evenings (U)
Illustration	"Yea but far as the parents here they will come if it's after like 4.30, after 4.30, they'll show for asthma workshop, so they'll be great. After 4.30 because most people here

	work." Pg 40 "I'll give up a weekend morning….between like 10-2." Pg 40
Finding	To minimise or prevent their child from triggers, some stated that they asked family members or guests to smoke outside their home (U)
Illustration	"Sometimes my family they smoke cigarettes and stuff but when it gets warm like this, I have a big back porch so I know a lot of them like smoke in the house, I make them go outside." Pg 36
Finding	Confusion between the names, appearance, and the type of medication that were given to their child was a concern (C)
Illustration	"Okay so she has two medications then?...Yes [Okay and the one and there's one that she takes every four hours?] ...Yes [Is that her albuterol?]...Yes." Pg 37
(14) Berg J, Anderson NL, Tichacek MJ, Tomizh AC, Rachelefsky G. One gets so afraid: Latino families and asthma management--an exploratory study. Journal of paediatric healthcare: official publication of National Association of Paediatric Nurse Associates & Practitioners. 2007 Nov-Dec;21(6):361-71.	
Finding	Fear, desperation and anxiety for the parents occurred when their child could not breathe (U)
Illustration	"One night he could not breathe…until he turned black and fainted and quickly I rushed him to the emergency room….When I arrived they asked me what was wrong with my child and I told them, "I do not know, he can't breathe"; they took him in and…they helped him quickly and this is when I really got scared because I saw him this way." Pg 366
Finding	Parents took their child to the hospital or emergency department when they were unable to help their child recover from an asthma episode. Trips to the hospital often took place at night (U)
Illustration	"I would spend more time at the hospital than at home…my….son would get frightening asthma…..I would have to run to the hospital at 2 o'clock in the morning…..I thought that perhaps he could die." Pg 366
Finding	An even more upsetting event for the parents occurred when their child expressed fear of dying (U)
Illustration	"It [son's talk about dying] causes me great anxiety because my child tells me that he is not going to get to grow old. I ask him, "Why?" And he says, "Because I have asthma and I am going to die. I cannot breathe like you." Pg 366
Finding	Not knowing what was happening with her child in the emergency department (U)
Illustration	The nurse would tell me don't worry; I ask, "Are you going to admit him?" and she would say, "No, just a half an hour….he is okay, everything is going to be okay, just calm down", that's it. Pg 366
Finding	Never told their child had asthma (U)
Illustration	"Until my daughter was out of breath I was not told [she] had asthma." Pg 366
Finding	Unable to explain what they thought was wrong with their child because of a language barrier (U)
Illustration	"There are some doctors that don't know Spanish and I cannot speak with this person and say, "My child has this, has that, this happens, take care of him quickly, and things like that." Pg 367
Finding	Participants perceived, and were sometimes told that there was "no time" for them (U)

Illustration	"I tell him [the doctor] I got this problem and this problem and he responds, "Just tell me one problem. Do not tell me any more problems because we don't have too much time to spend with one patient." Pg 367
Finding	Parents also told stories of cold, rude treatment (U)
Illustration	"There was this girl that worked at one of the clinics who was very rude….This woman told me I had to have brought her earlier…..I was upset. I had nerves. I had taken my child very sick to that place and I had another child with me too….I don't think it was right for the woman to treat me like that…..I have seen the receptionists, the nurses talking, laughing at us, and they have us waiting until they feel good and ready to call us." Pg 367
Finding	Parents emphasized the need to know what to do for their child with asthma, including during emergency situations (U)
Illustration	"Well the most difficult is to see him [my child] there [in the emergency room] without knowing what to do." Pg 367
Finding	Parents' perceived lack of knowledge compounded their problems and further escalated their fear and anxiety (U)
Illustration	"What makes it hard is the lack of information. If one would be well informed, one could deal with it better…..[What's hard is] the not knowing what to do, to see your child sick and not being able to do nothing [sic]." Pg 367
Finding	Their desperation led parents to seek help from coworkers, other parents at their child's school, and from neighbors (U)
Illustration	"But then, my friend told me that there was an asthma truck at his school…..I started visiting this truck and, from there on thank God [he improved]." Pg 368
Finding	Parents' perceived gaps in knowledge might have resulted in part by what they learned from family and friends that may have differed from what they were told in acute care settings (U)
Illustration	"A lot of people say, at least in my family, they say not to drink anything cold because....it is bad....I do not believe those things, but I have an aunt that is older and since she switched religion she says that...she no longer suffers from asthma....she says, "Well, you have to take care of him [Marta's son with asthma] that he doesn't drink anything cold...Or when it's cold he should always have his back covered." Pg 368
Finding	Participants demonstrated considerable courage in their determination to "do the best for our children" (U)
Illustration	They explained that they needed to "pay attention to the treatment, be sure medication is never lacking at home," and "be consistent with doctor visits." Pg 368
Finding	Parents talked about things they did for their children so the children would believe that they were living a normal life (U)
Illustration	"During my free time, my wife and I enjoy going to the park with our kids." Pg 369
(15)Borhani F, Asadi N, Mohsenpour M. The experiences of mothers with asthmatic children: a content analysis. Journal of caring sciences. 2012 Sep;1(3):115-21.	
Finding	Participants were worried because of the respiratory issues the children were faced with. They were afraid that the child might suffocate during one of these respiratory attacks (U)
Illustration	"I'm so afraid because I think my child will suffocate any moment. It is really difficult for

	me, in such a way that life has become unbearable for me." Pg 117
Finding	Concern of the side effects of the medicine the child uses (U)
Illustration	"Not taking into account all other issues, the one thing that I am always thinking about is my child's drugs, like the corticosteroid that she uses. Will it affect my child in the future or not?" Pg 117
Finding	They were saddened by the fact that they could not have a comfortable life like others and that they were affected by the stress concerning their child's illness (U)
Illustration	"I have to keep him away from everything. I have to be careful he doesn't catch a cold and that he doesn't play with water too much. I have to care twice as much for my child than mothers who don't have such children. You need to be lucky in child caring. For instance, some people let their children play in the dirt, but I wouldn't even put my child down so he couldn't touch the soil, or play with chickens. I have to always look after him, but my sister in law, whose child is as old as my son, has nothing to do with her child." Pg 117
Finding	Trusting the doctor and asking for his/her help in controlling the illness (U)
Illustration	"The doctor is very important, because if it wasn't for the advice and treatments of the doctor, I would have never become used to these circumstances." Pg 118
Finding	Mothers emphasized that they would be unable to adequately manage unforeseen and critical situations caused by their child's illness without their spouses' help (U)
Illustration	"When my child has a respiratory attack, he can't breathe any longer and his skin changes to black. I panic and I don't know what to do, so it's better when my husband is there. We take him to the hospital immediately, but it's very difficult when he isn't there. For instance, yesterday we had a hot sandwich and my child's color suddenly changed to black. He was suffocating. My husband took him outside, washed his face with cold water and gave him a cold orange juice and he was better. I was so afraid he wouldn't breathe again. We took him to the hospital straight away and I was praying the whole way. I don't know what would have happened if my husband hadn't been there with us!" Pg 118
Finding	Participants expressed some degree of guilt (U)
Illustration	"It was our first child. We weren't experienced. We could see the child was coughing all the time and wasn't eating well, but we didn't take it seriously. If we had taken our child to the doctor sooner this wouldn't have happened." Pg 118
Finding	Mothers reported their desire to watch all of their child's activities during the day, because they were afraid of the worsening of the attacks (U)
Illustration	"I monitor everything my child eats, and make sure he doesn't play with dirt or water, so that he doesn't get sick. He really likes playing in dirt and water but I am really careful that he doesn't." Pg 118
Finding	Mothers were worried about their child's uncertain future, and thought that asthma could affect their educational, vocational and marital status in the future (U)
Illustration	"I don't know how much longer this situation will last. Well I'm a mother and I'm worried about my child's future, about his education and work." Pg 117
Finding	They regularly referred to the doctor in order for the child to be under medical supervision (U)
Illustration	"I used to visit many doctors, I would go anywhere and do anything for my child to get

	better. Finally, I was given the address of this place and I brought my child here so that he might get better." Pg 119
(16) **Chen SH, Huang JL, Yeh KW, Tsai YF. The Stress of Caring for Children With Asthma: A Qualitative Study of Primary Caregivers. Journal of Nursing Research. 2015 Dec;23(4):298-307.**	
Finding	Many primary caregivers expressed difficulties with accepting the asthma diagnosis (C)
Illustration	"A lot of times, it's very difficult because I didn't really have much of an understanding about asthma, of what it actually is…Is it just a cough, or is it a true attack?.....Most physicians had neither the opportunity nor the free time to tell us about asthma. I did not understand the cause of asthma, you know." Pg 3
Finding	Information that should have been provided by the healthcare team was absent or incomplete (U)
Illustration	"He has always suffered from bronchitis, but I was never told that he had asthma. Health teams never provided information on asthma attack care." Pg 4
Finding	Many participants expressed concern about the impact of the side effects of asthma (e.g., reactions to drugs, rejection of medication, and the impact of the disease on normal childhood learning) (U)
Illustration	"I am worried that the asthma could affect my child's future….I feel that her condition is stable and has improved, but the medicine might damage her body. I have often said that she should stop taking this medication." Pg 4
Finding	Participants expressed concerns about their child not being able to breathe properly. They described their fears that their child would die during an asthma attack (U)
Illustration	"It was terrible. I felt like this every time he has an acute asthma attack….I remember those times as nightmares. The first time he had an asthma attack it really frightened me and put me at a loss as to what I should do. I get a pain in my stomach when I think about it. I try to forget it." Pg 5.
Finding	Their inability to control the symptoms of the disease often resulted in feelings of sadness, anxiety, frustration, and powerlessness (U)
Illustration	"I am frustrated with the asthma attacks, and if my child has to eliminate the persistent cough and wheeze, I don't know what we'll do. I know that doesn't make sense, but denial seems to be the only solution I can come up with at the moment, I am so depressed." Pg 5
Finding	Participants expressed feeling helpless (U)
Illustration	"There was no one who could tell me about this and I had to figure out everything by talking with other asthma patients in order to deal with the asthma attacks. I felt helpless." Pg 5
Finding	Participants experienced increased levels of distress with a greater adverse impact on their own health and daily lives (U)
Illustration	"I have never slept well since my son's first asthma attack. I often have mood swings, brain fog, dizziness and ringing in my ears. I was afraid that he would not survive an attack". Pg 5
Finding	Burden of care was not distributed equally (U)
Illustration	"I don't get any help from my family. They think that I can do it all by myself. What they don't realize is that it has affected me both mentally and physically and the stress is

	sometimes unbearable." Pg 6
Finding	Participants reported facing economic hardship caused by expenditures on treatment and income losses (U)
Illustration	"We have spent a lot of money on her treatment; I cannot work because I need to take care of the children." Pg 6
Finding	Participants reported that there were disagreements regarding the proper approach to patient care, care options and the proper approach to handle a patient who refuses treatment (C)
Illustration	"We often had a lot of disagreement about the children's medicine. My husband did not accept the use of steroids because of their side effects. In his own understanding, using steroids is a kind of drug addiction. And I was always blamed by my family about how I gave medication to the children." Pg 6
(17) Bokhour BG, Cohn ES, Cortes DE, Yinusa-Nyahkoon LS, Hook JM, Smith LA, et al. Patterns of concordance and non-concordance with clinician recommendations and parents' explanatory models in children with asthma. Patient education and counseling. 2008 Mar;70(3):376-85.	
Finding	Parents described concordance - using controller medication the way the clinician recommended (C)
Illustration	"And then sure enough, she had a flare up and she went way back, and way over the amount that she was on initially. And then, since she's had a couple of medications added. And she's never come off completely. When she has a flare up, she ends up having to go way up on inhaled and then occasionally go on to oral steroids as well. So she's never come off." Pg 380
Finding	Parents described unintentional non-concordance - they reported following the clinicians recommendation, but their description differed from the clinician's instructions given during the audiotaped visit (U)
Illustration	"She gave me a couple things. She gave me, I think Prednisone he was supposed to take for 3 days. And there was another one he was supposed to take for 6 days. I've forgotten what that was, the Prednisone I remember. There was something else….she gave me some chewables, chewable something. That he takes once a day." Pg 380
Finding	Parents described unplanned non-concordance. These parents reported that although they intended to give controller medications daily as directed, they were unable to do so (U)
Illustration	"I probably would not give it to her if like I forget it, it's like, like I said, if she stays the night somewhere I might forget to send it, but it doesn't worry that much if I forget the, um, Flovent." Pg 380
Finding	Intentional non-concordance - Parents stated that they intentionally did not give their child controller medications as recommended (U)
Illustration	"He is on his – he is on Cromolyn, which because he has been doing so well, I haven't been giving it to him on a daily basis…I do like whenever he starts to come down with a cold. You know, if he has the sniffles, then I will start him. I will say okay, you should definitely be on your medication….When I think that he is well enough to be taken off of the medication then I do." Pg 380
Finding	Fear of steroids (U)

Illustration	"I just think you hear so many things about steroids. When he was four months, he was given Prednisone, his teeth were coming out….They got ruined….Some kids who get a lot of steroids, studies show that they have got hip replacements. Something that eats your bones or something." Pg 380
Finding	Parents described their child's asthma using a chronic explanatory model. Parents understood asthma as something that children had all the time, regardless of whether they were actively symptomatic (U)
Illustration	They explained that asthma caused their children to react to different environmental and viral triggers, leading to symptoms such as cough, wheezing and difficulty breathing. "it's like [asthma] is always there." Pg 379
Finding	Parents described an intermittent model of asthma. Asthma was viewed as an acute illness something that "comes and goes," and does not exist in between episodes when triggers "bring the asthma on" (U)
Illustration	"When he's having asthma, it's bad; but when he's not, he's fine. So when it's happening, it's not good; but when it's good, it's good." Pg 379
Finding	Predictability of asthma symptoms (U)
Illustration	"I've become very good at treating it and hearing it, before it comes." Pg 381
Finding	Others described their children's asthma as unpredictable (U)
Illustration	"So, we can't pinpoint what it is. We do not know what the triggers are. It could be anything. It could be everything. It could be nothing." Pg 381
Finding	Contextual barriers to using medications (U)
Illustration	Home life was described as a constant juggling of many competing priorities such as inadequate housing for their families, financial struggles and other family illnesses. Pg 382
Finding	Many parents viewed daily medications as necessary (U)
Illustration	"As long as she is on a 24/7/365 regimen, as long as she takes her medication on a daily basis, she builds up that wall she needs." Pg 379
(18) Jonsson M, Egmar AC, Hallner E, Kull I. Experiences of living with asthma - a focus group study with adolescents and parents of children with asthma. Journal of Asthma. 2014 Mar;51(2):185-92.	
Finding	As soon as asthma symptoms became apparent to immediately give the inhaler device to their children so they not became more impaired and needed to go to the emergency ward (U)
Illustration	"As soon as I hear sniffling I start to give medication four times a day, you must be as quick as possible so you don't reach the peak." Pg 188
Finding	Another treatment strategy among parents was to use the Peak Expiratory Flow (PEF) to check their child's asthma symptoms (U)
Illustration	"You can see from the values when she starts to get worse, then it will only reach a level of 90 when it should be 130 and then you know that it's time to inhale lots of drugs, because you see that an infection is on the way." Pg 188
Finding	Parents expressed that they needed to adapt to their child's everyday life so the children could participate in the same activities as children without asthma. This adaptation could sometimes result in infections for the child (U)
Illustration	"When there's a party you stand the risk that your child will get a cold in about three

	days." Pg 188
Finding	Struggle and communicate well to get staff in healthcare to understand his child's needs (U)
Illustration	"…you have to struggle to get help from someone and you have to be strong and communicate well." Pg 188
Finding	Parents expressed feelings of inadequacy and frustration when their child had exacerbations (U)
Illustration	"I want the best for my children, so much that it hurts (pointing at her heart) but when they are sick it becomes very difficult to handle." Pg 188
Finding	Feeling of inadequacy in relation to seeing their child was ashamed of having asthma (U)
Illustration	"It's really hard and tough for me to see that my daughter is ashamed of her illness so she goes into the toilet and hides when she takes her inhaler medication, she feels that she is not like other children, and 9 years is a sensitive age. Other children just stand around and watch her when she takes her medications, it's really hard. I wish that she could meet other children with asthma, now she feels alone." Pg 188
Finding	Not sure if their child inhaled in the correct way (C)
Illustration	"Every time she had a cold, we gave her the inhaler device and the professional asked if we did it in the right way, but it's hard to know if we inhaled the right way, because the child took such small breaths at the beginning." Pg 188
Finding	Parents had expectations to be treated by a competent healthcare professional which did not always occur. Parents felt it had taken too long to achieve the asthma diagnosis for their child (C)
Illustration	"It was my daughter, it began when she was six months, then it was 15 times acutely with colds, in and out of hospitals, the doctor said its pneumonia again and prescribed more penicillin, then at age two they said it was not pneumonia, it was asthma." Pg 189
Finding	Healthcare professionals should understand and support them (U)
Illustration	"I need help from someone who knows and understands my needs." Pg 189
Finding	Support received from the asthma nurse at the Child Outpatient Clinic (U)
Illustration	"I have a direct number to the asthma nurse so I can easily reach her. I could not do it without her support, she calls me up and asks how my child is doing and really supports me all the time." Pg 189
Finding	Parents had expectations to get repeated patient education in asthma care (U)
Illustration	"Sometimes the healthcare professional thinks that you have knowledge about the asthma disease and when you get another child with asthma, the professional assumes you already have knowledge, but that isn't always the case, I think they missed giving repeated information to the same parents." Pg 189
Finding	Parents wished that school teachers had more knowledge about asthma care and were able to give asthma medication if needed (U)
Illustration	"I remember one day….my child was allowed to go to nursery school if they gave her the medicine, but the teacher had forgotten about it." Pg 189
(19) Klok T, Brand PL, Bomhof-Roordink H, Duiverman EJ, Kaptein AA. Parental illness perceptions and medication perceptions in childhood asthma, a focus group study. Acta Paediatrica. 2011 Feb;100(2):248-52.	

Finding	Resistence against medicines in general (U)
Illustration	"I don't like medicines altogether." Pg 250
Finding	If parents were convinced of the necessity of using ICS, this was mostly because they had observed an improvement of their child's symptoms after starting ICS (U)
Illustration	"Her asthma may not disappear, but with the medicines you can suppress it." "The well-being of my daughter depends on the use of the medication." Pg 250
Finding	Some parents would use Inhaled Cortico-Steroids (ICS) only intermittently or stop using it altogether (U)
Illustration	"We wanted to find out how he would do without his medicine. Well, he was fine. So now we only give the medicine when he needs it." Pg 250
Finding	Parents reported that after the initial visits to the healthcare provider, during which a diagnosis was made and maintenance medication was prescribed, they did not receive regular follow-up appointments (U)
Illustration	Parents would receive repeated inhaled corticosteroid prescriptions for their child without seeing a healthcare provider for up to three years, with parents managing their child's asthma on their own. Pg 249
Finding	Many parents expressed strong criticism about healthcare providers in primary care (U)
Illustration	Many parents expressed strong criticism about the healthcare providers in primary care. They did not feel having been taken seriously by these healthcare providers in their concerns about their children. Pg 250
Finding	Parents had to be very assertive (U)
Illustration	Parents emphasized that they had to be very assertive to receive the treatment they felt their child needed. Pg 250
Finding	Limited amount of information (U)
Illustration	Another complaint about primary care was the limited amount of information patients received, making it difficult to self-manage their child's asthma. Pg 250
Finding	In specialist care, their opinion changing the medication dosage was a shared decision between parents and the medical team (U)
Illustration	"I think the time changed that doctor's as the "all-knowing". Therefore, nowadays it is more a two-way conversation. Again, it is your child, you know the best if he is ill." Pg 250
Finding	In specialist care, all children received regular follow-up (U)
Illustration	Parents reported that in specialist care, all children received regular follow-up by the paediatric chest physician and by the asthma nurse, with a frequency of at least two visits a year. Pg 250
(20)Dixon-Woods M, Anwar Z, Young B, Brooke A. Lay evaluation of services for childhood asthma. Health & social care in the community. 2002;10(6):503-11.	
Finding	Outcomes of care - Parents saw health services as a resource in maintaining control over asthma and judged the success of health services in achieving this outcome (C)
Illustration	"It's really excellent, I really feel that's [care provided] one of the major factors that's getting her stabilized onto regular medication that keeps her able to function properly and also, because it's a consultant who specializes in that particular area, I feel like I'm seeing somebody who really knows what they're talking about." Pg 508
Finding	Quality of care – credibility of professionals was crucially dependent on their ability to

	demonstrate adequate and consistent clinical knowledge (U)
Illustration	"The nurse, well she'll tell you one thing one time and another thing another. I just remember one incident […] it was to do with using other inhalers when they were at school and about how often you're allowed to use it during the day above and beyond the prescribed dose, and on one occasion, she said "Ooh, you can have it as many times a day as you like, you can't overdose on this, it's not a problem", and the next time, it's "Oh no, you can't overdo this, they can only have it so many times a day, or they'll be really ill and become immune to it." Pg 508
Finding	Parents emphasised the need for careful monitoring, continuity and for the condition to be taken seriously (C)
Illustration	"…I'm not happy with the GP we've got, 'cos half the time when you go up there, he's got your prescription written out as soon as you walk through the door….All he's interested in is the computer system." Pg 508
Finding	Parents emphasised the need for careful monitoring (U)
Illustration	"..[T]here should be more monitoring of the patient […..] they get them on a level, you know, you're issued with your inhaler and that's it. I think it would be a good idea at least once a year, to call that patient back, and monitor how he's going, you know, is the inhaler effective, are you using it too much, are you doing this and that." Pg 508
Finding	Parents wanted to be given competent and understandable explanations of their child's condition and treatment, but about half of the parents were dissatisfied with the amount of information they were given (U)
Illustration	"the only thing I don't like is asking, like going along to the doctors and saying, look does he need more Ventolin or flexotide. I'm worried about him, it makes me feel as though I'm thick, you know, I don't understand, I don't understand it […..] cos I'll go in and I'll say, Look, M's wheezing again and they'll check they'll listen to his chest and they'll say to me, "Well, increase his inhaler to four times a day, you know probably three or four times a day", and then that's it then, they just say "tarr-ra" [goodbye] and I go, so I'm no better off when I've been, I know I've got to increase it but I still, back to square one where I don't understand it." Pg 508
Finding	Some parents were keen that health professionals include their child in consultations (U)
Illustration	"He often asks [the child's] opinion…He'll talk to [the child] and ask her how she is, he doesn't talk above her, we don't talk over her head, she's part of it." Pg 509
Finding	Access to appointments in primary care as an important issue. Ease of access was very highly valued (U)
Illustration	"I feel so strongly that I could ring up now and be there in 10 minutes and somebody would see me, and that's worth a lot to us." Pg 509
Finding	Parents also wanted what they could bring to the consultation, in the form of their unique knowledge of their child, to be valued by health professionals (U)
Illustration	"....[B]ecause I'm quite an independent person, because I'd already decided that's what I thought it was anyway he was very good in letting me talk about it and give my views, so in my mind he supported me according to what he know of me." Pg 509
(21) Raymond KP, Fiese BH, Winter MA, Knestel A, Everhart RS. Helpful Hints: Caregiver-Generated Asthma Management Strategies and Their Relation to Paediatric Asthma Symptoms and Quality of Life. Journal of paediatric psychology. 2012 May;37(4):414-	

23.	
Finding	Ignoring symptoms, only going to the doctor when the child was sick, or dealing with symptoms once they expressed themselves (U)
Illustration	"Well actually, we just go when he needs it, he is all caught up on his shots and everything". Pg 418
Finding	Caregivers offered strategies that included some form of planning ahead . Thinking ahead with regard to management activities including making appointments with health-care professionals, organizing the household through the use of reminders such as charts and journals, filling medications ahead of time, and cleaning ahead of time when the child is not present so he or she is not exposed to extra dust or cleaning supplies (C)
Illustration	"I found that cleaning the house at night worked the best because you can't vacuum, you can't dust when they are around you." Pg 419
Finding	Caregivers offered strategies that included some form of emotional component. Stress reduction and attempts to make the child feel like he or she is the same as other children (U)
Illustration	"Stay calm. That is the number one thing because when they get the attack you've got to slow the breathing down." Pg 419
Finding	Caregivers offered strategies that included some form of social collaboration such as involving other family members and maintaining positive relationships (C)
Illustration	"Talk to people, see how they've handled it, ask them who their doctors are, what they've like, what they haven't liked". Pg 419
Finding	Caregivers mentioned avoiding triggers such as tobacco smoke and pets (U)
Illustration	"I do not let him near anyone who smokes. He has a friend whose mom smokes and he is not allowed in that house and he can never go in her car." Pg 419.
Finding	Caregivers described cleaning strategies (U)
Illustration	"Dust is an issue, keeping the dust down is a big thing. That means more cleaning and regular vacuuming." Pg 420
(22)Reece SM, Silka L, Langa B, Renault-Caragianes P, Penn S. Explanatory models of asthma in the Southeast Asian Community. MCN: The American Journal of Maternal Child Nursing. 2009;34(3):184-91.	
Finding	Family Explanatory models for causality were primarily tied to environment exposure (U)
Illustration	"cold weather or air (which) freezes lungs," "dry air," "winter," "exposure to cigarette smoke", "mold", "stuff in the environment". Pg 187
Finding	All families described treatment in terms of western medicine, including home treatments that reflected knowledge about standard asthma guidelines (U)
Illustration	"Nebulizer, inhaler, nothing but the nebulizer, Flovent, Allergy medications, Prescriptions, Specialist care" Pg 188 "Vaporizer with eucalyptus oil or peppermint oil boiled on the stove to get in the air" "Vicks VapoRub rubbed on chest and back", "Carrot juice – helps build up lining of lungs." One participant mentioned coining, which is a common SE Asian healing practice for "wind illness" that consists of rubbing warm coins on the chest and arms and one mother stated "no coining." Pg 188-189
Finding	All but two of the parents portrayed their child's illness as very severe (U)
Illustration	"One time it was so bad that we ended up bringing him to the emergency room, because he was not breathing at all for a few minutes." Pg 189

Finding	Families expressed the impact of asthma in several different ways. They demonstrated chronic worrying (U)
Illustration	"I am always worried, always stressed"; "I worry about her stopping breathing"; "about her suffering." Pg 189
Finding	They also described their constant vigilance about monitoring symptoms (U)
Illustration	"I am always calling to see if he is ok"; "If he runs, I have to monitor his breathing." Pg 189
Finding	Families were also exhausted (U)
Illustration	"The main problem is lack of sleep for me and my husband." Pg 189
Finding	Plagued by the labour intensiveness of dealing with asthma (U)
Illustration	"Besides the attack, you put him down for 10 to 20 minutes on the nebulizer; I need to keep the house clean, change the linens weekly; I try to keep her healthy as possible because if she gets viruses it contributes to her asthma." Pg 189
Finding	Genetics were also mentioned (U)
Illustration	"It comes from the family," and "My husband had it." Pg 187
Finding	Other causes listed were infections, activity and "vaccines" (U)
Illustration	"sicknesses and viruses"; "too much physical activity, running, hyperactivity"; and "vaccines." Pg 187-188
Finding	What asthma does was described as (U)
Illustration	"tightening up airways," "mucus build up," "swelling," "cutting circulation," and "breaking down breathing." Pg 188
Finding	System barriers were mentioned (U)
Illustration	The major system barrier expressed by families was the lack of an available MD. Pg 190
(23) Chiang LC, Huang JL, Chao SY. A comparison, by quantitative and qualitative methods, between the self-management behaviors of parents with asthmatic children in two hospitals. The journal of nursing research: JNR. 2005 Jun;13(2):85-96.	
Finding	Parents had less knowledge about asthma disease (C)
Illustration	Parents could not differentiate between the symptoms of asthma and those of a common cold. When asked "What kind of disease does your child have", they would respond with hesitantly and with uncertainty. Some parents did not like to use the word "asthma" to describe their children. The word "asthma" in Mandarin Chinese means "cannot breathe" or "difficulties breathing".
Finding	Many parents avoided admitting that their child had moderate asthma (C)
Illustration	"If my daughter did not catch a cold, she would not have gotten asthma. She just has a weak airway and allergic reactions....she has mild [asthma]." Pg 91
Finding	Some parents had difficulties differentiating the anti-inflammatory and bronchodilator (U)
Illustration	Some recognised Pulmicort as a bronchodilator. Pg 91
Finding	Lack of confidence in environmental controls (C)
Illustration	"I cannot nuture the child in a sterile glass bowl. They need to go to school and play with other kids. How can we just change the environment at home? How do we control the environment at school?" Pg 91
Finding	Cost of some supplies, like anti-mite sheets, was too expensive (U)
Illustration	"We cannot afford anti-mite bed sheets. They are too expensive." Pg 91

Finding	Doubt about effectiveness (C)
Illustration	"I just wonder what the most effective methods to control asthma attacks are? I am tired of searching for the answer among different doctors." Pg 92
Finding	Parents tended to use alternative treatments and traditional Chinese medicine and not to use the Western asthma medications until the child had an acute attack, when they started looking into Western medical care (C)
Illustration	"I will buy herbal medicines or food to improve my child's immune system....Western medicines are good for symptom control but not for boosting the immune system." Pg 92
Finding	Parents insisted on taking their children to hospitals (C)
Illustration	"How do I manage asthma attacks? I am very afraid that I cannot help him properly. Taking him to the hospital is the only thing I can do for him." Pg 92
Finding	Lack of use of peak flow meter (U)
Illustration	Some parents mentioned that they had heard about it but it was very difficult to monitor PEF every day. Most parents complained that life is too busy to remember to use the PEF. Pg 92

(24) Crosland A, Gordon I, Payne A. Living with childhood asthma: Parental perceptions of risk in the household environment and strategies for coping. Primary Healthcare Research and Development. 2009 Apr;10(2):109-16.

Finding	Emotions expressed by mothers about their ED experience - Noise levelsabout asthma from a variety of sources (U)
Illustration	"Once we found out that (Name)'s allergy was to the dust mite I then wanted to know more about the dust mite, so I got the leaflet and sort of went on line and had a look." Pg 111
Finding	Preventers - This group of parents were also most likely to encourage their asthmatic child to be physically active to help build their strength and to try and prevent serious attacks (U)
Illustration	"I push them to do all the sports as it will build their lungs up rather than them just sitting as couch potatoes and then the next thing you know they've got to run down the street and cannot even run." Pg 112.
Finding	Taking preventative action helped them assume a sense of control over the situation. However, if their preventative action then failed it could leave them with a sense of personal failure (C)
Illustration	"I felt I probably hadn't cleaned enough so I sort of set to….pulling the books out and wiping the tops so I felt I had…maybe I was just being sensitive about not having cleaned thoroughly enough." Pg 112
Finding	Reactors were most likely to wait until an asthma attack occurred before taking action to minimise its effects. (C)
Illustration	"When we went to the appointment we worked out he had been given the inhalers all the wrong way. All that time. And this was the first time it was picked up on, and I still think even now that we are giving the inhalers the wrong way. I still think we are doing it wrong." Pg 112
Finding	Reactors - often demonstrated a lack of trust in the advice available. (C)
Illustration	"Sometimes I feel that they [the doctors] don't know enough about it." Pg 112

Finding	There was a sense of preferring not to know too much about triggers (U)
Illustration	"No don't want to know, bad enough looking at the picture without finding out what they actually do as well." Pg 112.
Finding	Reactor parents developed coping strategies through a process of trial and error (C)
Illustration	Strategies included hot baths, using chest rubs and keeping their child off school should an attack occur. "I just do, like, what I've always done, if they are bad I keep them in do you know what I mean, lie them on the settee just give them Calpol or Paracetamol and use the em, the smelly for them." Pg 112
Finding	Reactors - were more likely than others to rely on the use of reliever medication and were often confused about what the "brown" preventer inhaler was for: (C)
Illustration	"He's only been taking the blue one like when and if needed. He's never really needed his brown one." Pg 112.
Finding	Reactors - were more likely to see their children's asthma as a mild form of the disease (U)
Illustration	"I've never needed any support, its just very mild asthma and it doesn't really get in the way of his daily living so, not that bothered." Pg 113.
Finding	Compensators - recognized the role of environmental triggers in general and triggers within the home environment in particular. However, rather than avoid recognized triggers such as smoking or keeping pets, they talked about compensatory activities (U)
Illustration	"I don't smoke everywhere in me house. If I was like sitting and smoking on top of him I would say it's my fault, you know, but there is none of that…this is just a free household and I keep on top of me polishing and me hovering, and I have always done." Pg 113
Finding	Maintaining normal family life (C)
Illustration	All groups were unified in their motivation to maintain normal family life. Pg 113
Finding	Reactors - reported mixed messages from professionals (U)
Illustration	"I notice like if you talk to one doctor the idea is totally different to another doctor then you've got another doctor that will tell you a totally different idea, and you're like, wow okay." Pg 112
Finding	Compensators - there was a sense of denial amongst some others as to the harmful potential of this exposure (U)
Illustration	One parent reported that their child's asthma was triggered by dog hair and even though they had a dog in the house they reported it was only other people's dogs who posed a risk. "He's not [allergic] to the dog we've got, but he is allergic to my sister's dog." Pg 113
(25) Freidin B, Timmermans S. Complementary and alternative medicine for children's Asthma: Satisfaction, care provider responsiveness, and networks of care. Qualitative health research. 2008 Jan;18(1):43-55.	
Finding	The mother's decision to rely on alternative medicine depended primarily on her satisfaction with prescribed medications (U)
Illustration	Thirty-four mothers were satisfied with the drugs their children received. The reasons for satisfaction varied. For some children, the medication fulfilled its intended purpose: Biomedical drugs prevented or controlled the children's asthma symptoms and were able to stabilize breathing in crisis situations without worrisome adverse effects. Pg 46-47

Finding	The mother's decision to rely on alternative medicine depended primarily on her satisfaction with prescribed medications (U)
Illustration	Other mothers had relatives who died from asthma or experienced life-threatening crises. They put great faith in prescribed medications, even if these drugs caused side or adverse effects. Some caregivers reported voicing concerns about drugs' adverse effects to health providers but had been reassured that such efforts were minor and unavoidable. Pg 47
Finding	Networks of care - "people obtain normative guidance by comparing their attitudes with those of a reference group of similar others." (U)
Illustration	Interviewees discussed asthma treatments with relatives, coworkers, acquaintances, or friends. These ties constituted an ad hoc network of care on which mothers relied for information, support, and advice for asthma treatment options. Occasionally, mothers consulted friends and relatives before seeking professional care but typically, members of these networks were consulted after the professional diagnosis of asthma was made to discuss the clinical encounter, the prescribed drugs, and other recommendations. Pg 47-48
Finding	Biomedicine-only pattern - If a mother who was satisfied with prescribed drugs had few friends or relatives familiar with alternative medicine, she tended to stick with what the physician prescribed (U)
Illustration	A respondent - she, her own mother, and her daughter had been diagnosed with asthma. Her 9 year old daughter relied on prescribed inhalers and a nebulizer. No one in the family had used alternative treatments for asthma because, as the mother put it, "I don't think they really work." This mother attributed great efficacy to the medication for her daughter's asthma. She stated that she would not discontinue the inhaler because it had worked "awesomely" to prevent allergic-based asthma episodes. Pg 48
Finding	Pragmatic pluralist pattern - Mothers satisfied with prescribed medication but considering adding complementary and alternative treatments greatly relied on the knowledge, advice, and support from their networks of care (C)
Illustration	"My mother's very much into herbal medicine, she's always reading Prevention Magazine and health magazines and always giving us ideas." Pg 49.
Finding	Mothers explicitly rejected the use of complementary and alternative medicine (U)
Illustration	"A lot of people have told me about [alternative] medications for asthma but I don't dare to give them to him [her grandson], he's already taking so many medications, I don't want him to have any complication." Pg 49
Finding	Mothers worried about potential long-term effects of taking drugs for lengthy periods at such a young, developmental age (C)
Illustration	"I am not really concerned about actual asthma. I am concerned whether the drugs he's taking will be a problem when he's older. Will they cause any form of damage to his lungs?" Pg 50
Finding	Mothers' ability to convince their care provider about the seriousness of their concerns mattered greatly for the treatment plans they followed (C)
Illustration	When a mother reported to the paediatrician that her daughter reacted badly to montelukast sodium, the doctor stated that she had never heard of such a reaction but there was aways a first. The mother concluded that "she believed me" and her

	daughter was taken off the drug. Mothers finding health professionals responsive to their concerns rarely introduced complementary and alternative forms of treatment but rather argued about specific drugs and their adverse effects. Pg 50
Finding	Mothers who do not succeed in having their concerns heard satisfactorily (or do not raise their concerns) tend to look for complementary and alternative treatment solutions (U)
Illustration	Five mothers in our study, however, expressed frustration when they brought up concerns with healthcare providers. They felt that their concerns were not taken seriously and that their questions were dismissed. Pg 51
Finding	Mothers may rely on biomedicine by default but desire other treatments (U)
Illustration	"I just wait and see. I don't give him his inhaler or....none of his medications at first, because I just kind of want to wait and see if his own body, you know, his own immune system will boot it out and will take care of it. But it hasn't yet. Always at the end, I have to use his meds." Pg 51 "If there was something that I could give him or that I knew that would work, if there was an alternative that I knew that would actually work, I would give it to him." Pg 51
Finding	Satisfaction with prescribed medications (U)
Illustration	Some lower income mothers were satisfied with the medication because they had received the drugs free of charge through government programs, and they were relieved that they had access to medications. Pg 47
Finding	All mothers using complementary and alternative medicine preferred natural herbal products (U)
Illustration	Latino mothers typically used aloe, vera, bee honey, onion or garlic derivatives, and over-the-counter syrups and rubs available in local "bodegas", whereas non-Latino mothers relied more on echinacea and herbal teas. Pg 48
Finding	Familiar with complementary and alternative medicine and used it selectively to complement prescribed biomedical treatments (U)
Illustration	"Sometimes he asks for water, so I make a tea not as medicine but because it is warm (....) When it is too much and he can't stand it and it starts hurting...He takes everything I give him, even garlic with honey. I grind it well and he swallows it. I think that it relieve him a little." Pg 49
Finding	Corticosteroid prednisone was a great concern because of familiar side and long-term effects (U)
Illustration	They described their children as crabby, ornery, and emotional on the drug. One mother attributed her son's recurrent headaches to the steroid. Pg 49
Finding	Quick relief bronchodilator also caused concern (U)
Illustration	Many mothers noted that their children became hyperactive after taking the drug. They mentioned that it negatively affected their children's concentration level in school, interrupted their sleep, and made them tired, cranky, restless, and jumpy. Pg 49
Finding	Another source of concern was the efficacy of the drug (U)
Illustration	Inhaled quick-relief drugs, such as albuterol, often have immediately noticeable effects, whereas long-term control drugs, usually administered as pills, show no or less dramatic effects. Mothers questioned the need of continuously exposing their children to medication if positive changes were not observable. Finally, mothers were also

	concerned about the amount of drugs their kids took, fearing a life-long dependency. Pg 50
Finding	Mothers unwilling to confront their care providers or unsuccessful in such a confrontation but with a knowledge of complementary and alternative medicine will incorporate alternative medicine in their treatment plans (U)
Illustration	A non-Hispanic white mother who was not convinced that her 9 year old daughter had asthma. She went to the paediatrician with what she thought was persistent pneumonia, but her daughter was diagnosed with asthma, and the doctor prescribed an albuterol nebulizer, a long-term control corticosteroid, and prednisone. According to the mother, the prednisone made her daughter "absolutely out of her mind." She called her doctor to express her concern but was told to "ride it out." Instead, the mother talked to her own mother and a friend about prednisone and was told that it was a powerful steroid with serious side effects. She discontinued the drug with the explanation that her daughter may have been wheezing but was not on her deathbed. Her first line of defence was homeopathic. Pg 51

(26)Horner SD. Catching the asthma: family care for school-aged children with asthma. Journal of paediatric nursing. 1998;13(6):356-66.

Finding	Learning the Ropes began with the diagnosis of asthma in a child family member (U)
Illustration	Family efforts were focused on learning about asthma and gaining some control over it. Asthma symptoms and asthma management were a central focus of the families' lives as they followed new treatment regimens and tried out various management strategies in the home. Pg 359
Finding	Uncovering Asthma Patterns (U)
Illustration	Parents focused on learning their children's asthma patterns (presenting symptoms and elements that trigger asthma) to be able to intervene or get help before the asthma escalated into an unmanageable episode. Parents related that before the diagnosis of asthma was made, they believed their children were having bad colds that lasted longer than usual, with paroxysms of coughing so severe that children vomited, which the parents "did not realize was asthma." Pg 359
Finding	Coming to Know Medications (U)
Illustration	Initially parents treated the symptoms the same way they had treated the earlier "colds". They gave medications only when asthma symptoms were present. With experience the parents became adept at using medicines to prevent asthma episodes. "It took me a long time to realize you needed to get ahead of it rather than wait until he was knock-down drag-out sick." Pg 360
Finding	Changes in the environments to reduce the children's contacts with potential triggers (U)
Illustration	The most common strategy taken was the implementation of "no smoking" rules in the home. "We took all of the carpet out of the entire house and we bought the central humidifier system that zapped dust particles as it recycled air." Pg 360
Finding	Parents' increased awareness of possible trigger events or precursor symptoms enabled them to intervene much earlier to prevent some asthma episodes and shorten the duration of other episodes (C)
Illustration	"See at night sometimes a couple of days before she really kicks in [with asthma], at night she wakes up coughing." Pg 361

Finding	Families stepped up treatment before or with the early onset of presenting symptoms (U)
Illustration	"When he gets symptomatic we add in a third Slobid a day or we immediately put him on the nebulizer. [Preventively] we see [MD] for sinus infections to get him on an antibiotic." Pg 361
Finding	Parents' actively evaluated the effectiveness of medications administered (U)
Illustration	"I thought that some of it was just guessing [about when and what kind of medicine to give]. But the medicine he takes every day, when I missed those two times, he was having bad problems the next morning, so that is when I realized this stuff really works." Pg 361
Finding	Each year, parents, usually mothers, established links with significant persons in the school, such as the children's teachers, counselors, or school nurses with whom they would entrust their children's safe keeping (C)
Illustration	"The beginning of school we had to…..do a lot of explaining each year….explaining that he was allergic to dust, and I began to feel there was some emotional ties [family stress] to the illness as well." Pg 362
Finding	Parents engaged in an appraisal process whereby they would weigh the risks and benefits in each situation to arrive at a sound decision to optimize their children's healthy or normal childhood experiences (U)
Illustration	"She really wants cheerleading, but I'm afraid…because it really gets hot out there and she goes and gets a little sweaty and coughs and wheezes. I'm going to let her try this next fall and she what happens." Pg 362
Finding	Managing work role demands was an important component of balancing demands. Time missed from work for the children's illnesses was generally viewed negatively by employers (U)
Illustration	"I work off and on and sometimes I can't work steady because of him….Because a lot of people don't understand when you say the child is sick and you've got to go. You know they're quick to hire someone in your place." Pg 363
Finding	The importance of taking time to care for self was expressed by many parents (U)
Illustration	"I take time for myself. I have a quiet 30 minutes, when I get home from work before I start dinner, and the boys know not to bother me then. I'll read, take a short nap, or soak in the tub." Pg 363
Finding	Limiting Rewards (C)
Illustration	Because an asthmatic episode is a frightening and dangerous event, children receive a great deal of attention during these episodes. Their solution was to establish a ritual in which the father and son (non-asthmatic child) spent time together alone every Saturday doing various activities – it became "their time". Pg 363
Finding	Deciding on appropriate discipline to be used was another issue each family confronted (U)
Illustration	"Well I'm still afraid to discipline him because I worry whether getting him upset by disciplining him will bring on another asthma attack." Pg 363
Finding	Older children evaluated the effectiveness of measures taken and discussed their interpretations with their parents (U)
Illustration	"I use him as a valid informant. He seems to know when his medicine is at its limit and this is when he comes to me." Pg 363

Finding	Through a trial-and-error process, parents came to learn which preparations were beneficial and which had untoward effects (U)
Illustration	"He lived with a runny nose....I was very frustrated, I would try anything on the market....One night we gave him Sudafed for the first time and he ran up and down the hallway throwing toys...He just went crazy on us." Pg 360
Finding	Changes in the environments to reduce the children's contacts with potential triggers (U)
Illustration	Nursery and school personnel were given instructions about weather conditions and the need for rest intervals during recess or play times to help the children avoid asthma trigger events. Pg 361
Finding	Conflicts arose between parents and school personnel concerning the management of children with asthma. (U)
Illustration	"The school nurse, she's an LPN, left him alone in the clinic while she took another child to the doctor's office. She didn't have anyone look in on him, she just left him there by himself and he had been complaining about trouble breathing." Pg 362
Finding	As children matured and demonstrated proficiency in asthma self-care, parents were able to focus on meeting some of their own needs (U)
Illustration	"I have just in the last three months been able to start a regular exercise class three times a week and it is making all the difference in the world. I feel like another person." Pg 363
Finding	Parents expressed concern about what their children were learning as a result of the entire asthma experience (U)
Illustration	"We are very worried about our other child. When he's sick he immediately thinks that we don't care if we don't give him medicine. I'm so afraid of what this whole situation is turning him into; I mean I see the potential drug abuser in my child because to him a drug is the answer to everything." Pg 363
Finding	The sibling of a child with asthma supported the family's work of managing the environment (U)
Illustration	"vacuuming the house to get dust out of the rugs so it will help (brother's) breathing. He is a good helper. " Pg 363
(27)Horner SD. Uncertainty in mothers' care for their ill children. Journal of advanced nursing. 1997;26(4):658-63.	
Finding	Children seemed to be 'sick all the time' (U)
Illustration	"For 3 years H was in the hospital I know every 2 or 3 months and stayed for a week each time." Pg 660
Finding	Many mothers could not make sense of the experience as they did not have any context for interpreting their experiences. The illness episodes had no recognizable pattern and reccurred frequently (U)
Illustration	"During the first year of R's life he was having recurrent throat infections and we really did not at the time know if anything was related to allergies or not but we knew he was kind of sickly as a baby. He was constantly catching stuff." Pg 660
Finding	Often the information which was provided by healthcare professionals was lacking or incomplete, and several mothers expressed dissatisfaction with the answers they received (U)
Illustration	"I used to take M to the health centre…and don't seem like they were helping him any

	and I mean he got in a state and I didn't know what was wrong with him. They didn't tell me." Pg 661
Finding	Mothers described an experience of staying up through the night while watching their child struggle to breathe. For most of the children this occurred relatively frequently at any time of the year (U)
Illustration	"Her attacks were every 2 weeks and they would last about 16 hours". Pg 661
Finding	Disruption in sleep patterns accompanied by the worry over the children's condition contributed to the mothers wearing out (U)
Illustration	"As much as you love your child and you don't want them to be discomforted, it gets to the point where your attitude is, "I'm sorry you're sick but I can't deal with it."…I was up five and six times a night and by the time morning comes you are just already pooped." Pg 661
Finding	As episodes continued to occur, mothers began asking more detailed questions about their children's symptoms, the prescribed medications, the expected outcomes, and explanations of possible causes (C)
Illustration	"I had been going to the paediatrician's office all summer long and I'd say, "Why doesn't anything seem to be working?" We'd gone through I don't know how many meds [medications] and she just couldn't throw it off." Pg 661
Finding	Mothers tried various other remedies (U)
Illustration	"During this time R was under chiropractic care and he was improved. And when he would have the coughing spells we would take him for an adjustment. So I mean that is a very non-traditional treatment of asthma but I must say that it, he did get some results from that when he would be in the middle of a bad coughing spell." Pg 661
Finding	Mothers began demanding attention by demanding a change to treatment plan, seeking referral to experts, or finding another paediatrician to coordinate their children's healthcare (U)
Illustration	"I felt like K could be damaging something internal. I got angry with the doctors because I finally went in to [the paedatrician] and K was having an attack every 2 weeks,, they were lasting 16 hours or so and the child would turn blue. I said, 'Is it time to go see a specialist or something?' He says 'Well you might want to try that'. Pg 662
Finding	Children were symptomatic only during specific seasons of the year and mothers did not view the episodes as unusual. The children in these families were found to have asthma of less severity and frequency (U)
Illustration	"We just thought this was a normal pattern for M." Pg 661
Finding	The need to be ever vigilant also contributed to wearing out (C)
Illustration	"It was a lot of sleepless nights and then at the same time I had [younger child] ....I felt like there would be months at a time when I never came out of hibernation...what with having to deal with their illnesses." Pg 661
Finding	Another mother recounted her experience of following suggested family and 'folk' cures (U)
Illustration	"My friend told me to use salt water to keep M from being stuffy. And another lady told me to stand him by a tree and put a nail in the tree above his head. And really I tried all of it, but none of it helped." Pg 661
Finding	Mothers did not feel that they were supported in their search for answers (C)

Illustration	"It was frustrating when I'm sitting here and...they wanted to treat you like you were stupid." Pg 662
(28) Grover C, Armour C, Van Asperen PP, Moles RJ, Saini B. Medication use in Australian children with asthma: User's perspective. Journal of Asthma. 2013 Apr;50(3):231-41.	
Finding	Worry, concern and anxiety at the initial diagnosis (U)
Illustration	"I was really upset when I came to know my son has asthma, as my elder one also had asthma but now he is better. I am really worried about him, they say one third of the children outgrow asthma when they are 12 or 13 years just wish he recovers soon." Pg 6
Finding	Some mothers reported the need to be available for support of their child's variable asthma exacerbations; this limited their employment opportunities (U)
Illustration	"….I stopped working. Sometimes I try to work part-time as I have to take care of my son." Pg 6
Finding	Parents reported that their child experienced embarrassment when using inhalers in front of their peers or in public initially. However, this embarrassment seemed to fade with the passage of time. (U)
Illustration	"…..Initially he used to feel a bit embarrassed of using inhalers at school but now with time he is comfortable." Pg 6
Finding	Most of the parents appeared to be confused over the purpose and classification of asthma medications, i.e. how a reliever or a preventer works (C)
Illustration	"With the preventer I am a bit doubtful, but Ventolin I know it works." Pg 6
Finding	They stopped preventer medication when their child appeared well and asymptomatic (U)
Illustration	"I am not sure…..but when he is better at times we stop the inhalers, especially in summers and he is just fine but when winters start we have to give the preventers and Ventolin." Pg 6
Finding	Parents commented on their child's inhaler and spacer technique and care, suggesting that confusion over use may be attributed to issues with information delivery from the healthcare professionals (C)
Illustration	"Previously we used two devices now both are the same kind of puffers; it was difficult for us to remember the technique of both." Pg 6
Finding	Parents/carers reported the use of CAM for their child's asthma. Most reported using herbal medicines, vitamins and steam therapy (U)
Illustration	"I tried some herbal medicines, but not sure if they were effective as we never stopped the inhalers." Pg 6
Finding	The affordability of medicines and devices was a common concern raised by parents. Despite financial stress many parents reported willingness to spend money for medication if there were evident benefits to their child (U)
Illustration	"I am not worried about the dollar value to the medications, they are expensive, but till my daughter benefits from them we are ready to pay." Pg 6
Finding	Parents expressed that the doctors in primary care had educated them well at the time of diagnosis and discussed the treatment plan (U)
Illustration	"They told us what we wanted to know at the time of diagnosis." Pg 6
Finding	Some parents voiced that children had to miss school due to acute exacerbations of

	asthma (U)
Illustration	"When she is not well, I don't sent her school as she is very careless about her medications. They expect her to tell when she needs medicines, so I keep her at home." Pg 6
Finding	Some parents voiced that asthma affects their performance in class (U)
Illustration	"At times I feel he is not performing as his classmates, he gets tired easily." Pg 6
Finding	Parents revealed concerns about potential side effects of oral and inhaled corticosteroids (U)
Illustration	"He has really bad teeth and the dentist thinks it's because of medications he is taking for his asthma." Pg 6
Finding	Most had problems taking medication due to the aesthetics, including taste or smell (U)
Illustration	"She doesn't like the taste of Predmix; always have to run after her to give the medicine." Pg 6
Finding	Unintentional nonadherence to preventer medications (U)
Illustration	"We try to follow the prescribed schedule give by the doctor but when my daughter is well she always misses one or two doses." Pg 6
Finding	A few parents commented that they did not receive any formal education at the time of diagnosis (U)
Illustration	"I don't remember we got any formal education about medications or the treatment plan." Pg 6
Finding	Parents reported that they had a written action plan (WAAP). Most felt that the WAAP was easy to follow and improved their child's care (U)
Illustration	"the doctor gave us the Asthma Action Plan, it is easy to follow. We have stuck it on our fridge, so that I and my husband can follow it when required." Pg 6
(29) Meah A, Callery P, Milnes L, Rogers S. Thinking 'taller': Sharing responsibility in the everyday lives of children with asthma. Journal of clinical nursing. 2009 Jul;19(13-14):1952-9.	
Finding	One mother was outspoken in her opinion that children should be actively encouraged to take responsibility for themselves and their actions, both in their everyday lives and in relation to their asthma (U)
Illustration	"…the thing is with other parents they don't actually think the child is capable….But kids, they are not stupid, no matter if you think they are, they're not, you know, they are only doing it your way because that makes you happy….So unless you're giving them the responsibility of doing it for themselves they're not going to take it up are they?...If you're going to sort of run around after that child, it's not going to do anything…." Pg 1956
Finding	Parental concern was most likely to be caused by children's adherence to using 'preventer' medication as prescribed and it was in this domain that parents were most likely to continue to play a supervisory role, reminding and often 'nagging' children to use their inhalers (C)
Illustration	"We both take them at the same time so I know that he's, I don't let him know that I'm watching. I sort of try and give him the responsibility, he's got to do it himself but as I'm taking mine I make sure sort of like he's taking his and he does them very well." Pg 1956
Finding	Parents reported their shock at discovering daily examples of coughing and chest-pain,

	which one child shrugged off as 'just normal' (C)
Illustration	"By the time he comes home maybe it's not hurting anymore and he's forgot. You know like I said, like when, when he's actually all right I think it goes out of his mind. And then when it's hurting, yeah he's probably come home and it's, the pain's gone and so he's just forgotten about it and I thought, I wonder how many times that does actually happen and he's come home and he's forgot and I don't get to know?" Pg 1958

(30) Koenig K. Pilot study of low-income parents' perspectives of managing asthma in high-risk infants and toddlers. Paediatric nursing. 2007;33(3):223-30.

Finding	Not knowing the diagnosis left families in the limbo of worry for the child and shared suffering (U)
Illustration	"Like it was more frustrating when I didn't know [the diagnosis. And receiving various diagnoses] was frustrating 'cause I like, "OK, well what is it then?"….This doctor is saying this. This doctor is saying that…I talked to one of the doctors and they said that….it was upper respiratory infection and it turned into croup. And then with the croup it became bronchiolitis…I'm not a doctor so I don't know if that's possible. I don't know if it's basically all the same thing but just different…" Pg 226
Finding	Relief at knowing the diagnosis clarified the problem as treatable condition with clearer prevention and management goals (U)
Illustration	"It's asthma so, it's not like a mysterious thing that we don't know about that we can't cure or help....They know what to do." Pg 227
Finding	Mothers described long ED waits (up to several hours) prior to diagnosis (C)
Illustration	"One time we had waited hours [in the ED]. And he still wasn't being seen. And he was wheezing and breathing very fast. I got loud and told the nurses and doctors that he had asthma, not bronchitis and that he needed to be seen right away. They took him right away." Pg 226
Finding	Some had more involvement from their child's primary care providers than others. Despite provider support, Lisa was often conflicted about accessing emergency care (C)
Illustration	"I called the doctor and he told me, "Well, how do you feel?" They're like "you know your child better than we do so if you feel she needs to go to the hospital you bring her in." So finally I counted her breathing. I think I counted like 61 or something. I freaked out. And I'm like OK "You know what Dad? We're going." Pg 227
Finding	Maintained vigilance over symptoms by regularly interrupting her own sleep (U)
Illustration	"I get nervous. When she's sleeping I stay up, sometimes a lot….I still wake up every night to feel her back…Sometimes her back is vibrating. You feel little vibrations in her back….Ever since she was little I've been doing it. And [even] when she's in the hospital." Pg 227
Finding	Managed anxiety with a clearly structured plan to access emergency care base on the frequency of Albuterol treatments (U)
Illustration	"If I feel his asthma is life threatening I will go to the emergency room…If it's just acting up he won't be rapid breathing and everything. He'll cough here and cough there…If it's life threatening then I'll know because he's coughing and I'm giving him treatments every two hours instead of every four hours and that he's starting the rapid breathing and I'm looking at him and I'm watching his stomach suck in. I can see his rib cage…And another thing about him, if he's about to have an attack he'll go and sit down. He wants

	to just lay down." Pg 227
Finding	The experience of assessing and managing symptoms, and making choices about how and when to access care helped them feel more confident about what to expect and what to do (C)
Illustration	"In the beginning yeah, I was nervous but now I'm used to it so I know what to expect whenever it acts up." Pg 227
(31) Newbould J, Smith F, Francis S-A. 'I'm fine doing it on my own': Partnerships between young people and their parents in the management of medication for asthma and diabetes. Journal of Child Healthcare. 2008 Jun;12(2):116-28.	
Finding	Parents described how they worked together in the management of the young person's medication (U)
Illustration	"It's teamwork really, we do it together, I do some things, she does others – we are always talking about how she is feeling, how wheezy she is sounding and making decisions together about things really." Pg 122
Finding	Transfer of responsibilities from the parent to the young person was reported most commonly as being without prior planning but as a response to specific occasions or circumstances (U)
Illustration	"I think it was just part of the process of growing up really, wanting to do things for himself without us interfering." Pg 125
Finding	Parents felt health professionals were not interested in being involved in issues of transfer of responsibilities (U)
Illustration	"She [asthma nurse] didn't really give us any advice or help. I didn't come away feeling very reassured – I mean, I want Kate to be independent, but I don't want to give her more responsibility than she can handle." Pg 125
(32) Jones V, Whitehead L, Crowe MT. Self-efficacy in managing chronic respiratory disease: Parents' experiences. Contemporary nurse. 2016 May;52(2-3):341-51.	
Finding	Parents described full accountability for their child's health and well-being as the responsiblity of only one parent within the family (U)
Illustration	"I don't want to be the sole "knower" of it all, but it's the way it's worked out." Pg 345
Finding	Asking others to take on the caring role was described as difficult and parents did not feel that they could pass on the responsibility. (U)
Illustration	"It's just not like you can put that responsibility onto someone else." Pg 345
Finding	The primary carer often struggled with the overall responsibility and other family members did not know how, or could not alleviate, the responsibility; (U)
Illustration	Dad: "…..it's not that I don't know what's happening, it's just that I'm not always sure about what I need to do to put it right." Mum: "In 2008 it was really hard, really hard because he was only 1-2 and I tried, I have taught (husband) a lot, but like I said, he's at work and I think you take responsibility on board." Pg 346
Finding	Access to health professionals was perceived as readily available and a strong relationship existed, parents felt supported (U)
Illustration	"Doctors here are fantastic, we have a really good relationship with them. I just ring them and they see him straight away….the GP talks to them as a person, you know (son) wasn't taking his medication one period and so I just marched him in there and I says well (son) seems to think he doesn't need this and he goes, "Oh come on (son)

	you're 14, your mother doesn't need to tell you or hold your hand anymore." Pg 346
Finding	Relationships with health professionals were also described as impacting negatively on parent's sense of self-efficacy. Parents talked about the pressure they felt from hospital staff to be fully responsible for the care of their child. (U)
Illustration	"On the ward I find that you are made to feel the pressure's on, that you have to stay all the time and sometimes you just want to get out of there, you know both of you. You want to get out of there are unless we can call on our parents, we can't do that." Pg 347
Finding	In primary health setting lack of continuity of staff and availability of appointments impact negatively on sense of support. (U)
Illustration	"Because I want to be sure, and I want to know that he's alright…It's really hard to get down, in to see someone down there and they have got a record of him and I can call them and say, look I want him looked at. But you can get anybody and I don't always want anybody." Pg 347
Finding	Overall sense of responsibility pervaded most aspects of their life (U)
Illustration	"Some people may think it sounds ridiculous but it just impacts so much. It effects so much…But even while you are waiting there is, I suppose there is feeling of anxiety, paranoia or something and looking for the signs….so it does take over." Pg 347
Finding	The speed at which symptoms could exacerbate and health deteriorated, contributed to caregiver's perception of the need for constant vigilance (U)
Illustration	"…but even now it just throws us, generally within the space of a couple of hours, he gets really tired….just you know like when he's not responding, you just know straight away and this can all happen over a period of a couple of hours, you know, like, just goes downhill very, very quickly…deteriorates very quickly." Pg 347
Finding	Symptoms did not follow the typical asthmatic presentation (U)
Illustration	"My son's behaviour isn't normal, so initially you are treated like a normal asthmatic and then it's never working….so we were just on a spiral of always going down the same path." Pg 348.
Finding	Being the one accountable for managing their child's disease meant having to be vigilant and constantly reassessing their child's symptoms to ensure they did not miss anything (U)
Illustration	"Guessing...so I don't know so I always think which is it?..Has he had enough? (medication) Has he had too much? (medication)...At the right time?...It's so complicated. It takes up a huge amount of time and energy...it's really, really stressful." Pg 345
Finding	Parents found it hard to relinquish the responsibility of managing their child's health to others (U)
Illustration	"We'd always done his medication and it was like that was being taken out of my hands and I don't like that." Pg 345
Finding	Inability/reluctance of second parent to assume greater responsibility in managing their child's disease was described as a lack of confidence in managing the disease (U)
Illustration	"Managing that medical care at home? I'm fine with it. (Husband) refuses, he wouldn't do it. He's not confident; he's scared." Pg 346
Finding	In order for the primary care giver to maintain their child's health, siblings often had to miss out emotionally and/or physically (U)

Illustration	"So they have definitely missed out on some things, sometimes it has had some negative effects on their world." Pg 346
Finding	Fostering a relationship with a specialist respiratory nurse was described as providing them with the support they needed to manage their child's condition (U)
Illustration	"Having a good relationship (with the respiratory nurse) pretty good at diagnosing over the phone...I mean that would be the person I would go to if I'm worried about what's happening for him there's something not right I know that he's got a guts ache or he's got a chest infection or whatever my first port of call would be to talk to the (respiratory) nurse." Pg 346
(33)Palmer EA. Family caregiver experiences with asthma in school-age children. Paediatric nursing. 2001 Jan-Feb;27(1):75-81.	
Finding	The process begins with the diagnosis of asthma for the child. One mother recalled the diagnosis of her child as a very scary thing (U)
Illustration	"I was so upset when I first heard that word [asthma] because I mean before I knew about asthma, for me to hear "asthma," it was almost like hearing "cancer"….I actually got goosebumps…my child has a terrible thing." Pg 77
Finding	Once the diagnosis was made, caregivers described the beginning of high expectations from healthcare delivery team. This was viewed by the families in a negative fashion. (C)
Illustration	"The paediatrician checked his lungs and they said to me, "He has asthma, here's an inhaler." Never showed Andrew how to use the inhaler, never told me what kind of asthma he had, never told me what he was even taking. I had no clue, I had no clue what I was doing." Pg 77
Finding	Families experienced varying degrees of denial (U)
Illustration	And still another stated that up until this point, she had a lovely healthy child and upon hearing the word asthma she said "I went into….denial" Pg 77
Finding	Following the diagnosis, the caregivers moved into a phase of conflict or battle. Caregivers described instances of having to fight with their children's physicians to get a referral (U)
Illustration	"I mean our primary care physician was bumping us off….saying "she doesn't have that many asthma episodes…." And nobody did any tests…so I said, "I want to go to an asthma doctor." Pg 77
Finding	Lack of support was the most frequently mentioned problem by caregivers (U)
Illustration	"From the time she was little I had to drag this nebulizer to childcare with me, and the childcare providers that we found, when they saw something like that they looked at you with horror. They did not want to be responsible for operating this machine." Pg 77
Finding	Parents identified a variety of conflicts within the context of school. One of the most remarkable battles that arose for the caregivers was the carrying and storage of the child's inhaler at school (U)
Illustration	"When I asked if he could go to the school nurse to do his inhaler before he goes out for lunch and she said, "He can't keep trouncing up there every time to go to the nurse."…So I said, "Can he put it in your desk?"…She said "I'm not being responsible." So I said "Andrew, do this for Mommy…Put it in your book bag in the hallway." And he had to know when to get up and raise his hand and go up and do it…And she'd say, "He

	just wants to get out of class"….So I said to my son, "When you’re ready to go, raise your hand, go out and do it, hide it in your book bag and don’t let nobody see it"….And this was ridiculous." Pg 79
Finding	One mother said that she did not believe that the school personnel realize the seriousness of asthma (U)
Illustration	"I don’t know what symptoms they need when a child is saying she needs it…a child dying for breath that is serious!" Pg 79
Finding	Caregivers reported that they did not receive enough information about asthma in the diagnosis phase and began seeking information on their own. Networking with other families who have children with asthma was an important strategy for gaining knowledge (U)
Illustration	"I network…At the bus stop we get into conversations because you’d be surprised at the children who are school-age who actually have asthma. And we’ll start talking and then we just exchange notes you know, that’s how I really have had the support that I need." Pg 79
Finding	Self-teaching was described by mothers as reading everything they could get their hands on in order to gain some insights into asthma management (U)
Illustration	"But I myself went out, I researched it. I read books and I sort of became a self-made expert because at that point I figured if they didn’t even tell me at the hospital what was wrong with her I wasn’t going to count on anybody to inform me." Pg 79
Finding	It took time to learn these management strategies (U)
Illustration	"My daughter was diagnosed between 15 and 18 months…and it took until she was about 4…." Pg 79
Finding	Becoming a vigilant caregiver. The vigilance described by these caregivers transcends all of the work and management required to take care of the child's asthma (C)
Illustration	"Momma’s doing it now….His medicine had to come just like the nurses do in the hospital. It was religiously done." Pg 80
Finding	A final battle reported was that of family conflicts (U)
Illustration	Caregivers reported that they were sometimes fighting with grandparents who could not understand why their grandchildren were always ill, which they felt guilty or upset about as it implied that the mother was doing something wrong. g 79
(34)Van Sickle D, Wright AL. Navajo perceptions of asthma and asthma medications: clinical implications. Paediatrics. 2001 Jul;108(1):E11.	
Finding	Asthma symptoms were commonly described as being a struggle for air resulting from air passages that were closed or constricted, obstructed, inflamed, or swollen. (U)
Illustration	"It seems like there’s a narrow opening – a narrow opening like if you took a paper towel roll…and twisted it and made that crimp in it. That’s how I would feel. That’s what’s happening in my lungs…" Pg 3.
Finding	Children had responsibility for taking their own medications (U)
Illustration	"I told her, "You’re the one that knows your body. You need to know how to deal with that asthma. So, if you think that you need to use your inhaler, use it." Pg 3
Finding	Parents expressed hesitations about asthma medications. Parents specifically feared that their child would become dependent on asthma medications (U)
Illustration	Families reported attempts to get through episodes without using bronchodilators, to

	“teach” the asthmatic child’s body how to handle the symptoms, or to avoid dependence on the medication. Pg 4
Finding	Parents believed that an episode could only be conclusively treated in the ED, trying to control the symptoms at home with prescription medication was sometimes perceived to only "prolong the suffering" of the child (U)
Illustration	"If I don’t get them treated, they’ll just get worse. So, I take them in right away and they get their breathing treatments." Pg 5
(35) Klok T, Lubbers S, Kaptein AA, Brand PL. Every parent tells a story: Why non-adherence may persist in children receiving guideline-based comprehensive asthma care. Journal of Asthma. 2014 Feb;51(1):106-12.	
Finding	Parents deliberately deviated from the paediatrician's advice. They adjusted the ICS dose according to what they thought was the desired level of asthma control in their child (U)
Illustration	"No, I don’t follow each of the paediatrician’s recommendations. I look at my child, whether he needs the meds or not." Pg 109.
Finding	Child raising issues, were found to be important barriers, parents would skip a dose when children refused the use of their inhaler simply to avoid upsetting their child (U)
Illustration	"Do I have to upset him completely, only for such an inhalation? How hard should you push? That’s a difficult decision sometimes." Pg 109
Finding	Simply forgetting giving the medication altogether (C)
Illustration	"I should stick to the rules that we decided on, but that’s not what happens." Pg 109
Finding	Children 8-10 years of age were given full responsibility for taking their own medication, without parental supervision. (U)
Illustration	"When he received the powder inhaler, when he was eight, we thought he could take the meds on his own." Pg 109
Finding	Parents were astonished to find out that adherence rates recorded for a year turned out to be much lower than they had expected (U)
Illustration	"That he takes is meds only half of the time, that’s quite shocking to me."” Pg 109
Finding	Children were given a single daily ICS dose instead of the recommended two (U)
Illustration	"Giving the meds every day once a day, that’s so obvious to me, and the right thing to do. I think that’s the reason I don’t report this to the paediatrician." Pg 109
Finding	Lacking the drive to achieve good adherence (U)
Illustration	"Well, I do notice he doesn’t take his meds. I see the counter of the inhaler still on the same number, just like some days before. Then you think: okay…but, you know, I have to deal with a lot of problems…." Pg 109
Finding	Ineffective ways of solving problems (C)
Illustration	"In the evening, he usually falls asleep on the couch. Then I don’t wake him up for his meds." Pg 109
(36) Englund AC, Rydstrom I, Norberg A. Being the parent of a child with asthma. Paediatric nursing. 2001 Jul-Aug;27(4):365-73.	
Finding	Mothers' actions: Being on guard and constantly standing by always involves the responsibility, meticulous planning, and control of the child's daily life (U)
Illustration	"It calls for the careful planning of everything, when you are in the city, it’s just not possible to go and have dinner if someone is hungry. You must consider: Can we have

	a meal here? Is there a non-smokers' restaurant? Do they have some food we can eat? Is the ventilation good enough? And Do we have the right medicine at hand to do this? You can't do anything when you are in the mood, or you can say, the mood mustn't play such a big role. You must always live with a 'built-in' structure. You must always think in advance about what to do, and there must always be a way to escape." Pg 368
Finding	Mothers' actions: To retain one's hold is to hesitate to leave the care of the child to someone else (C)
Illustration	"I mean, if you have a child, you must have enough strength, there is nobody else, you feel the main responsibility yourself…. " Pg 368
Finding	Fathers' actions were mostly related to liberating. To be action-aimed is to care about the child in a somewhat tougher way (C)
Illustration	"Yes, actually I think that as a man and a father....I, for instance, I think, and what you can, you say more rationally...Yes I think I am more rational...In other words, I believe that the mothers are more emotional, they think more of feelings, more of...that doesn't mean that rational thinking is more important, because I think it's extremely important that there exist both rational and emotional thinking in the relationship with the child." Pg 369
Finding	The dominant feeling for mothers was sadness (U)
Illustration	"You see, I don't only have him to take care of and then rest. I have two other children. Sometimes I feel sad, I get angry, I don't know what I get angry at, but I cannot express my feelings. I want relief. I just want somebody to come and say "It will be all right. Now we will take care of him for a while, you can relax." This is the way you want it to be." Pg 369
Finding	Mothers' feelings - To feel guilty about not having sufficient time for the healthy children in the family (C)
Illustration	"This is really very sad, but it is like this. And I think it is wrong. I think it is a serious fault, because, the healthy child, he is healthy and it is wonderful that he is, but the healthy child cannot understand, and he thinks it is wrong. And I agree, it is wrong, and he has to live with this. But we must try to talk about it sometimes when it becomes too acute. But of course it's wrong." Pg 369
Finding	Mothers' feelings - Feeling anxious about the future (U)
Illustration	“"Yes, you often read that their lives will be shorter than others' lives, one can die of this disease. You cannot help wondering if they will one day take a place in statistics. I have it in the back of my head that the risk exists." Pg 370
Finding	Fathers' feelings - To feel hope (U)
Illustration	"…you can say that there is improvement since she was an infant, and I mean, if you have some optimism, like I do, you hope that the improvement will continue…I can't say that it will be like this, but…." Pg 370
Finding	Fathers' feelings - Adjust to life's situation (U)
Illustration	"No, it's as it is. He has his asthma, he has his asthma, so he has, and it's just a matter of making the best of the situation." Pg 370
Finding	Despite the fact that the fathers are confident, they also have feelings of anxiety (U)
Illustration	"…she was near death, and you are afraid to lose her….yes, you are afraid like hell…." Pg 370

Finding	Retaining one's hold is sometimes difficult when the child's asthma is so serious that the mothers are forced to leave the child in care of medical providers (C)
Illustration	"Then a lot of people stood around him and listened and did a lot of things, and then it was as if it burst inside of me, it was too much, and I nearly started to cry. And then I pattered out through the door, not wanting to show this. And when I stook in the corridor crying, then I thought, I can't stand here crying, I must be in there and support my child here and now. He shouldn't be alone in there...." Pg 368
Finding	Fathers' actions. To be action-aimed also involves an attempt to clear up difficult situations (C)
Illustration	"...there are sources of unrest and stress factors....if something happened, what would you do? But in any case you have to clear up the situation." Pg 369
Finding	To feel sorrow is grieving for the sick child's inability to do all the things that other children can do (U)
Illustration	"What do you think then? You don't feel sorry for yourself, but you can't help thinking it would have been wonderful if...they had all been healthy." Pg 369
Finding	Fathers described feelings related to acceptance. Having trust in other people's knowledge and ability to take care of your child, and daring to relax when other people have taken over responsibility are all important factors in being confident (U)
Illustration	"You have to see to it that you are prepared, so the leaders know it's so and so and that there is medication so if something happens he can call if an acute situation arises. Then it's just a matter of relaxing: there is no reason to worry. Worrying only frustrates the situation." Pg 370
(37)Mansour ME, Lanphear BP, DeWitt TG. Barriers to asthma care in urban children: parent perspectives. Paediatrics. 2000;106(3):512-9.	
Finding	Some parents were hesitant to administer medications on a daily basis. They believed children would develop an addiction or become dependent on the medication, become immune or tolerant to the medication, or experience side effects (U)
Illustration	"Why do people give their kids medicine, push drugs into their kids, and they ain't having no trouble breathing, they ain't wheezing....their body will be immune to it." Pg 515
Finding	Parents were worried about the impact of physical activity restriction on their children. Many parents unnecessarily restricted physical activities based on lack of knowledge or misinterpretations of their doctors' advice. (U)
Illustration	"What I wanted to know about is how...how the children act when they are playing. I was watching this program where they say it is good for a child to exercise while they have asthma. I'd never heard that." Pg 515
Finding	Other parents did not restrict activities because they worried about the psychological impact of the restriction, but they were uncertain if this contributed to increased symptoms in their children (U)
Illustration	"That is why I am allowing him to play football and all. I went through the whole mind set with my husband – like he shouldn't be playing that, but if I stop him from living and growing, then I will hinder him more on the positive state of mind that can really make him physically not want to do nothing." Pg 515
Finding	Parents voiced concerns about their own quality of life and the constraints placed on them by having a child with asthma (C)

Illustration	"Everything is like life is turned upside down just to keep him healthy." Pg 515
Finding	Judgmental attitudes of providers toward people from lower socioeconomic or minority backgrounds (U)
Illustration	"Especially people in specific socioeconomic backgrounds are treated like they don't have a clue about what is going on. That is a main concern. People are not treated across the board in terms of attitude and knowing what is going on….with their child's body." Pg 516
Finding	Some parents believed that physicians delayed diagnosis or diagnosed less severe asthma to "save the system money." (U)
Illustration	"When they say they don't want to diagnose someone with asthma it's not because they care about you – it's about saving the system money." Pg 516
Finding	Parents preferred healthcare providers take a more holistic approach to managing their child's asthma, including both physical and mental well-being of their children. (U)
Illustration	"They deal with medications and treating symptoms, and it's not a holistic approach to managing care." Pg 516
Finding	Almost all parents stated that trusting their provider was paramount to receiving quality care. Factors that adversely affected the relationship of parents with their child's provider were: 1) healthcare providers distrust of parents' knowledge and familiarity with their child and child's disease (C)
Illustration	"Especially people in specific socioeconomic backgrounds are treated like they don't have a clue about what is going on. That is a main concern. People are not treated across the board in terms of attitude and knowing what is going on...with their child's body." Pg 516
(38) Riera A, Ocasio A, Tiyyagura G, Krumeich L, Ragins K, Thomas A, et al. Latino Caregiver Experiences With Asthma Health Communication. Qualitative health research. 2015 Jan;25(1):16-26.	
Finding	Latino limited English proficiency caregivers encountered significant burdens related to their children's asthma care. Emotions centred on the inevitability of asthma attacks and on a collective fear that a lack of preparation and/or knowledge could render caregivers powerless to act. The dread of an asthma-related mortality event for the child was frequently mentioned (C)
Illustration	"It is an illness that seemingly is not such a big deal, but it actually is. It affects the whole family because when a child has an asthma attack and the family does not know what to do, it is very dangerous. The child could die from it if you do not know how to solve the problem or where to call to ask for help." Pg 19
Finding	Ineffective communication with healthcare providers was commonly described. This occurred when an LEP caregiver was unable to get his or her message across well and/or felt dissatisfied or frustrated with an exchange (U)
Illustration	"On top of the asthma attack he was having an allergic reaction and it was horrible. So I hurried to the hospital and, what can I say? All you want is to hear words that you can at least understand. But they speak to you in English. You feel frustration, fury, anger, and you feel like grabbing the doctor and telling him, "Look tell me something I can understand." But he's telling me something strange and I cannot understand, and that makes it worse. It's frustrating." Pg 20

Finding	Several factors that related to experiences with professional healthcare interpreters seemed to perpetuate ineffective communication. Mothers reflected on experiences with interpreter availability (U)
Illustration	"In the hospital there's a record of my son because I've gone so many times. Someone who speaks English always approaches me. There's never anyone who speaks Spanish and, if they go look for an interpreter, I have to wait two or three hours until he shows up…if he even shows up." Pg 21
Finding	Caregivers discussed issues related to trustworthiness (or lack thereof) placed on unfamiliar interpreters (U)
Illustration	"Because of my daughters, the most important thing for me is to have a Spanish-speaking doctor. Many things are lost in translation. I do not want anyone to have to interpret because, after so many years in this country, I've seen too many times that you tell the interpreter one thing and he says another." Pg 21
Finding	Many caregivers who reported using an action plan described a series of intrinsic benefits to having a home treatment plan (U)
Illustration	"It helped me, truthfully. I can honestly say so. The woman who sent me the packet of papers told me, "Put it on your fridge [refrigerator], and each time your son has an attack you write it down so that each time I call you're going to look at the paper." So like I said, it worked for me. It helped me a lot." Pg 22
Finding	The plan was used as a motivational instrument for all family members to learn when the primary caregiver was not available (U)
Illustration	"Yes, it works, and I try to always have it somewhere visible in case I'm not at home and someone else is taking care of my son. That person can look at the plan if he or she does not understand what's happening with my son at any moment." Pg 22
Finding	Importance of having a language-concordant plan and how a self-administered language-concordant plan might be ineffective if the words used are difficult to comprehend (U)
Illustration	"I kept it on the fridge and I would look at it, I would try to read it. I would try to do what it said but I did not understand. …..My husband does not speak English either, so I did not have anyone to help me. So, my method, my action plan, was to rush to the emergency room." Pg 22
Finding	There was an overwhelming, unified desire to expand asthma-education opportunities for LEP caregivers (U)
Illustration	"I think that there should be more Spanish speakers who conduct those meetings about how we as parents can help our children. The problem is that we do not speak the language, so it's hard for us to go to those meetings…I think that would make it more interesting and parents would want to go because they're concerned about the well-being of their children. In that case, we would go to these meetings to listen and learn about asthma." Pg 22
Finding	Detailed depictions of striking physical changes observed during a child's asthma exacerbation were given. A discrepancy was noted between the caregiver's emotional burden and the urgency of subsequent interventions by healthcare providers (C)
Illustration	"Usually, when one goes to the hospital they just give you an albuterol treatment and refer you to your doctor. I can do that at home When one goes to the emergency room

	with a child with asthma, I think that they should pay more attention to him. If someone takes the time to go it's because it's really necessary. Maybe I'm not the most informed person, but I do have a daughter who I know to have been sick since she was just four months old, and it's been an uphill battle with her. I'm not sure, but I think that they could do a better job." Pg 19
Finding	The emotional toll that seemingly routine asthma treatments imparted for LEP caregivers was also expressed. The caregiver's emotional burden was linked to their struggle with cumbersome and/or absent communication with the child's health provider (U)
Illustration	"It was a little complicated because when I got there my daughter was very ill. She was breathing very heavily. Her lungs were sinking into her chest considerably. So, I was very worried. I wanted to find out what was happening to my daughter, and when I got there the doctors treated her....They spoke among themselves and I wanted to find out what they were saying, or what they were administering, or what she had, or what their plan was for my daughter. So it's very difficult, because one gets frustrated because of not knowing what's going on-in this case with my daughter." Pg 19
Finding	Participants also shared their experiences with language-discordant written transactions (U)
Illustration	"The child's doctor speaks Spanish, but she does not write it down that way, like what I have to administer and all that. It is all in English." Pg 20
Finding	Often, caregivers relied on family members or even children to interpret because they were viewed as reliable and capable (U)
Illustration	"Because even though she's young [six years], I can tell she's capable of helping. You understand? With an interpreter or an adult I feel bad because I think that maybe they're thinking that I do not try hard enough." Pg 21
Finding	A preference for language-concordant healthcare providers was mentioned (U)
Illustration	"Because of my daughters, the most important thing for me is to have a Spanish-speaking doctor. Many things are lost in translation. I do not want anyone to have to interpret because, after so many years in this country, I've seen too many times that you tell the interpreter one thing and he says another." Pg 21
Finding	During situations in which a barrier to good communication was present, a spectrum of advocacy responses was observed. Individual emotional responses seemed to play a significant role. Emotional responses spanned a vast range, including shame, anxiety, helplessness, and anger (U)
Illustration	"[I felt] impotent....because I would have liked to have been the one that was receiving all the information. To have had the doctor explain to me what I had to do. Well, and to not have to wait for my dad to listen to him [the doctor] and then explain to me what I had to do." Pg 21
(39) Rose D, Garwick A. Urban American Indian family caregivers' perceptions of barriers to management of childhood asthma. Journal of paediatric nursing. 2003;18(1):2-11.	
Finding	The most frequently mentioned provider barriers identified by family caregivers were related to the amount and quality of information that they received about asthma (U)
Illustration	"Just because somebody's a young mother doesn't mean they're stupid. If you give them the information and you treat them like you treat anybody else, with respect, they understand what you're talking about. My niece, she may have been young when her

	baby was born, but she had good mothering instincts. Another thing, the probabilities can kill a kid. I mean, they need to diagnose and if they're not sure if somebody has asthma, like they should have told us, "He has upper respiratory infection; however, he may have asthma. Here's the information about asthma. If any of these signs come, come in immediately." They didn't do that for us. It was more or less we were left on our own, and they had the information. They could have provided it to us and they didn't, and it was like they weren't very helpful." Pg 6
Finding	Family caregivers also described experiences in which they felt mistreated or misunderstood by providers. One third of the participants described what they perceived as prejudice, in which they felt that providers were insulting or talking down to them, as well as not listening to them. (U)
Illustration	"Sometimes I feel that the doctors, when I go to the emergency room, are very arrogant, and I don't like to ask them questions, because I feel that I'm less of a parent because I don't know all this stuff about my child's needs. So, I just feel that they need to be more sensitive, and sometimes they act like you're really stupid. I mean, they read stuff slow to you or they look at you strange and it's just not very helpful. It's like, because you're Indian, or whatever you might be, that you don't know anything." Pg 6
Finding	Some participants thought that providers did not recognize their knowledge and expertise regarding their own children. Being told to wait while their child was in respiratory distress was particularly stressful (U)
Illustration	"I took her down to the emergency room, and when I got there the administrative desk was like, "OK…have a seat." And, I'm like an assertive person and I said, "No. My daughter needs to be seen as soon as possible. She can't breathe." And they are like, "Ma'am, I told you to take a seat!" And I said, "NO, I would like to see the doctor as soon as possible. If you don't let me see him I will walk in there by myself, right now." So…they admitted her right away. They put her on the nebulizer machine and gave her some oxygen because, at that time she was just….very short of breath." Pg 6
Finding	Some thought there was a lack of cultural understanding of American Indian families when, for example, providers did not understand the importance of the extended family/kinship network (U)
Illustration	"And usually the security guards will walk up and say, "You know what, you guys can't all be here." They don't realize just because that isn't our child, it's a member of our family and we feel deeply, and I mean we're very close. I mean you can see that I have a very small house, but come Christmas time every family member that I have will be in the house, including extended family members. And we're all very close, and that's something that a lot of hospitals don't understand, and then it's like they stick their security guards on you." Pg 6
Finding	Family members also had concerns about providers' approaches to diagnosis and treatment of their child's asthma. Some felt that physicians over-relied on drugs to treat their children and were not willing to explore alternative treatments (U)
Illustration	"I believe in Indian way, the traditional way. But, being able to go to a traditional healer is harder than going to a regular clinic because….we don't have that with anybody we know…the healers I know, they're on the reservation and it's a long travel, a long journey and we don't always have the money to get there, or transportation to get there."

	Pg 7
Finding	Family caregivers were also concerned about management of their child's asthma at school (U)
Illustration	"It's really hard, and the school nurse is never there when my daughter needs her, or when I go to drop off a new medication at the school that the doctor's giving us, the personnel at the school don't want to listen, because it's not their job. When really you know, a child is their concern. It should be their job if they're working in a school. So the nurse is there like every other day in the afternoon. I mean, my daughter could have an asthma attack anytime and nobody really understands what to do." Pg 7
Finding	The majority of family caregivers described the unique features of asthma that also were barriers to effective management of the illness. Flare-ups at night, seasonal changes, unexpected episodes, and the critical nature of the episodes are examples of condition-related barriers presented by asthma that typically created lack of predictability and an urgent need for care (U)
Illustration	"He gets sick just immediately. It's not like he gets a cold and it progresses into illness. He just, one minute he's fine and an hour later he's really, really ill with this reactive airway disease and with the fluid building up in his lungs, and it usually ends up that he makes a visit to the emergency room….it comes on so fast that it's scary. It's scary for me to deal with it." Pg 7
Finding	Almost all of the family members described personal barriers to effective management of their child's asthma. Two described feeling inadequate or inferior in the presence of healthcare providers. Although half expressed having a lack of understanding about asthma, a few were reluctant to ask questions or felt afraid to ask questions without other family members present (U)
Illustration	"It is hard for Indian people to ask for the services they need, because it is our way that you should have your family members there to help you. If we don't ask a question, it's not that we know it all, but it's just that we might be afraid to ask the question because of feeling inferior." Pg 7
Finding	Another participant felt that a parent's fear could be misunderstood by care providers (U)
Illustration	"They need to know that number one, Indian people are very, very edgy about their children, especially when they're sick, and I think doctors at hospitals mistake that for parents being, some parents are really quiet because they're so worried. They mistake that for parents not caring or parents try to act all tough and that's not what it is. Most Indian people that I know, when their kids get sick are just scared to death." Pg 7
Finding	Some participants also experience role strain when they had one child in the hospital and other children at home or when more than one child was sick with asthma (U)
Illustration	"It was hard, being he was the baby, but yet I had a 2 year old and a 3 year old at home, so it was always hard to find someone to come in and take care of my children when I was at the hospital. There was times Dad, when we were still together, he would take days off from work because we couldn't find someone to stay with the kids, and then we would take turns. He would stay a night at the hospital for a day, and then I would come take care of things at home, then I would go back, so…I would be just stressed out, tired cause I couldn't get any sleep. I was always taking care of him and Dad was missing work." Pg 7

Finding	Some family members expressed their concerns about long-term use of medications, especially steroids, to treat their child's asthma (U)
Illustration	"I've seen a lot of quick fix, here's a prescription, get this filled. They don't talk about the possibility of these drugs being habit-forming. They don't talk about him being on steroids for his asthma at least 7 times in his life, and he's 4 years old. They never once told me how dangerous steroids could be for him or what some of the possible side effects are. I asked a pharmacist about it and then went to my doctor and said, "Isn't this true, that this could have problems with his growth, that it could possibly shorten his life span?" And the doctor just dismissed it by saying, "Well, yes it could have side effects but look at the long range help that it's going to do for his asthma." And I asked him about alternatives to this and he was just insulted that I would ask about that and more or less said, "Well, who's the doctor here, you or me?" Pg 8
Finding	Caregivers described socioeconomic barriers. Finding and paying for transportation to the hospital emergency room or the primary care clinic were a major concern (U)
Illustration	"Especially in the middle of the night, you know, and you don't have any family members around, you don't have transportation, and if your current medical supplier doesn't supply a cab for you, how are you going to get down there? You don't want to call 911 because that ambulance ride is going to cost you $300, you know." Pg 8
Finding	Accessing care for the child was also made difficult by winter weather (U)
Illustration	"It seemed like when he would have the asthma attacks it would be mainly in the winter time, the coldest months, when they'd come on and so I always made sure I had money put away for cab fare, especially in the winter time." P8
Finding	Nighttime visits to the emergency department during winter months were even more difficult when families needed to find care for their other children or else take them along (U)
Illustration	"Sometimes we have to get up in the middle of the night, if her medicine isn't helping her, and we have to take her to the emergency room a lot of times during the winter months. It's hard, it is hard. And it's really stressful to have to get up some times at 3, 4 o'clock in the morning, get the other kids up or try to get someone to come sit with them or haul them to the neighbors at 3 o'clock in the morning and take her to the ER [emergency room]." Pg 8
Finding	Participants described how frightening it was for them when their children were so sick (U)
Illustration	"Our children are sick, and sometimes we're afraid they're going to die." Pg 8

(40) Garro AC, Jandasek B, Turcotte-Benedict F, Fleming JT, Rosen R, McQuaid EL. Caregiver Expectations of Clinicians during the Asthma Diagnostic Process in Young Children: Thematic Analysis of Focus Groups. Journal of Asthma. 2012 Sep;49(7):703-11.

Finding	Caregivers satisfied with the diagnostic process often conveyed that the child's primary doctor communicated a plan of action to diagnose asthma after the child first manifested respiratory symptoms (U)
Illustration	"Our doctor laid it out for us what the possibilities were. And then as time went by she would reevaluate what she felt my daughter's condition was. And she was reluctant to say that is was asthma until she was sure that it was asthma but we always had a

	course of action when we left there." Pg 706
Finding	Caregivers dissatisfied with the asthma diagnostic process frequently described scenarios in which a diagnostic strategy was not communicated. (U)
Illustration	"I think after this first episode it was obvious. And I don't know what they are waiting for….they tell me they don't want to do it that young, but they don't want to tell me when they want to do it." Pg 706
Finding	Some caregivers suspected their child might have asthma soon after symptoms manifested. Caregivers were dissatisfied when they perceived concerns about asthma were not acknowledged by the medical provider (U)
Illustration	"…her father's side has it. So there's a good possibility that she does have it. And they….should have considered that a little more….it just seems like they didn't take me as seriously as they should have." Pg 706
Finding	When providers were perceived as responsive to their concerns, caregivers were satisfied with the diagnostic process. (U)
Illustration	"I said, "I think it's asthma." And [the doctor] said, "it's kind of too early….we're going to keep an eye on it and we're going to continue to see her often until the point where we can say, yes for sure, it is asthma." Pg 706
Finding	Asthma controller medications being prescribed before they were told their child had asthma (U)
Illustration	[Participant commenting on a doctor's wait-and-see approach to diagnosing asthma]"…if [the medicines] are working…..she's better when she's taking them…what's the problem?" Pg 707
Finding	Belief is that if they are not diagnosed with asthma, children should not be getting medicines for asthma. (U)
Illustration	"[Referring to asthma medications]… there are so many side effects….are they sure enough that he has asthma to give that to him?" Pg 707
Finding	Many caregivers had strong opinions that families should be referred to asthma specialists to provide answers about their child's illness and manage their child's care (U)
Illustration	"They send you to a specialist and that specialist knows for sure because they have all the tools and everything else they need to test your child." Pg 707
Finding	Caregivers who perceived their child as having more severe disease manifestations expected a more expedient asthma diagnosis. (U)
Illustration	"If you go to the emergency room seven times in one year for the same exact thing, but they still wait a whole 'nother year before they tell you that your child has asthma, it puzzles me." Pg 707
Finding	In children with milder perceived illness, expectations were different. (C)
Illustration	"Two years sounds like it might have been long, but because [my child] wasn't as frequent as [another participant's child], maybe it may have kind of been just right. Because the longer you look at something, the longer it starts to show the pattern of it." Pg 707
(41)Newbould J, Francis SA, Smith F. Young people's experiences of managing asthma and diabetes at school. Archives of disease in childhood. 2007;92(12):1077-81.	
Finding	Parents expressed concern for their child when they moved to secondary school. In

	primary schools, particularly village schools, parents described talking to the young persons' class teacher about their condition, but at secondary schools such contact was not possible (U)
Illustration	"I do talk to them, but in secondary school she goes all over the place – you can’t, it’s different teachers. Whereas in primary school it’s one teacher really, so there has been less involvement now she’s older." Pg 1080
Finding	Parents perceived staff as unsympathetic to the needs of their sons/daughters, unaware of the serious nature of the condition and lacking in sufficient knowledge to know if the young person was having difficulties. (C)
Illustration	"I mean it’s frustrating for us parents, when you have the medicine there and you know all she (the teacher) has to do is make sure he takes it. But then you hear stuff about teachers being sued for touching kids, and you think they have to be really careful you know, they have to cover their own backs." Pg 1080
Finding	Parents were often unaware of practical issues regarding medication at school (U)
Illustration	Some parents were unable to answer questions relating to where the young person's medication was stored at school or what happened when they wanted to use it. Many parents were unaware of whether or not there was a medicines policy at the school. Pg 1080
Finding	Anxieties regarding policies were commonly expressed (U)
Illustration	Parents of young people with asthma were most often worried that the storage of medication outside the classroom would cause delayed access in the event of an asthma attack. Pg 1080
(42) Peterson-Sweeney K, McMullen A, Lorrie Yoos H, Kitzman H. Parental perceptions of their child's asthma: management and medication use. J Paediatr Healthcare. 2003;17(3):118-25.	
Finding	Universally, in two-parent families, the mother controlled asthma management including medication administration, healthcare provider visits, management and communication with school and day care, and other activities outside of the home. Mothers assigned the role of caretaker, as needed, to other family members with whom she felt comfortable. (U)
Illustration	"The main part of asthma I do myself, because I think what I know about asthma keeps her out of serious trouble. We go to the paediatrician for her annual visit and I kind of let him know what is going on. It took a long time before she really stayed with my mother or sister. She mainly stayed with my best friend. Her daughter has asthma, so she feels comfortable with taking care of my daughter." Pg 121
Finding	Once they were comfortable with asthma management, parents assumed the primary role of initiating or changing asthma therapy based on symptoms. Over time, parents believed that they became more confident in this role through 'trial and error." (U)
Illustration	"It’s kind of a sliding scale or action play style thing that we do. We would go months without using Albuterol in our home life, and then we’d go on a trip to see her grandparents where there are animals and she would end up in the emergency room. Now we start her medications 3 to 5 days before we visit and things are much better." Pg 121
Finding	Outside of established relationships with the primary care physician or specialist, one

	third of the parents expressed distrust in professional management (U)
Illustration	"He saw another doctor in the office who said our son had an ear infection. My children don't usually get ear infections. He was coughing and we knew he needed prednisone, but the doctor just gave us medicine for an ear infection. We ended up in the emergency room." Pg 121
Finding	Parents who had children with long-standing asthma expressed a lack of understanding or confusion about how medications worked (U)
Illustration	"It was the day after Christmas, and he (the doctor) was just seeing emergency patients. That day he prescribed an inhaler, and I knew nothing about an inhaler, I didn't know how to work them. I felt very frustrated in that I thought through the system I should have gotten more information through his doctor's office or the pharmacy." Pg 122
Finding	Mothers of teenagers stated that their children understood the reasons for medications; in fact, they also stated that experiential learning for teenagers helped them with adherence to daily therapy (U)
Illustration	"Since the episode last year she realizes that she does have it (asthma) and how severe it is. She is better about taking her medications now." Pg 122
Finding	Parents perceived that their school-aged children needed reminders so that they could be spared the negative consequences of not taking their medication (U)
Illustration	"She's thirteen, and I say, "Do your medicines" and I expect her to do it, and she didn't – so the next thing we know she's in this horrible flare-up." Pg 122
Finding	Parents described initial struggles with their children who resisted taking medication (U)
Illustration	"He just goes on strike and says he's not taking his medication." Pg 123
Finding	4 parents preferred the nebulizer to the metered dose inhaler, stating that, with the nebulizer, they were sure that the child received the entire dose of medication (C)
Illustration	"They taught us how to do the inhaler. My husband is concerned because he thinks that Zachary doesn't keep it on there long enough to get the full dose. But the nurse practitioner says that he gets the full dose." Pg 123
Finding	Nearly half of the parents preferred oral to the inhaled delivery of medication (U)
Illustration	"I know exactly what goes down." Pg 123
Finding	One parent preferred inhaled delivery to oral medication because pills gave her child a stomachache (U)
Illustration	"I like the inhaler, because it's more direct to her lungs. It goes more directly to where it's needed. It's not going throughout the body. To me liquid medicine is a trial throughout the body until it gets to that area, but the inhaler goes right to the area." Pg 123
Finding	Many parents did not like giving medications but saw improvement with medication (U)
Illustration	"On one hand I just feel "let's leave him (on medication)," he has done so good, but on the other hand, certainly if he could be medication free that would be good too. But I'm not willing to let him be uncomfortable like he was before. To be medication free is not the most important thing. For his symptoms to be under control is what I want." Pg 124
Finding	Parents had many concerns about both classes of medications (U)
Illustration	Mothers stated that they had concerns about the bronchodilator albuterol, using such words as "hyper," "tachy," "jumpy," and "shakes" to describe effects experienced. Pg 123

Finding	Parents wanted to be acknowledged for their own assessments, knowledge, and evaluation of previous therapies (C)
Illustration	"Once we got rid of the doctor who didn't listen to us and thought it was a temper tantrum, things were better." Pg 121
Finding	They reported initial explanations of medications being given, but even these seasoned parents said that they could benefit from review and reinforcement (C)
Illustration	"Even the structure of the follow-up appointments isn't such that there is any mechanism for the education to happen. You go to check to make sure everything is clear and the prednisone worked. It was a 15-minute appointment and it sounds good and off you go!" Pg 122
Finding	Learning occurred over time, with parents identifying multiple resources, such as asthma-based Web sites, the library, an asthma network and newsletter, family members who were nurses or who had asthma, and the pharmacist (C)
Illustration	"I just feel that parents should stick with one pharmacy, who knows my child, who knows her medicine. If she is going to have side effects due to this medicine the pharmacist will tell me." Pg 122
Finding	One parent even articulated that she had no concerns about asthma medication, now that her daughter was young and she was controlling the medications (U)
Illustration	"So I think when she becomes a teenager I would definitely be concerned, but since I'm controlling it I guess I don't have any concerns." Pg 122
Finding	Remembering or giving or taking medications on a daily basis was the most difficult aspect of asthma care (U)
Illustration	"It's a pain to remember to take medication twice a day." Pg 123
Finding	A method of medication management offered spontaneously was the use of devices, charts, and systems that organize medication administration (U)
Illustration	"The diary helps me stay organized. I think it helps me because when I go to the doctors and they ask me questions, I can refer back." P123
Finding	Participants discussed many concerns about the oral antiinflammatory medication prednisone (U)
Illustration	"Facial bloating" was a concern for 2 mothers, and 6 expressed concerns over weight and weight gain. 2 mothers stated that they equated steroids with "body builders" and "football players". Pg 123
(43) Peeler A, Fulbrook P, Kildea S. The experiences of parents and nurses of hospitalised infants requiring oxygen therapy for severe bronchiolitis: A phenomenological study. Journal of Child Healthcare. 2015 Jun;19(2):216-28.	
Finding	For mothers, their child's admission to hospital was a critical event, which they perceived as a life-threatening crisis that they were not equipped to deal with. This was compounded by their lack of information and understanding, which brought with it great fear - the fear of the unknown (U)
Illustration	"Stacey looked like she was having a lot of trouble breathing. We knew then that she had to go to the hospital. When we arrived at the hospital they quickly attached her to machines and put her in a headbox, which gave her oxygen, and put a drip in. It was horrific, we didn't know if she would live or die." Pg 219
Finding	Their intense fear stemmed from their inability to comfort their child or understand what

	was happening and especially their fear that their child might die (U)
Illustration	"I just cried at first as it was so scary. I was tired and worried that Rachel might die. My one reaction that I wanted to do was hold her and keep her with me but she was whisked away and put in this headbox thing. It was not what I was expecting." Pg 219
Finding	Parents' feelings of ignorance about their child's illness and their need for knowledge and information (U)
Illustration	"It was like I had stepped into another reality - a black hole. This medical world suddenly became my reality and I couldn't get my head around it at first. It was so foreign and I didn't know what was happening. I didn't know if she was going to get better. I didn't understand her illness, I just didn't know anything. I felt so ignorant." Pg 220
Finding	Parents' lack of trust in nursing staff. The mothers felt that they needed to have a strong trust in the nurses before they felt comfortable with the care they were providing for their child (U)
Illustration	"I stayed with her day and night. I didn't trust anyone to look after her. For example, would anyone comfort her if she cried? I didn't do much for her. I wasn't allowed. They said it was too difficult and that they would do most of the day-to-day care while she was so sick." Pg 221
Finding	Mothers stated that they were less involved with their child when he/she was receiving headbox oxygen therapy, which was described as a barrier that made them feel isolated (U)
Illustration	"I couldn't breastfeed her or hold her or do anything for her I mean I was anxious and stressed out and I needed to feel Stacey close to me....When Stacey was on the high-flow system she was able to be held. I had felt so useless when she was in the box [headbox] as I could hardly do anything for her. It was horrible. She was still incredibly sick yet I knew that she needed me to hold her. It felt so much more natural to be able to hold her again. I was a proper mother again." Pg 221
Finding	All mothers felt unable to assist their child in any constructive way and described this as either feeling helpless or having no control (U)
Illustration	"I didn't feel that I was being a good mother because a good mother would have been able to comfort her child when her child needed her. I felt inadequate, more than useless. I just cried from frustration a lot of the time as I was not able to touch her. It wasn't the natural thing to do. Who would normally sit by and watch their child suffer without feeling devastated? I had no way of knowing how long she would be there or if she would get better or worse. Not being medical made it further isolating." Pg 222
Finding	All mothers agreed that it is instinctive to want to hold their child close to comfort and care for them. They wanted to not only be involved in their child's care but have their child physically close to them (U)
Illustration	"I needed her to feel my heart beat and for her to know that her mother was near and loved her. She was so isolated from me. It was really, really awful." Pg 222
Finding	Participants were unified in their perception that high-flow nasal prong oxygen therapy provided a more positive method of treating the children (U)
Illustration	All mothers stated that when their child received the high-flow nasal oxygen therapy, they were able to be involved with their child's care and described the joy of being able to hold their child again, which helped to relieve their stress. Pg 223

(44)Watson R, Castleden H, Masuda J, King M, Stewart M. Identifying gaps in asthma education, health promotion, and social support for Mi'kmaq families in Unama'ki (Cape Breton), Nova Scotia, Canada. Preventing chronic disease. 2012;9:E139.	
Finding	Virtually all caregivers were aware of asthma triggers specific to their children and had developed strategies for avoiding them (U)
Illustration	"We got this house...because [my son has] asthma...our last house we lived in had mold in the basement and it was causing him to get really sick." Pg 4
Finding	Some caregivers used strategies that were developed on the basis of trial and error representing years of asthma management, others worked closely with their doctors to minimise the occurrence of asthma attacks (U)
Illustration	"[My daughter's] asthma is induced by exercise. During her games she takes her inhalers when she gets sick. But we have learned this year to take the inhaler half an hour before the game and then play. This reduced her chance of getting an attack. That's what the doctor told us to do." Pg 4
Finding	Caregivers reported a lack of community-level asthma support resources (U)
Illustration	"Right now there is nothing. I never even heard of anything outside the community." Pg 5
Finding	Caregivers indicated that language barriers were contributing to existing asthma support gaps (U)
Illustration	"My kids are fluent in [our Aboriginal language]…and my youngest one, he is more comfortable speaking [our language] than English, so a lot of times there's that barrier of understanding." Pg 5
Finding	Caregivers rely on family members to provide them with the support they need to manage the demands of raising a child with asthma. Often these family members have direct experience raising their own child with asthma (U)
Illustration	"When [my children] are having an attack, it is really hard watching them suffering. Talking helps me cope. I have a really good support network with my sisters and my mother, family, and friends….you just don't feel so alone and my sisters, 2 of them have kids with asthma, so it helps talking to them because they know what you're going through." Pg 5
Finding	Many caregivers identified the need for increased information and educational resources (U)
Illustration	"My biggest wish is…if every health centre in [our region] would take 1 person and really seriously train them on this topic. So then they could pass on the information to the parents. Because a lot of the parents don't have the proper information or they are not sure how to give the medication. That's all I wish for." Pg 5
Finding	Although doctors are acknowledged as asthma support providers, many caregivers feel they would benefit from additional education (U)
Illustration	"The doctor, like all she ever did was give him inhalers. That's it. No information. I really don't know anything about asthma right now." Pg 5
Finding	Not only did caregivers want asthma education for themselves and their children; they also wanted the community to be better informed. Caregivers considered community education and provision of resources that promote community-wide understanding of asthma a priority (U)

Illustration	"When she came back, she was coughing, and her clothes smelled like smoke because the person who drove them was smoking in the car with them." Pg 5
Finding	Caregivers also expressed a strong desire for support groups in their community (U)
Illustration	"We need support groups….I really don't have anybody else to go [to] other than my doctor." Pg 5
Finding	Caregivers voiced concerns about a lack of asthma-friendly school policies (U)
Illustration	"My daughter's old school didn't want her to take [her inhaler]. They thought that she would get addicted to it. Teachers don't like your child to take it when they need it, only when they feel that the child should take it." Pg 6
(45)Gibson-Scipio W, Krouse HJ. Goals, beliefs, and concerns of urban caregivers of middle and older adolescents with asthma. Journal of Asthma. 2013 Apr;50(3):242-9.	
Finding	Caregivers identified goals that related to the desire for the adolescents to become more independent and responsible for controlling their asthma. (U)
Illustration	"I think moving towards them being more independent with more self management. You know that you're not going to be there all the time and if something happens you're not (the teen) going to be ready." Pg 245
Finding	Caregivers wanted their teens to be able to verbally express their asthma symptoms and needs to others. (U)
Illustration	"Having my children speak up. Teaching them not to be scared to say I need my inhaler or I can't breathe." Pg 245
Finding	Caregivers agreed on the need to have youth take preventive measures by avoiding triggers. (U)
Illustration	"Trying to have her watch out for triggers and especially animals because she loves animals." Pg 245
Finding	Caregivers identified strategies they had taken to help the teen take their medications. The most common strategy was the establishment of routines (U)
Illustration	"I've set a routine when my son gets up in the morning. Generally I tell him to take a shower and immediately use his inhaler that way I know he's done it before he goes out the door. And then after hopefully he's good for the day but if not he's got an extra one in his pocket that goes to school with him or in his backpack just in case. I just keep my son's medication in the cabinet next to the toothpaste so he brushes his teeth, he takes his medicine. He doesn't have to take it during the day. That's not an issue." Pg 245
Finding	Caregivers sought to maintain continuity of care for their adolescent through relationships with medical providers and pharmacist. (U)
Illustration	"We don't go regularly but we keep the same provider, so that she's come to know her over the years. She knows when I call her I can get in that same day." Pg 245
Finding	Caregivers developed goals for having an adequate supply of medication available. (U)
Illustration	"We make sure that we have enough medicine. We always have at least one extra one so before you start on your last one, get the new one." Pg 245
Finding	Involving the family as a support system for their adolescent, especially as it related to medication management (U)
Illustration	"Besides the rescue inhaler she's not taking her other medicine properly, and we as a family need to get on her about that because she will wait until it happen and you know, it gets out of whack. Yeah, so we as a family have to get on her and watch her because

	she’s 16 but she knows what she’s supposed to do and she just don’t do it. They need to know how important it is for her to, and for us, to keep on her about taking that medicine. So, yeah, that’s a goal of mine." Pg 246
Finding	Caregivers shared concerns and general health goals for their teens regarding exercise, other activities, diet and maintaining a healthy weight. (U)
Illustration	"The biggest thing with my son would be the weight gain due to the steroids so initially he put on a lot of weight and we really had to keep after him not to over eat, try to be active and things like that." Pg 246
Finding	Another caregiver wanted her teen to know his limitations with exercise (U)
Illustration	"Not to overdo it when he’s doing his exercising and then they already know like, at the school that he has asthma. So if it gets bad they already know that. But I just tell him to take his time and don’t overdo it as he’s doing his exercises." Pg 246
Finding	Caregivers used other activities to improve their adolescents’ asthma. (U)
Illustration	"I had my niece start playing trumpet to help. I thought it would help her control her breathing with the asthma." Pg 246
Finding	Caregivers agreed on general goals around environmental controls. (U)
Illustration	"I just try to make sure the air quality in the house has no smoke. Like I smoke, but I don’t smoke in the house. I don’t allow anybody to smoke in the house, in the car, you know,, because of her." Pg 246
Finding	Practices regarding use of cleaning products (U)
Illustration	"My house is carpet free and we wash blankets and pillows every week. Everything in the room that they lay on gets washed"…."We don’t use spray for household cleaning we use oil, and it keeps her breathing better" "….I noticed when I had those oil scents that you put in a little container that seemed to make it worse." Pg 246
Finding	Caregivers shared several common beliefs about their teen's asthma such as a decline in symptoms of childhood asthma as the person grew older. (U)
Illustration	"Well, like I said, my daughter’s growing out of it, really she is. She’s actually gotten better." Pg 246
Finding	Perceived effects of exercise on asthma symptoms (U)
Illustration	"My teen he does pretty good with his asthma at exercising with his asthma it’s like the more he exercises it’s getting better." Pg 246
Finding	Caregiver concerns related to medication dependency and adverse side effects (C)
Illustration	"Once my son became diagnosed with asthma he started getting much bigger…but what I had to explain to him was that he has to take medication. I say medications can help you in one sense and they can hurt you in another." Pg 247
Finding	Directing their teens to do whatever was necessary to gain access to their asthma medications, even if it meant getting into trouble at school (U)
Illustration	"What I’ve told my daughter is if something like that were to happen where somebody’s not letting you go get your medicine, go get is anyway, and I’ll take that up with the teacher, after she gets in trouble"…."I found face-to-face works better than a letter." Pg 247
Finding	Caregivers were concerned that in their absence, teens needed to know how to respond to an asthma'crisis' and that if they did not respond themselves, others might take inappropriate actions that were unwarranted (U)

Illustration	"For my goal is to make sure that she knows how to manage during a crisis because I can't trust other people to be there to know what to do. I'm afraid that they will want to right away use the epi-pen, which may not be the most appropriate thing at that moment." Pg 245
Finding	Beliefs about their teen's asthma (U)
Illustration	"My daughter she gets bad during the time of the month when her hormones are off balance." Pg 246
Finding	School officials, administrators, teachers and coaches were perceived as having a lack of knowledge about the seriousness of these acute symptoms for the adolescent (U)
Illustration	"We have a form that's filled out and signed by a doctor also, saying that a child can carry their inhalers on them. But what I've noticed is the people that work in schools...do not think asthma is serious. Asthma is serious, it kills." Pg 247
Finding	Caregivers were concerned about the schools' ineffectiveness in readily communicating important information on medical forms to permanent staff and substitute teachers (U)
Illustration	"I think she's right because we fill out those forms. They send forms, written forms that you have to fill out about their asthma and I don't know if it is just sent back to the secretary and it's not communicated to all the teachers or what, but there is a problem." Pg 247
Finding	Lack of knowledge among staff on the variations in presenting symptoms that a teen might experience during an asthma exacerbation (U)
Illustration	"It's like they all got different triggers, with all different symptoms. They don't all wheeze, they don't all get tightness of the chest." Pg 247
Finding	Lack of credibility given to their teens when reporting acute asthma symptoms (U)
Illustration	"Well my daughter says I need my inhaler...well they're not going to let you go to the locker room to get it or wherever it is. The problem is they won't believe the child." Pg 247
Finding	Caregivers shared experiences related to problems with teens accessing rescue medications during an asthma attack at school (C)
Illustration	"I'm a former substitute teacher, and I have a big concern because a lot of the schools will say, we have to keep the medication and lock it up, and then you have a teacher or assistant teacher who do not believe the child...you know is aware of what's happening in their own body." Pg 247
Finding	One caregiver tried role playing to influence her teen's behavior (U)
Illustration	"I lead by example. She sees mine (asthma inhaler) in my purse and she doesn't see me using it all the time but because she sees it in my purse she's like 'oh okay, so you have it on you.' Kids are recorders she's using exactly what I do so that she'll have it case she needs it as well." Pg 245
Finding	Caregivers advocated on behalf of their adolescent children through actions directed at the school's administrative level to develop and implement policies aimed at improving asthma management during school hours (U)
Illustration	"I actually had to send a letter to the school...so that was how I had to communicate with them. I had to get the doctor to write a letter so they'll let her take her inhalers when she's having an attack"..."I actually did an asthma action plan with the nurse practitioner. We did asthma action plans for the schools, and so when I went up there and I made

	sure all the teachers had it in the office, and I explained it in detail." Pg 247
Finding	Strategies to resolve questions about medication (U)
Illustration	"But you know what you can always call the pharmacist and if they're closed you can always call emergency they never close. You can just ask to speak to a nurse, and they can tell you better." Pg 247
(46)Santati S, Ratinhorn A, Christian B. Parents' experiences in asthma attack prevention: struggling to take control. Thai Journal of Nursing Research. 2003;7(3):186-98.	
Finding	Parents experienced early symptoms of asthma and tried to find the meaning for these unexplained symptoms of their children (U)
Illustration	"At first she complained that she felt tired. She couldn't climb up the stairs. She complained all time that she felt tired. I don't know what happened to her. She said that she could not breathe. At the first time, I thought she was pretending." Pg 189
Finding	Parents felt more anxious and frustrated, so they tried to seek help from someone they believed in order to get a specific diagnosis and proper treatments (C)
Illustration	"The doctor said there was something wrong in her lung and sent her to take a chest x-rays at…hospital. The doctor at that hospital said there was nothing wrong in her lung….might be because she was sick so she would have rapid breathing. The doctor couldn't tell my daughter's diagnosis because her chest film was normal. Her symptoms were off and on all the time. I brought her to get some treatments every time whenever she had a symptom. When she had difficulty breathing, I would bring her to the hospital. It seemed to be a cycle like this…got some oral medication but didn't know what was wrong." Pg 190
Finding	Parents tried to shop around to find a second opinion and better treatments. (U)
Illustration	"My daughter was admitted to the hospital several times in 2-3 months because of pneumonia. She had severe cough especially at night. No one could sleep. The doctor still didn't know what happened. He said it was from psychiatric problem. I didn't know how to do…so I brought her to another hospital. I thought there was something wrong with her nerve. Nurse who worked at that hospital said there was no clinic on that day and sent me to another hospital. I didn't know at that time where to go. One of my friends suggested me (…) hospital. I could bring my daughter to every hospital if there was some expert in taking care of these kinds of symptoms. My daughter had got bronchoscope that time, but the doctor still found nothing." Pg 190
Finding	The parents believed that hospitals in the cities or private hospitals could provide modern and effective treatments but it needed much money and accessing (U)
Illustration	"My daughter couldn't breathe. She had got convulsions and cyanosis. My mother sent her to the hospital nearby. She needed admission and followed up several times but there was nothing better. I needed referral to this…hospital because this hospital had modern technologies and drugs. In my hometown hospital, there was no medicine like this. I went here several times to consult nurses and doctors. I wanted to know what I could do if I wanted to refer my daughter to this hospital. One of my neighbors – her son had symptoms liked my son. She had no money so she couldn't bring her son here." Pg 191
Finding	Receiving an asthma diagnosis made some parent feel relief because they knew that it was not as dangerous as they had thought before. (U)

Illustration	"I am afraid that her disease couldn't be cured. Did the doctor treat her correctly? I am afraid she would die. When my daughter had convulsions, I thought she couldn't survive. I cried. I had only one daughter. The doctor didn't give exact diagnosis until now. When I knew that she had asthma, I felt relief and when I knew that asthma could be cured, I was so glad." Pg 191
Finding	Once the diagnosis was made, parents described high expectations created by healthcare providers (U)
Illustration	"The doctor said my daughters had asthma and needed percussion. I gave them percussion like this (she showed how she did percussion) hit…hit…at their chest wall. The more I hit, the more they coughed and got dyspnea. I had to do it. I hit until they felt a lot of pain…no one taught me how to do percussion. I did like this because I saw nurse at treatment room did like this with my daughters. I knew later that if they coughed, I had just vibrated upon their chest and encouraged them to spit the secretions out. I couldn't hit during coughing period because it would induce severe cough." Pg 191
Finding	Because they received insufficient or unsuitable information, the parents mastered what was effective and what was not by trial and error. (U)
Illustration	"The doctor said my child needed inhaled bronchodilator every 1-2 hours when she had asthma attack. If symptoms weren't better, I had to bring her to hospital. Because I had nebulizer machine at home, so one time that she had asthma attack, I tried to give her inhaled bronchodilator every 4 hours all night. She didn't feel better. I brought her to the hospital in the next morning. Her symptoms were worsening and she needed hospitalisations. I had to remember…didn't do this again." Pg 192
Finding	All mothers in this study had to manage the asthma alone. In addition to maintaining household activities and their office work, they also had to accommodate the added role of asthma manager (C)
Illustration	"When my 2 daughters got asthma attack. I had to give them nebulized bronchodilator every morning. The nebulizer machine worked for about 20 minutes and then cut off. When it cut off, I had to wait for another 30 minutes to get it operated again. I had no time to wait that long because I had to go to work. I had to give same medication to my second daughter. The doctor ordered 3 times a day – in the morning, noon, evening – not 1 time a day. When I finished with my 2nd daughter, it was almost 12am. I had to start with my 1st daughter again liked a cycle. On Saturday and Sunday, I didn't do anything except these. I had to do chest percussion right after that….I had no time at all." Pg 192
Finding	About environmental control, parents acknowledged the importance of it because it could be a trigger to cause an asthma attack (U)
Illustration	"About dog and cat, we still had a dog because everyone in our house said it lived separately from us. They didn't see how it would contact us….so we couldn't solve this problem. But for cat, we had to give away. We didn't want to do it, but we had to because the doctor asked if we wanted to take care of our daughters or cat?" Pg 192
Finding	Because no other family members helped the mothers, they left all the responsibilities to mothers. Lack of support from healthcare providers and family members increased the stress of the mothers, and, in turn, affected the children's and family's life (U)

Illustration	"No one could bring my son to hospital. They always said they couldn't communicate with doctor. I was the only one who knew everything about my daughter's symptoms, all treatments, and her medications so I had to do this. My husband had to work and couldn't desert his work so I had to manage by myself. When my child got worsen, the doctor gave him an appointment during the month that I was sick so I didn't have any day off left…I was so stressed." Pg 193
Finding	Asthma treatments affected both parents and children. (C)
Illustration	"My emotion affected my child. Whenever I yelled, she would cry. Whenever she cried, she would have bronchospasm. She couldn't breathe got dyspnea and then had asthma attacked. I tried not to yell or hit her." Pg 193
Finding	Even though all these matters affected the lives of both parents and children, parents did not give up. (U)
Illustration	"Because I cared and loved him. Sometime I couldn't resist. If I'd got asthma instead of him, I would. I could handle and could do this, but my son was still young. Sometimes he resisted some treatments such as nebulized bronchodilator. OK. Sometimes he could do it 100%, but sometime only 60%, 80% sometime I felt angry and wanted to give up. I just gave up only for a while and then I had to go back and took care of him again. I really cared about him. I said that I wanted to get asthma instead of you." Pg 193
Finding	The ones who succeeded with modern treatment, continued to use it, but the ones who did not, tried to use alternative methods to accommodate their prevention and child health (U)
Illustration	"My daughter's symptoms had got better since I used natural therapy. I used natural therapy because my daughters took a lot of drugs. They got a lot of steroids since they were 1 year of age. Steroid had some effect with children's health, I knew…the doctor gave several kinds of drug…this drug…that drug. Sometimes I thought the doctor try to do drug experiment on my daughters. My daughters got steroids for a year. Finally, the doctor gave her 3 tabs. When the doctor gave 3 tabs…one of my daughter had edema over all of her body and face. My elder sister said she asked a doctor about steroid. The doctor told her that steroids would cause body fluid overloaded and kidney couldn't secrete. I was afraid, so I started to drop out steroid drug. You know now, I don't give any drugs to my daughters. When doctor asked…I told him I still used them all. Natural therapy, yoga, meditation would help promote body immunity. If they had strong body immunity, all systems would work normally." Pg 194
Finding	Most of them still preferred to hand over control to professionals and modern treatments when their children were having acute asthma attack (U)
Illustration	"Even though I gave up all medications that doctor ordered, I still come to hospital to follow up…because I thought they could help when my daughters had asthma attack." Pg 194
(47) Samuels-Kalow M, Rhodes K, Uspal J, Reyes Smith A, Hardy E, Mollen C. Unmet Needs at the Time of Emergency Department Discharge. Academic Emergency Medicine. 2016;23(3):279-87.	
Finding	Desire for lay language and simplified terms. Parents reported feeling uncomfortable with medical terminology and how that led to leaving the ED without full comprehension (U)

Illustration	"They'll give you a printout at the end of the day when you leave about what happened with the visit. But I know a lot of times I'll go home and Google because I really didn't understand like what that meant….what it really mean in layman's terms…for me it would be more helpful if it was already written in those terms, in just like general speaking terms." Pg 283
Finding	Parents emphasized the importance of written information (U)
Illustration	"I think legally you have to put all this stuff down, but like if you give us just our own separate page just for us as parents, like especially me. I'm working, I'm tired, and then I'm trying to go back to school, but it's just like I don't need a whole lot of pressure, like oh I have to read this or I'm a bad parent because I don't know what I'm talking about." Pg 284
Finding	Parents emphasized the importance of demonstration of medication administration and dosing (U)
Illustration	"Actually show me, so that way I know exactly everything instead of me, you know, guessing or assuming…I had to give him 5.2mls, and the-what is it called- the medicine tube thing, it only had 5mls on there, so like I didn't know like where the two point was at, like 5.2. So if someone would have showed me like this is where 5.2 is. I would know." Pg 283
Finding	Parents reported a desire for more information from ED providers (U)
Illustration	"I want them to pretty much be more detailed about stuff, letting me know what's going on, just don't go out there and talk, it's my child. Let me know what's going on, too." Pg 283
Finding	Parents emphasized the importance of protected time and space for discharge communication (U)
Illustration	"If we could have just like a room right before we leave, like a nice little room where it's quiet and he's treated and everything, and we could just actually sit down and just talk with our physician and our nurse, like what can we do to like make sure this doesn't happen again, and there's no distraction." Pg 284
Finding	Information inconsistency was mentioned frequently by parents with limited literacy (U)
Illustration	"I actually think the box instructions is pretty much always different from what the doctor say do….a lot of times when he's discharged, I'll follow up with his doctor and it's different instructions of when to come back and it kind of get-a lot of times it gets like this tug of war between emergency and his regular primary care, when to go to either place, so I don't really know." Pg 283
Finding	Concerns about being judged by providers (C)
Illustration	"Some people, they just don't want to ask questions because they don't want to feel like they're being like a bother or a pest." Pg 284
(48) MacDonald H. 'Mastering uncertainty:' mothering the child with asthma. Paediatric nursing. 1996;22(1):55-9.	
Finding	Mothers sought information from multiple sources including books, nurses, and physicians. However, they did not always get the information they needed (U)
Illustration	"I found the nurses up there very kind and understanding. I found them supportive but they did not teach me about asthma and I needed to know. I educated myself." Pg 3
Finding	As symptoms persisted, the mothers became more and more vigilant (C)

Illustration	"…I'm just watching for the minute he gets wheezy." Pg 3
Finding	The decision of when to go for help was a difficult decision at first (C)
Illustration	"You learn to trust your instinct….If you're worried then go." Pg 3
Finding	The fear experienced by these mothers was great. There was fear related to the responsibility of caring for an ill child (U)
Illustration	"so he came home and that was really scary too, you know, because all of a sudden the responsibility of caring for an ill child was overwhelming." Pg 3
Finding	The often unpredictable symptom pattern heightened the feelings of uncertainty (U)
Illustration	"asthma is changing and the child's condition isn't always the same either. And with asthma, that's another thing, it's so unpredictable and there are so many factors that can cause an attack. It's a very frustrating disease because you just do not know and what might be a trigger to one child isn't for another." Pg 3
Finding	Mothers shared how monotonous and confining the day-to-day treatments were (U)
Illustration	"the compliance thing is real tough, it's a daily ongoing thing. You know that you have to do it because that's what is going to prevent him from being sick. You have to just stick with it day in and day out." Pg 4
Finding	Fatigue was constant and influenced many of the mother-healthcare professional interactions (U)
Illustration	"The healthcare team sees me at my worst, after Ive been up all night with a sick child, and they expect me to be sane and rational." Pg 4
Finding	There was an expectation that because she was staying with her child in the hospital, that she should monitor her child and administer any treatments (U)
Illustration	"It was scary and I was exhausted and I sat and I held him the whole night. I was so afraid because he couldn't go an hour and I'd have to ring for the nurse and she would bring me another aerosol." Pg 4
Finding	Mothers learned a way of communicating with the healthcare system that was not always positive. This communication was viewed positively by the mothers since it allowed them feelings of control and it served to allay fears (U)
Illustration	"I have learned to play the system. I fear being left in the emergency department with my sick child so I tell them he is cyanotic or unconscious and I get immediate attention." Pg 4
Finding	The mothers spoke of how they wanted to be considered a member of the healthcare team but that efforts to fulfill this desire were not always welcomed. The mothers were appreciative when their knowledge level, daily experiences, and daily monitoring were recognized (U)
Illustration	"He discussed it with me knowing that I had some knowledge….it was kind of a joint decision to put him on Intal. That was a new experience – one gets used to just going to the doctor and being the patient. It was nice to be acknowledged." Pg 4
Finding	Fear for their child's life (U)
Illustration	"I think the scary part is that you know that people die from this disease and when I look back and remember seeing my child barely breathing..." Pg 3
Finding	Not knowing what to do was another fear (C)
Illustration	"sometimes when you are sent home from the hospital before you feel your child is ready...you feel like you're being throw out into the murky dark." Pg 3

Finding	They were terrified by any suggestion of changing their child's treatment (U)
Illustration	"I'd be too terrified to take him off his medication and just try an alternative because you know, breathing is life, life and death. I feel totally dependent on this machine and this medication." Pg 4
Finding	Mothers felt that they were being labelled as demanding and obtrusive (U)
Illustration	One mother recounted how in an attempt to be assertive she suggested having her child discharged to home care. The response she received "if we send you home on home care the next thing you will want is meals on wheels." Pg 5
(49) Rydstrom I, Dalheim-Englund AC, Segesten K, Rasmussen BH. Relations governed by uncertainty: part of life of families of a child with asthma. Journal of paediatric nursing. 2004 Apr;19(2):85-94.	
Finding	Mothers of a child with asthma consider themselves as controllers and the child thereby feels as though he or she is being controlled (U)
Illustration	"Well, you go sneaking in her toilet bag, I do so if it isn't opened and then I know that she hasn't taken her medicine, and you have to control, you can't just bother about it….I would be happy to get rid of this." Pg 88
Finding	The mother at time diminishes the control (U)
Illustration	"Sometimes you have to dare, otherwise the child's daily life will be too restricted…..Sometimes you feel that you tempt fate, but in the same time you feel, are you going to isolate the child, are you really? It has turned out well so many times. It is awful to say so, one day it may not turn out as well." Pg 89
Finding	There are tight bonds between the mother and child with asthma (U)
Illustration	"The relationship is a little bit different. Because of the child's disease I had to stay with him at the hospital a great deal of time, in these small isolation rooms….You learn to know this child in another way. It (the relationship) becomes closer; it will be a little bit different. You try not to have it in this way, but it still becomes different." Pg 89
Finding	Both are longing for a relationship that is like the one between a mother and a healthy child, as well as a life with fewer restraints (U)
Illustration	"Me and Anne would like to be like a normal mother and a healthy child, able to do what others do." Pg 89
Finding	The mothers' engagement in the care of the sick child affects the relations to the healthy sibling. The mothers are not at hand for the healthy child, and the child feels left out (U)
Illustration	"….and you can feel he comes a little, well, he brushes his teeth and he washes and puts on his pyjamas, and then he's ready, it's so simple. Yes, the others, you have to listen to their breathing, they shall blow their peak flow, they have to be rubbed with ointment and get their medication, but you can feel, that he sometimes wishes that his mother also sat down and rubbed him…." Pg 89
Finding	Lack of understanding between the mothers and the fathers is also described. The mothers take the greatest responsibility for care of the sick child and feel that the fathers do not understand how laborious and hard this can be (U)
Illustration	"I have shouldered the responsibility myself, I mean if you get a child with a disease, both parents are jointly responsible. After all, you should raise claims on the father, you should just stand there beside the table and say "It's your child too"." Pg 90
Finding	Relations between mother and friends often are disturbed because of the friend's lack of

	understanding of the child's disease (U)
Illustration	"Our best friends bought a dog without asking us….it's very hard. We used to stay the nights at their place, celebrate Christmas and birthdays together since we are relatives, and I don't understand how they think, they say we are their best friends who always stand by. Well, sometimes one starts wondering." Pg 91
Finding	The mothers and the fathers have problems with spending time together. Living with a child with asthma reduces the time they have for each other (U)
Illustration	"We don't have time for each other, we don't do anything together, and we are never going anywhere." Pg 90
Finding	In an asthma family it is sometimes difficult to understand the expectations and needs of the other. Sometimes it is hard for the healthy child to understand the mothers' laborious situation (U)
Illustration	"He gets less time, he gets less attention.......This is really very sad, but it is like this. And I think it is wrong, I think it is a serious fault, because, the healthy child, he is healthy and it is wonderful that he is, but the healthy child can't understand and he thinks it is wrong, and I agree it is wrong, and he has to live with this." Pg 90
(50) Ungar WJ, MacDonald T, Cousins M. Better Breathing or Better Living? A Qualitative Analysis of the Impact of Asthma Medication Acquisition on Standard of Living and Quality of Life in Low-income Families of Children with Asthma. Journal of Paediatric Healthcare. 2005 Nov-Dec;19(6):354-62.	
Finding	Although parents believed the prescribed asthma medications were expensive, they understood and accepted the importance of maintaining a proper asthma medication regimen (C)
Illustration	"We've always dealt with the XY drugstore and when my husband went through that recession thing, of course the place he was at weren't paying their drug plan, so we ended up owing the pharmacy like, $1500 bucks through all this." Pg 357
Finding	Given that these drugs were necessary and perceived to be the "only option," parents believed that the monthly asthma drug expenditure was "money well spent" and represented good value (U)
Illustration	"I'd pay anything for him to be comfortable….to say that I'm not getting value for my money, I mean, of course I'm getting value for my money because it's helping him with his asthma….it is doing the job, but it is pricey." "I think a kid's medication is more important than your own interests, right?" Pg 357
Finding	Respondents believed that they had no choice but to pay for the drugs or their children would suffer. Parents expressed a sense of helplessness regarding getting financial help to cover drug costs (U)
Illustration	"There's totally no choice involved. If you have a child you have to get that medication whether you have to rob a bank to do so. You have to get that medication." Pg 358
Finding	A few parents indicated that when they were short of funds and two prescriptions were needed, they would purchase only one of the two prescribed medications (U)
Illustration	"Sometimes I buy Ventolin only because the money's short….it helps the most immediately." Pg 359
Finding	A common theme identified by all parents was the negative impact on their standard of living compared with families with drug plans. Parents reported being stretched

	financially each month because of asthma medication purchases (U)
Illustration	"I can't afford to get anything that isn't absolutely necessary….we haven't been able to get his eyeglasses because we haven't got the money….he's wearing his old glasses right now….because I have not been able to replace them….no birthday presents….holes in socks....no piano lessons…no money to help our daughter with university….no holidays." Pg 359
Finding	Interviewees believed that government programs should pay for at least a portion of their drug costs (U)
Illustration	"I would like the government to supply medication for everyone….especially the ones who need it." Pg 360
(51)Trollvik A, Severinsson E. Parents' experiences of asthma: Process from chaos to coping. Nursing & health sciences. 2004 Jun;6(2):93-9.	
Finding	Parents reported several episodes of being afraid of what could happen if their child was unable to breathe properly. The child might wake up in the middle of the night, and the parents would sit at the bedside not knowing what to do. They described feelings of uncertainty, helplessness and being alone (C)
Illustration	"I was never at ease with my son's illness, and I'm still not. I think it is frightening, and I believe it is important to get an answer to all my questions….I have never slept well since my son's first asthma attack….I wake up at the drop of a needle….I felt so anxious about him when he developed asthma, I was afraid that he would not survive an attack. It was awful, I felt like this every time he had a severe attack….Those times I remember as a nightmare. The first time he had a severe attack it was terrible, I get a pain in my stomach when I think about it. I try to forget it." Pg 95
Finding	Some parents reported seeking a deeper understanding of why their child became ill (C)
Illustration	"I was shocked when my child took ill. I was so sad because I myself suffer from allergies. I found it so depressing that she developed the same disease. It's fine that they can inherit money or houses from us, but not the bad things like illness." Pg 95
Finding	For a number of children, asthma is not a clearly defined illness. At the onset of the illness, parents revealed that they had been to the acute clinic several times without receiving help (C)
Illustration	"We saw the physician he examined her, but could find nothing wrong. We were sent home and he told me I was hysterical because I argued too much. I consider it wrong that my daughter, who was 2 years old at the time, cried because she longed to play with other children, something she was unable to do. I felt something was wrong, as she often had a high temperature and was always tired. However, the physician did not believe me." Pg 96
Finding	Some parents reported a lack of respect on the part of healthcare professionals, who trusted neither in the parents' competence as parents or their assessment of the situation (U)
Illustration	"We were advised to call the hospital when our child started wheezing. There [in the emergency unit] we met a physician who knew nothing about asthma and didn't listen to us parents. After that I lost my respect for physicians. We know more about our child than a physician who meets him once a year." Pg 96
Finding	The child's illness represents a turning point in the family's life. Parents reported a

	change in their life perspective (U)
Illustration	"We had planned to have another child, a baby, but we are so afraid of having another child with asthma. I do not want to go through the same suffering again, now when our child is better able to cope. Therefore we will not have any more children." Pg 96
Finding	When parents use the trying out strategy, they learn new things about managing their child's asthma. They can try out medicine or treatment, what they should avoid or can participate in, or what the child is able to manage in terms of allergens (U)
Illustration	"We have learnt something important; to try out medicine. We had to carry our daughter in a rucksack when walking in the mountains. We were not in the habit of giving her medicine before walking. One day we gave her medicine before we went to the mountains. She walked in front of us. The day after, we did not give her any medicine and we had to carry her. The third day we gave her the medicine again, she ran in front of us." Pg 97
Finding	Even healthcare professionals have different opinions and parents reported that they received insufficient information from them. This prompted parents to seek information about the disease themselves (U)
Illustration	"I need to get an answer to all my stupid questions." Pg 97
(52)Shaw MR, Oneal G. Living on the edge of asthma: A grounded theory exploration. Journal for Specialists in Paediatric Nursing. 2014 Oct;19(4):296-307.	
Finding	Living on the edge of asthma is a constant balancing act that affects the entire family as well as the child with the asthma diagnosis (U)
Illustration	"So she was kind of always on the edge of asthma, she gets sick, all these things just push her over." Pg 299
Finding	Balancing is how families manoeuvered through the asthma experience with their child prior to the final decision to seek immediate medical care through a hospital or ED visit (C)
Illustration	"So whenever he gets a cold, it triggers the asthma and it usually shows itself through the coughing. And so then he does the abuterol inhaler, and then, um it just was not helping. Um, he was just having, not so much wheezing but just it’s an asthma cough." Pg 300
Finding	Families described how prior asthma experiences helped them notice the difference between an asthma flare and what may turn into an emergent asthma attack (C)
Illustration	"So a little history on her, so she’s had asthma attacks, what I call an asthma attack, where she has trouble breathing and I can hear wheezing and I start noticing retracting. Like if she starts to become a little compromised and I can feel retracting, then I know she’s having some issues. Normally I can get through." Pg 300
Finding	Personal experiences strongly affected the parents’ and caregivers’ actions and assessments of their child’s asthma (C)
Illustration	I have exercise-induced asthma, so I'm able to relate to a lot of it." Pg 300
Finding	Making judgment refers to the part of the balancing process where families begin to question the severity of the acute attack (U)
Illustration	"You just don’t know, you just think, oh, they’re sick and then they’ll get better, you know? But you wait three days and it’s too long, and you don’t think as a parent, oh three days my child could be dead." Pg 300

Finding	Losing control can be described as the moment when the families realized that the asthma attack has become severe enough that medical attention must be sought. (U)
Illustration	All of the families shared detailed accounts of when they knew they could no longer wait it out or try and balance the situation. At this point the asthma attack was described as full blown and going over the edge. Pg 300
Finding	Fear was integrated deeply in this part of the process of losing control (U)
Illustration	"She started coughing, started crying a little bit. And I couldn't get her to focus and get control and I got really worried. It just wasn't subsiding at all." Pg 301
Finding	Families often described a struggle between wanting information and not necessarily having access or the ability to clearly articulate their needs for the information (U)
Illustration	"But, you know, even the doctors up there, um you could ask them any questions if you had one. I wouldn't have known what to ask them because I didn't know what information. I didn't have any information." Pg 301
Finding	Seeking control included actions to change the environment (U)
Illustration	"Um to finally get it under control we ended up removing both cats from the household. Um, removing the allergens because we went from him being sensitive to extremely allergic." Pg 301
Finding	Some families clearly felt empowered by the asthma action plan and knew how to follow each step without hesitation (U)
Illustration	"We have one right now and after he's had a few good months, we're going to redo, because we established that 220 was his best (peak flow) score and if it was under 120 that's an ED visit." Pg 301
Finding	While most of the families knew what an asthma action plan was, many were unclear about where it was located or how to follow the plan (U)
Illustration	"Right now, um- I'm sure there is some type of plan. I guess I don't feel totally like I get to say step one, step two, step three, but I kind of know in my head." Pg 301
Finding	Seeking control also included the concept of taking care of it. Taking care of it covers how families and children with asthma decide to accept and know asthma (U)
Illustration	"I just feel so much more prepared since having this doctor (asthma specialist), um like everything's just under control and the doctor's really following him. But up until this point, I do not feel like it was managed very appropriately. I always felt like we were just reacting instead of being proactive." Pg 301
Finding	Other's taking control was described by families as feeling a sense of reprieve or relief by having healthcare professionals take over the care of their child experiencing an acute asthma attack (U)
Illustration	"In the hospital, you know, I was a lot more comfortable with them giving him really high doses of the albuterol 'cause they could monitor his heart and make sure that he's doing okay. They seemed to get it under control and he was sleeping really comfortably." Pg 302
Finding	Transforming can be described as the point in the process where families began to absorb the new information they had been exposed to, made lifestyle changes, and proposed and implemented ideas for prevention of future asthma attacks. (U)
Illustration	"If she started, you know, turning ash, I mean there's some clear cut signs and I won't wait this time." Pg 302

Finding	Families incorporated the newly learned information into actions demonstrated through actual lifestyle changes (U)
Illustration	"When she first went back to school, the nurse was more, can she play? Can she not play? But I sent the letter to tell them the doctor was saying he wants her to go outside and play." Pg 302
Finding	Importance of repeating information to children in a way the can understand it (U)
Illustration	"The more he hears it, the more he's going to retain it because ultimately he knows what he feels." Pg 303
Finding	The difficulty with diagnosing asthma at a young age was brought up by all of the families. Many families discussed how, looking back, they now believe their child had asthma at quite a young age and how they would have liked more education on what symptoms may be associated with an asthma diagnosis (C)
Illustration	"Well, I think if people have their babies, that if they could give them a pamphlet for asthma saying, you know, you need to watch the reps (respirations) and tell them- show them how to check the reps." Pg 303
Finding	Information on accurate and easy to access online resources was also brought up as an important educational tool (U)
Illustration	"Online support groups and having those more easily accessible instead of tracking through the backwaters to find them would be helpful." Pg 303
Finding	Families also suggested providing more information about environmental factors and how they affect asthma (U)
Illustration	"We would love more information on how to be able to use a wood stove using certain precautions and purifiers." Pg 303
Finding	Siblings of the children who participated in this study often had histories of asthma or other chronic conditions and the family experiences associated with this influenced how the family currently manages the child with uncontrolled asthma (C)
Illustration	"I know what retractions are because one of my other children has had her pulmonary issues; it was just kind of like this is not, you know, normal for what's supposed to be a healthy kid." Pg 300
Finding	Point of no return means that the severe symptoms have been identified by the family and child, and there is no longer a way to help control the asthma attack (U)
Illustration	"And then she just didn't have no reserve, you know? She wouldn't drink water or juice, she wouldn't take her medicine, when I decided she needed to go (to hospital), she was very listless, and it was hard to rouse her out of more of a stupor." Pg 300
Finding	Some families chose to deny the seriousness of asthma and instead shared perceptions of not being able to do anything to prevent an attack (U)
Illustration	"He's a boy and boys go to the hospital, so I'm kind of ready for that, not much you can do to plan for that." Pg 301
Finding	Families also discussed how their children had learned from the acute asthma attack experience (U)
Illustration	"He's learned that if he would cry, it tightens up his throat and makes it worse and so he's learned to remain calm." Pg 302
Finding	Families incorporated the newly learned information into actions demonstrated through actual lifestyle changes (U)

<table>
<tr><td>Illustration</td><td>"When the boys are home or going to be home I use vinegar and, um, cornstarch instead of the cleaning chemicals. I have a plastic sheet on his bed and the pillow cover on his pillow." Pg 302</td></tr>
<tr><td colspan="2">(53)van Dellen QM, van Aalderen WM, Bindels PJ, Ory FG, Bruil J, Stronks K. Asthma beliefs among mothers and children from different ethnic origins living in Amsterdam, the Netherlands. BMC public health. 2008 Nov 3;8:380.</td></tr>
<tr><td>Finding</td><td>The majority of the mothers were uncertain about the cause of asthma. The most striking similarities among the mothers was that they seemed to know that asthma has a genetic component (U)</td></tr>
<tr><td>Illustration</td><td>"It runs in the family." Pg 4</td></tr>
<tr><td>Finding</td><td>The most commonly reported explanatory model for the aetiology of asthma held by these mothers was the rainy, damp Dutch climate (U)</td></tr>
<tr><td>Illustration</td><td>"We live in a very run-down house and because of the damp climate, the house is also very damp. This is the reason my daughter suffers from asthma." Pg 5</td></tr>
<tr><td>Finding</td><td>Many of these mothers believed that the onset of asthma was related to a particular trigger (C)</td></tr>
<tr><td>Illustration</td><td>"My child only has asthma in her father’s house." Pg 5</td></tr>
<tr><td>Finding</td><td>The majority of the Surinamese mothers had the idea that, although their children would be affected by asthma their entire lives, they could live with it and manage the disease (U)</td></tr>
<tr><td>Illustration</td><td>"If my child takes his daily medication, he can live a normal life and will have no problems in the future." Pg 6</td></tr>
<tr><td>Finding</td><td>A remarkable similarity in all mothers was the concern about the duration of the disease (C)</td></tr>
<tr><td>Illustration</td><td>"When will my child get better?" Pg 6</td></tr>
<tr><td>Finding</td><td>All participants were quite sure of the provoking triggers and the following onset of symptoms (C)</td></tr>
<tr><td>Illustration</td><td>"Thanks to my maternal instinct, I recognise the symptoms immediately. Sometimes my daughter gets stuck half-way up the stairs. I can see in her eyes that she is having a hard time." Pg 6</td></tr>
<tr><td>Finding</td><td>Mothers knew that by avoiding triggers they could reduce the risk of an asthma attack. But even with this understanding that asthma triggers should be avoided, in actual practice it appeared to be sometimes difficult to do so (U)</td></tr>
<tr><td>Illustration</td><td>"In our culture, it is bad manners to ask a guest not to smoke in the house." Pg 7</td></tr>
<tr><td>Finding</td><td>When we asked more specifically about the proper use of ICSs as maintenance therapy, all mothers, with the exception of the Surinamese, expressed reservations in some form or another. (U)</td></tr>
<tr><td>Illustration</td><td>"If my daughter does not show any signs of asthma, I can’t give her uuhh, her orange medication. I think it’s very sad for children to take daily medication when they are feeling OK." Pg 7</td></tr>
<tr><td>Finding</td><td>Dutch mothers reported performing a detailed self-assessment of the state of their childrens' asthma before deciding whether or not to administer their ICSs. (U)</td></tr>
<tr><td>Illustration</td><td>"Often I do not give my child her Seretide, because I fail to see the point of it. Treatment based on maternal instinct is still the best." Pg 7</td></tr>
</table>

Finding	Another important element in the management of asthma, according to all the mothers and children, is their relationship with their doctors. The most frequently heard reasons for being satisfied with the care were the doctor taking enough time for the visit, listening to the complaint and taking it seriously, and being easily accessible and friendly (U)
Illustration	"He only looks at his computer, instead of looking at my son. As if the computer is his patient!" Pg 8
Finding	Another reason behind their decisions to sometimes not give the medication was that the Dutch mothers also worry about long-term side effects of ICSs (U)
Illustration	The most frequently mentioned side effects, which were also mentioned as the major factor preventing mothers from giving children their ICSs, were weight gain, growth retardation and addiction Pg 7
(54) Valerio M, Cabana MD, White DF, Heidmann DM, Brown RW, Bratton SL. Understanding of asthma management: Medicaid parents' perspectives. Chest. 2006;129(3):594-601.	
Finding	Parents who either had to deal with a child who required continuous asthma care or those who had cared for a child with asthma for a longer period of time appeared to have better mastered their fears (U)
Illustration	"I'm so used to it now, I just tell him to get on his asthma machine, and just calm down and usually he's all right." Pg 596
Finding	Parents often cited feelings of nervousness, frustration, anxiety, fear, or anger concerning their child's asthma (U)
Illustration	"I get nervous, I'm still not used to it, so I run to the doctor a lot. I don't know if I'm giving too much medicine, the right medicine. You know, sometimes they treat me like I ought to know but I don't know." Pg 596
Finding	Whether or not caregivers had received asthma education, they expressed a desire for continuous educational information on medications, asthma triggers, and symptoms (U)
Illustration	"But when you say asthma treatment, it is also asthma education, you know what I'm saying? Like when you're released from the hospital someone brings over a breathing machine, says this is how you work it and goodbye, good luck! That's it!" Pg 596
Finding	Although parents have learned methods to diminish the effects of environmental triggers, they continued to experience situations that were beyond their control (U)
Illustration	"We couldn't even go to restaurants because they have part of it [where] you smoke [and] one part you can't. So no matter what, if you're in there…smoke is in the environment and the child gets sick. And [if] you complain about it, well it's not a smoke-free environment." Pg 597
Finding	The level of asthma support and knowledge at schools experienced by caregivers varied greatly, as did their experiences with institutional willingness to support children with asthma (U)
Illustration	"The problem I had like S __ said, the school leaves it up to your child to be responsible. That's a kid. You can't leave it up to them." Pg 597
Finding	Perceptions of discrimination and indifference were mentioned as issues for parents of children receiving care insured by Medicaid (U)
Illustration	"Or you are not going to get the full care that you would if you had regular insurance." Pg 598

Finding	Caregivers noted the importance of physician verbal and nonverbal communication skills. Good relationships were those in which medical providers were characterized as good listeners and educators, willing to spend time with both the caregiver and child with asthma (C)
Illustration	"I just feel that the doctor letting me know everything that I need to know that can trigger the asthma helps." Pg 598
Finding	An unanticipated issue that surfaced from parents was the need for support and age-appropriate asthma education for teenaged children (C)
Illustration	"she got older she came to me, she said "Mom, I'm tired of taking all this medicine. It's nasty, I'm just tired'" And we went through a phase where she was half taking her medications." Pg 598
Finding	An additional barrier to ensuring good asthma care for children was the limitations set on refills by insurance (U)
Illustration	Caregivers believed it would be easier to manage their child's asthma if they were able to receive multiple inhalers; one for school and another for home. Likewise, they need to be allowed to refill medications that were lost prior to the Medicaid 30-day refill cycle. Pg 597
(55)Walker VG. Minority Caregivers' Emotional Responses and Perceptions of the Emotional Responses of their Children to Asthma: Comparing Boys and Girls. Issues in mental health nursing. 2013;34(5):325-34.	
Finding	I've got your back means that caregivers were willing to do whatever was required to help their child who had asthma. This was demonstrated by minority caregivers communicating in assuring ways with their children during asthmatic crisis (U)
Illustration	"I just tell him it's going to be OK. You know, I'm here, you know, don't worry about it. You know, you're going to be ok. It'll be over before you know it." So I just keep him calm….You know, I just keep him calm, tell him, "It's, it's you know, that's my, that's my worry, so you're gonna be ok." Pg 328
Finding	Leaving their jobs at inopportune times to take care of their children when having an asthma attack (U)
Illustration	"He is the last of five. But, you know what, I don't care how busy I am, if I'm at work, taking care of somebody else, you're still important, and if you need me, I'm here. Definitely to comfort him and make sure I pay attention, first and foremost. Cause I can get very busy." Pg 328
Finding	Experiencing sleepless nights while sitting up with their children who had asthma (U)
Illustration	"We both couldn't sleep at night because it was always like, up, you know, trying to get it out, and it would never….so we'd get him back on the machine." Pg 328
Finding	Taking the blame for changing medications that appeared to exacerbate an asthma attack, even at recommendation of a physician (U)
Illustration	"But the doctor took him off twice a day and put him on once a day. You know, for the fact,that I know that doesn't work effectively, like right there, it, and we did take him off. So I'm thinking if we would have left him on, that wouldn't have happened because he's never had an attack like that, ever….So I felt that it was my fault that I said, OK, let's get off." Pg 329
Finding	You Don't need to worry was an evident subtheme and was expressed by caregivers

	taking on multiple responsibilities for the care of their children's asthma (U)
Illustration	"And I try not to, you know, let him worry about it. He's a child; he shouldn't have to worry about it. And so I try to tell him, you don't worry about it, let me worry about it." Pg 329
Finding	Lack of understanding of the school coaches concerning asthma (U)
Illustration	"[Child's name] was playing football for little league, he was kind of saying his chest hurt….these coaches do push the kids pretty hard sometimes they don't give them time to go get their meds….And I've talked to some of the parents. They said what they do; they make sure the kid has the pump on the sideline somewhere, so they can get to it." Pg 329
Finding	I'm never too busy for you was expressed by how caregivers made time in their lives to care for the asthma needs of their children. Working caregivers who took off from their jobs to care for their children during asthmatic crisis (U)
Illustration	"I'm not going to work, I'm going to take him to the doctor and he couldn't breathe. And I went to my job for a little bit, I went to my work for a little bit, and then I left. And, um, I left him with my mother, came back and he was still breathing funny so I took him into his doctor, his paediatrician." Pg 329
Finding	Caregiver could not leave work, but instructed daughter from home during asthmatic crisis (U)
Illustration	"Yeah, I'm handling it sometimes from work and you know everybody, and everybody I work (sic) knows, my daughter. They know that she has that asthma problem and I have asthma myself….And they know to leave me alone, especially when she's calling. And they know I have to take care of the problem…I'm like, and I have to talk to her on the phone, you know, "You know what the deal is. You have to calm yourself down. Why don't you get a glass of water? Sit down, sip some water, and the take deep breaths, you know, and then I'll call you back in a little while and see how you're doing." Pg 329
Finding	I'll watch over you was expressed by caregivers as they talked about long nights spent watching over their children (U)
Illustration	"….and then try to get him to fall asleep and still, even when he'd sleep, he'd wake up every 30 minutes, just, you know, coughing and, and, then us elevating him again and then trying to get him, you know, nasal sprays, and everything to try to get him to be all right and for maybe four to five nights it was like that." Pg 329
Finding	Sometimes I get scared too was a subtheme expressing caregivers' fears related to potentially losing their children due to the ill effects of asthma (U)
Illustration	"That was, you know, real scary. Because I felt like I almost lost him, like really twice. 'Cause when he was younger, he had to be in, in [name of hospital]. Same thing. Once again, I was very busy, trying to work and take care of the other kids, passing everything off as just the flu or a virus, which really had been a severe asthma attack. So it's a really big deal." Pg 329
Finding	Caregivers of daughters often stated that their daughters were required to be responsible for aspects of their asthma, such as locating their emergency inhalers (U)
Illustration	"She's at an age, where when she wakes up she feels that, she can, you know, get up and get her inhaler. "I'm like, "[female child's name], have you taken your inhaler?" And,

	you know, "No." And so I said, "Well how come you haven't taken it?" I said, "That's something that you're supposed to take every day." I said, "You know you're supposed to take your Ventolin, you're supposed to take your Singulair, you're already getting bigger, you need to learn responsibility." Pg 330
Finding	It can be embarrassing as a subtheme for children who had asthma was reported by their caregivers (U)
Illustration	"You don't want to be embarrassed to pull your pump out in front of everybody 'cause you got to get, get uh, some air. So that's one thing we have to look out for." Pg 330
Finding	Why me was one strong child subtheme that came from caregivers' perceptions of their children (U)
Illustration	"So, sometimes she's like, "Well, why can't I do this, why can't I do that, because, because of my asthma. And that's not right, that's not fair." And I'm like, there's nothing I can do about it….So, she does feel like, "Why can't I be a normal girl?" Pg 330
Finding	I get annoyed and frustrated was the way caregivers described their children responding to having to perform the daily regimen of asthma care (U)
Illustration	"He gets frustrated with me because I'm the one that stays on him about taking his medicine. You know, it's either me, or his dad. But we stay on him about taking his medicine. You know "[Child's name], don't forget your pills tonight," you know, "[Child's name]….don't forget to take your pump". And then he's, "Do I have to take my pump tonight? Do I have to? You know, things like that, so he gets frustrated with me because I am on him you know, 24/7 about his meds." Pg 331
Finding	I may get excited or anxious was a theme that was identified specific to the girls when experiencing the effects of asthma (U)
Illustration	"She gets, she's the type of child that she gets really overexcited, so therefore, you know, when she feels it's coming on. I think she just wants to…."Ok, it's happening, I know it's happening. You know, we need to go ahead and do what we need to do." So, we like, you know, "Ok, just calm down, just calm." I think she just gets like, over worked up about it." Pg 331
Finding	Caregivers described their sons as having limited verbalization regarding their experience with asthma (U)
Illustration	"No he doesn't ever tell me it's a problem to him. He doesn't, not that I've known. I just know by what I see. Um, he just tell me, the feeling, he's not feeling himself. But he doesn't ever tell me that." Pg 331
Finding	I get scared was a child subtheme described by caregivers regarding their children when experiencing asthma effects (U)
Illustration	"it's just the look in his eyes, you know. He didn't really say anything, he was quiet, you know, so, and then he couldn't breathe, so I knew something was wrong." Pg 330

(56)Yinusa-Nyahkoon LS, Cohn ES, Cortes DE, Bokhour BG. Ecological barriers and social forces in childhood asthma management: Examining routines of African American families living in the Inner city. Journal of Asthma. 2010 Sep;47(7):701-10.

Finding	Many parents report that their children who are responsible for asthma management on the school bus are also independent with medication use at home. Reasons include parental work schedules, competing priorities, beliefs that children who are independent with medication use on the school bus, should demonstrate their independence at home,

	and perceptions that children's independence with medication is a "freeing" experience (U)
Illustration	"Basically I teach her so that will be something off of me. If she knows how to do it, she could set it up herself, she could get it done, and she doesn't have to keep bothering me constantly. So that's why I taught her…Before I felt trapped, trapped by something that's not even mine. Well, in a way it is mine because it's my child, but it's not mine. I was like homebound, and I hate being homebound. I can't stand it..Now I know I can leave her, and she knows how to take her medicine." Pg 704
Finding	Several parents report that their children who attend inner-city public elementary schools are required to keep their asthma medication in the nurse's office. Yet the children do not always have timely access to their asthma medication because the nurses in these particular schools spend limited time in one school building, and when present, have multiple responsibilities within the school that draw them out of their office (U)
Illustration	"He doesn't like to take the inhaler to the nurse's office because he said, "Mommy, half of the time she ain't there....She be all over the school and Mommy I be tired. I ain't got time to be walking all over the school wheezing." Pg 705
Finding	Many parents, however, report they prefer to keep their children home when experiencing an asthma flare-up because of the limited availability of the school nurse, and the lack of knowledge and expertise other school personnel have in managing childhood asthma (U)
Illustration	"I told them she has asthma. Then I explained to them, I sat down and showed the principal, the secretary, and her teacher what to do. But I have to show them again. They don't have nurses and all that. They'll pick up a phone and call 911 before that happens. I tell them "That's all good, but by the time 911 gets there, my child could be lying on the floor"….If she is sick then I keep her out of school. Bothers her a lot, but I don't want her to be there, and like I said, they can't control it or they are calling me because when I go there I always give her Albuterol and her Flovent I don't want to put nobody in a situation where they have to call me and I'm taking thirty, thirty-five minutes to get to her because I'm so far away So I just say, "You can't go." I would rather take care of it myself and deal with it." Pg 705
Finding	In contrast, many suburban schools have full-time nurses, and a few of the parents in this study discussed the value of interacting with these nurses (U)
Illustration	"the nurse at his school is there every single day. I can faithfully depend on her to call. One day she called and said, "Tyrone came in twice today and used his inhaler. He came to my office and then he came back in less than three hours." She is very in tune, and she's really good about keeping me updated. She calls me I would say two or three times a week." Pg 705.
Finding	Many parents report that poor air quality within their inner-city homes challenge their ability to effectively manage their children's asthma. (U)
Illustration	"I leave my window open so that there is always a constant air flow that changes the air in the house. I live in a house that is not lead free. So my concerns are great in terms of not ingesting but inhaling the dust. I notice that when it is really cold and I close all the windows down, shut off the house, the next morning she seems to be triggered. So she has to have that constant circulation of what you call central air. I have been

	considering moving just in terms of the dust off Elmwood Road, which is a main artery from the construction project. In front of my building there is no what you call landscape. Everything is dirt and I try to get the landlord to do the mulch thing. He don't [sic] realize that you actually inhale the dust off it and it can affect children and adults. I have been trying to work with the help desk at the medical center to find a new location to live." Pg 705
Finding	Neighborhood violence not only limits children with asthma's time outisde and exposure to outdoor air, but their participation in physical activity (U)
Illustration	"I don't let her walk to the corner store unless I be out the window yelling, "Hurry up!"so they can hear me. They be at the liquor store talking about, "Hey baby, what's your name?" Uh-uh, been there, done that. I don't send my baby out. She don't need to be subjected to that, and I'm not going with her. I make her brother go. And I shouldn't because she needs the exercise. She needs to get her butt down the stairs, and back up the stairs, and go get whatever. That's the one thing I know I'll need to change. I'll tell him, "You stand post. All you got to do is walk to the corner and stand post. Let your little sister go in the store." Pg 706
Finding	Many parents report their homes contain mold, mice droppings, and cockroach allergens, therefore they frequently clean their home to reduce these indoor toxins, which trigger their children's asthma (U)
Illustration	"One problem that we did really have was with mice. There were a lot of mouse droppings and stuff around. And it seems like his asthma has gotten a lot worse…The mice droppings get in the strangest places. I think my bedroom closet is their public toilet. They just come in my house, crap, and leave. All the trash is outside, and there are a lot of holes. There are like big gaping holes in the foundation. The landlord was making it seem like, "Oh, what mouse problem?" My house is the hot spot. This is the little club down here. It got to the point where they were like squeaking and dancing and frolicking at night and it was scary. I'm hoping with all the vacuuming and cleaning and exterminating. I'm hoping that maybe the kids won't get as sick as they normally do." Pg 706
Finding	Many parents report they teach their young children to self-administer asthma medication because they are often on a school bus without an adult who is knowledgeable about asthma management (C)
Illustration	"He has his inhaler. He has one in his backpack, he has one at the school nurse, and he has a couple in the house. He knows when he needs it. I tell him, he knows when he needs it. He knows how to do it if his asthma is really acting up." Pg 704
(57) Bellin MH, Land C, Newsome A, Kub J, Mudd SS, Bollinger ME, et al. Caregiver perception of asthma management of children in the context of poverty. Journal of Asthma. 2017 Feb;54(2):162-72.	
Finding	Monitoring their child's asthma symptoms and contexts that raise alarm for an exacerbation is an ever-present and demanding responsibility (U)
Illustration	"I tend to pay attention to my outer surroundings. And certain surroundings put my antenna up. So, I'm watching her and I'm watching the way she breathes and the way she's coughing. But with us, it has a lot to do with our surroundings, where we're at…you have to watch her, know their every schedule, know certain things, when

	something's wrong." Pg 4
Finding	The challenges of differentiating asthma symptoms from other health concerns (U)
Illustration	"When she gets sick…I can't really tell is it a cold, or is it her asthma kicking in? So it's like I [am] trying to treat both things. Because it really acts up when she gets sick, and it acts up when the weather changes….and it's just so much. So it's like I can't really tell when it's her asthma." Pg 4
Finding	To become knowledgeable of when to seek emergency care for their child. Most participants admitted that they waited too long to seek help from providers (U)
Illustration	"So, that's the thing. And that's why sometimes we do wait so long to bring them because we think we can turn them around." Pg 4
Finding	Managing the complex allergies experienced by their children was also identified as a significant caregiving responsibility (U)
Illustration	"My brother and I sat and ripped up the carpet. When I bought the house, it had carpet all the way through the house. We ripped up the carpet, when he turned four because I heard then that would help with the dust mites. Like you said "Bubble." They live in bubbles." Pg 4
Finding	Some parents were aware of the positive allergy but did not link home exposure to their child's symptoms (U)
Illustration	"I have a cat. And so the doctor said she was allergic to the cat. But I've had a cat for almost ten years. So, I know she ain't allergic to mine." Pg 4
Finding	The unpredictability of acute exacerbations was particularly worrisome (U)
Illustration	"To not be able to see it [flare] coming, that is rediculously scary…I think I'm gonna lose my mind." Pg 4
Finding	Uncertainty regarding child's future (U)
Illustration	"The long term concerns are what can we do, if it's at all possible for him to grow out of it? And if we're close to perfect with it, maybe he will, right? Can he live a normal life while having it?" Pg 4
Finding	The financial hardship of raising a child with severe asthma (U)
Illustration	"Some people are between a rock and a hard place. It ain't because they don't want to. It's because they just can't. Some people have kids come from single parent homes. My husband works two full time jobs for me to stay home with her." Pg 5
Finding	Wanting their child to become more autonomous in asthma self-management. Yet, they acknowledged the need for continued supervision and oversight in asthma care (U)
Illustration	"He'll go outside and I'll be like: [Child name], take your pump with you because you're outside….And then I'll look out the window, or I'll step outside and I'll see him bent over. I can see him retracting. And he has not pulled that pump out of his pocket, yet….his mind be like, "Oh, well, I'll just do it later." And later isn't promised to anyone, especially a person with chronic asthma. So it's like you gotta get it together, [Child]. You gotta get it together." Pg 5
Finding	Strategies to ensure that medications do not unexpectedly run short (U)
Illustration	"I had his doctor prescribe two at a time, so, like you said, I can have one, and he can have one. They never tell you they ran out until they're completely gone." Pg 5
Finding	Deciding when asthma exacerbations warranted emergency services. Those with older children, described a shared decision-making approach (U)

Illustration	"When we get to a hospital is because he's like mom, I need to go to the hospital. He's been having asthma since he was a baby so he is well aware of when he feels like he can manage through it or when he's like no, I need to go…I'm like at the first, I'm like let's go, you know, because that's how I was but now I'm learning to allow him – it's because I want him to start being more independent and responsible when it comes to his asthma." Pg 5
Finding	Multi-layered web of family and friends who are likewise engaged in monitoring and managing their child's asthma (U)
Illustration	"My sister had it [asthma] when she was younger really bad. So, she had a whole lot of hospital stays and things like that. So, we, my mother and we know how serious it is. So, my whole family, they be on it." Pg 5
Finding	Caregivers purposively limited the child's social outings to contexts where adults have knowledge of asthma management (U)
Illustration	"Their children have asthma too so they know the drill. They got the EpiPens. ….And I feel actually, sadly enough, I feel more comfortable with someone who do have it and know the drill rather than someone that don't." Pg 5
Finding	School policy created access barriers to asthma medications (U)
Illustration	"The one thing I didn't like, even though he doesn't have to carry one around in his pocket, was that they [school administration] told me he couldn't carry one around in his pocket….You gotta take it to them and they gotta hold it in the office." Pg 5
Finding	Refused to administer daily medications due to concerns about potential side effects (U)
Illustration	"I even admitted this to the doctors at the Emergency Room. One of them was looking at me like I was nuts, and the other one was like "I understand mom." Because I just told him that I don't give him Flovent every day. I'm like, "I think that a medicine on a person everyday has effects on them." Pg 5
Finding	Feeling more comfortable having health professionals manage the acute care of asthma exacerbations (U)
Illustration	"See how they do it in the Emergency Room….how they do it back to back-to-back? The reason why I don't do it like that because it raises his heart [rate]. When they're in the Emergency Room, they're right on top of it. So, it scares me to give it to him the way they do it." Pg 5
Finding	Barriers that impacted asthma management - Difficulties fulfilling prescriptions when inhalers are empty or lost (C)
Illustration	"But he lost it. Do you understand what I'm saying to you." Pg 5
Finding	A feeling of helplessness in their efforts to reduce child exposure to allergens (U)
Illustration	"I have done everything that I feel like I possibly can…I clean so much because I feel like if I clean, I'll keep everything out, keep everything away. But I still feel like it's not enough. If I see some dust, I'm gonna go crazy, and I drive my landlord crazy. "I want my vents cleaned. I want everything to be cleaned"….I don't know what else to do." Pg 6
Finding	A major concern was the ways their children encountered secondhand smoke, even when smoking bans were in place for the home (U)
Illustration	"She [sister] smokes like a chain smoker and she's always embracing and hugging. I have to say to her, "Girl, you can't do that." She'll wash her hands…but it's in her

	clothes. It's in her skin. And she would wear wigs. It's in her wig. And she's always hugging…I have to explain. "You cannot do that. You're sending me to the Emergency Room." Pg 6
Finding	Caregivers smoked themselves and lacked insight to how smoker permeates the home dwelling (U)
Illustration	"I smoke in the house. I don't smoke in the same room with him. And I don't smoke in my car at all. And I don't allow anybody else to smoke in my house. I know that's crazy because I smoke in there, but….he already knows don't come in my room. And usually if I smoke, I try to smoke in my room. Don't come in here. Or you know, just stay upstairs or something." Pg 7
Finding	Participants recognised the importance of reducing child exposure to triggers, smoking in particular (U)
Illustration	"One time he [adult friend] was about to [smoke], I said no, I'm not trying to go to the hospital, I'm not trying to be in there for 12 maybe 24 hours. Can you take it across the street?" Pg 7
Finding	Self-advocacy in encounters with healthcare systems. Some providers do not value parents as experts on their child's life (U)
Illustration	"Lately, I've been feeling like they aren't as understanding when it comes to him. I don't know if they're just trying to get you in and get you out or what it is. It's kind of rushed and they are dismissing what I'm saying as a parent….I just feel like they don't listen as much as they used to when he was younger." Pg 7
Finding	Advocate for themselves when faced with accusations of child abuse and neglect (U)
Illustration	"Or they're in the [child welfare] system became they miss so many [school] days because they're in the hospital or they're sick. The school system will come after you. "Why is your child missing so many days?" Pg 7
Finding	Need for greater sensitivity to plight of raising children with high-risk asthma in context of poverty (U)
Illustration	"I had a car, but I don't have a car anymore. I was told by a [medical] resident, "Maybe you need to get a new car." How am I gonna get a new car if I can't keep house on the job, if I'm here coming to see you guys? They say inconsiderate things like that, I'm here. Do you understand that I'm here? I'm an hourly person, and I'm screwed." Pg 7
Finding	Parents also struggled to describe what "well-controlled" asthma means and how it is achieved (U)
Illustration	"To me, it's when you're giving them the Flovent like they're supposed to have it, when you know when it's time for the albuterol, and when you know that it's time that the albuterol won't work again, you know that it's time for the Emergency Room. To me that's when it's well controlled." Pg 4
Finding	Family poverty and housing instability left their child vulnerable to allergen exposures that were out of their control (U)
Illustration	"You don't know where they're going to sleep. My son has the pillow [allergy proof pillow cover] that they gave him that keeps the dust mites away. He has that on his mattress. So, I don't know where he's gonna go with someone else and if they're gonna have dust mites." Pg 6
Finding	Parents check counters on inhalers to confirm dosages and frequently prompt their

	children to take medicine (U)
Illustration	Parent 1: "Yeah, and you know when they don't [use inhaler] too. There's some time they'll be like, "Oh, I took it, I took it." And I'd be like, "How did you take it when the count's still where it was?" Parent 2: "I'd be like, "I counted the counter so I know." Parent 1: "Clear giveaway." Pg 5
(58)Wales S, Nadew K, Crisp J. Parents' and school-aged children's views on managing treatment adherence in asthma or diabetes. Neonatal, Paediatric & Child Health Nursing. 2007;10(3):26-30.	
Finding	Some parents found that the unpredictable nature of asthma made it difficult to be in control at all times which was frustrating and left them physically and emotionally taxed (C)
Illustration	"It still scares me sometimes…." Pg 28
Finding	As children grow, there is an expectation by health professionals and parents that they become the primary managers of their illness and treatment. Parents believed that their ability to transfer responsibility relied on their own degree of control and the individual characteristics of their child (C)
Illustration	"…so I suppose its just being that little bit more aware for him and just at his age he probably needs quite a bit of prompting to get him to use it appropriately." Pg 29
Finding	Children’s knowledge of their illness played a major role in enabling them to accept their treatment and increase their level of responsibility in self-care. (U)
Illustration	"…he gives himself his own puffer at night and he knows its puffer, teeth, bed…he’s got a cold so he said "I’ll take it to school mum." Pg 29
Finding	As well as the way the family organised itself to undertake the new roles, the quality of relationships within the family were identified as an important component of effective management of the illness (C)
Illustration	Parents believed that the competence and resilience of their family unit served as a protective factor, defending their child from disruption to routines. Pg 28
(59)Williams B, Hoskins G, Pow J, Neville R, Mukhopadhyay S, Coyle J. Low exercise among children with asthma: a culture of over protection? A qualitative study of experiences and beliefs. The British journal of general practice: the journal of the Royal College of General Practitioners. 2010 Aug;60(577):e319-26.	
Finding	Many parents commented that GPs had encouraged their children to exercise and had stressed that asthma should not prevent the child from engaging in physical activities (U)
Illustration	"…I was told that although you have asthma it doesn’t stop you doing things….The GP and asthma nurse said to us "Get him right down that Ferry [seafront] and get walking right along." Pg e323
Finding	Some parents had not received any advice from practice staff and did not know about the health benefits of exercise (U)
Illustration	Interviewer: "Is Susan supposed to exercise when she has asthma?" Parent: "I have no idea. Just as a family we do try and encourage it you know…but I really don’t know. They’ve never said "Look swimming or whatever would help"…If it did help we would take her regularly." Pg e323
Finding	What appeared to influence parents' support of physical activity, and the child's willingness to take part in it, was their beliefs about the child's physical 'capability ' and

	the 'safety' of exercising in the presence of perceived 'triggers' (U)
Illustration	"[My son] is all right if he just cycles out with his friends or goes to the local farm….But his dad'll take him out on an 8 mile cycle…it's just too much" Pg e323
(60) Hudson N, Culley L, Johnson M, McFeeters M, Robertson N, Angell E, et al. Asthma management in British South Asian children: an application of the candidacy framework to a qualitative understanding of barriers to effective and accessible asthma care. BMC public health. 2016 Jun 14;16:510.	
Finding	Knowledge about asthma and its management appeared more likely if participants already had someone in the family with asthma (U)
Illustration	"And because we've never really been exposed to something like asthma within the, within our immediate families, neither my wife or myself, it was something which was slightly unusual for us, we didn't probably recognise it as an onset…I'd say, if anything, we were quite ignorant of the condition itself, and had no previous knowledge or of managing or living with people with asthma ourselves, so I think, we took it very much as okay, maybe this is just a small ongoing thing, he's quite young, he'll grow out of it, whatever it is." Pg 4
Finding	Advice was often given by relatives and close friends (U)
Illustration	"….you have this extended influence around you. There's no doubt that clearly, living in the UK and obviously born and raised here, that you're far more accepting of different opinions. However, because you really do interfere quite heavily with an extended family….so it's not unusual for the family to give advice because they'll see it as, oh yeah, you know, we just got, it's one of their own, it's not unusual." Pg 4
Finding	Difficulties being able to manage time off work in order to attend appointments (C)
Illustration	"we both worked at the same place so it was really hard….because of her going to hospital and being ill, all our annual leave's been eaten up like that and we can't have like a family holiday together because we go to work at one place." Pg 5
Finding	Difficulties managing their child's asthma-related healthcare, in terms of finding relevant information (U)
Illustration	"I wish I could ask someone. There's no one. Myself. Sometimes I just get the inhaler leaflet out, the instructions, read it over and over and over but still, you know, like, it's same thing you reading it, like to finally satisfy, I think, if I read it again, there might be something I missed out." Pg 5
Finding	Practice nurses dedicated to asthma care were felt to provide 'navigational assistance'. They often had more dedicated time and focus than GPs to spend with a family (U)
Illustration	"And she actually talks to you and asks him to show her exactly how he uses his inhalers and the spacer as well….The practical side; and how many seconds to wait between puffs and….So he actually has to do it in front of her so she knows he's going it properly…I think the asthma nurse is vital." Pg 5
Finding	Parents used strategies such as seeking out GPs who could speak the same language (U)
Illustration	"We try to go and see our Punjabi speaking doctor because we can understand what he is trying to tell us, but we have seen a white lady doctor as well, she is very nice but with her, we need someone's help to get the information." Pg 5
Finding	Parents used strategies such as choosing to access a local pharmacist who was often of

	the same cultural background or could offer advice in a language other than English (U)
Illustration	"You see [my wife] want more information, probably haven't got time or something so that's why she went straight to the pharmacist…the pharmacist says the same language she speaks." Pg 5
Finding	Healthcare professionals were reluctant to make a diagnosis (U)
Illustration	"Every time there is a different doctor! Every time different medicine! They cannot reach to a conclusion or there is no solid result or a procedure to follow….We were given various appointments and at every stage we had to wait for results. For example he had a blood test and then wait two weeks for the results. In the meantime if he had difficulties we just had to keep giving him medication. In short there was no quick diagnosis. Too late." Pg 6
Finding	Not having a diagnosis for their child's symptoms led to a great deal of uncertainty about how to proceed. Without an official 'label' of asthma, parents were unclear about whether to give medicines or how to manage symptoms (C)
Illustration	"Well the difference is that if; if you have got asthma then I can say that my child has got asthma. I mean if somebody ask me, I just say no, no, no the doctor hasn't diagnosed it as asthma, I always say that." Pg 6
Finding	Unclear decisions about management, and ambiguous advice about symptoms from healthcare professionals, could have a negative effect on experiences (U)
Illustration	"Now we, that's the funny thing. I just don't know if I'm coming or going with them. I want to know if she has got it. If she has, then, is it a permanent thing? Or is she going to get out the phase? So, when I did ask, he goes that "with kids, you can't tell." And I go, "What is the cause of it?" He goes "It could be many stuff." He's not given me a full diagnosis. He hasn't told me, he hasn't even confirmed she has got asthma." Pg 7
Finding	Concerns about long-term use of steroids (U)
Illustration	"I didn't think it was right. I've heard (…) body gets used to steroid, it's not good. Then nothing works on you." Pg 8
(61) Callery P, Milnes L, Verduyn C, Couriel J. Qualitative study of young people's and parents' beliefs about childhood asthma. British Journal of General Practice. 2003 Mar;53(488):185-90.	
Finding	Trial and error played an important part in decisions about asthma management. Professional advice was tested and adapted to fit with carers' own understanding, developed from experiences of each child's asthma (U)
Illustration	"I go through this process of just testing it (hmm) emm because he's stronger and his immune system I assume as he gets older is getting stronger, so I suppose I just feel that we have to keep trying because to me he seems better." Pg 187
Finding	Carers' beliefs about what constituted 'tolerable' asthma (U)
Illustration	Carers sought to minimise the physical, psychological and social impact of asthma and treatments. Their objectives for asthma management meant that some accepted a level of symptoms and restriction of activity as "tolerable'. Pg 187
Finding	Parents described their reluctance to make their children different from their peers by restricting activities, but some described this as necessary to avoid the risks of asthma (U)
Illustration	"You just have to explain it that she can't, you can't run without getting out of breath and

	there’s no point in pushing it, is there? She’ll only end up ill." Pg 188
Finding	Assessment of asthma uncertain (U)
Illustration	"Are we at the lowest end and we’re just coasting along and err, or are we middle? You could only see your child as he or she is. (Hmm) I don’t have another asthmatic to compare it to." Pg 188
Finding	Fear of acute attacks (U)
Illustration	"Would he have an attack I don’t know. I always assume that he would’nt but there’s always that small percentage that he might." Pg 188
Finding	Whether the child was experiencing acute attacks was an important component of tolerable asthma (C)
Illustration	"Well like I say she doesn’t have anything where she’ll end up in hospital (hmm). She might have a few odd twinges, pains in her chest but other than that she’ll be fine. As soon as she takes the inhaler she’s all right then." Pg 188
Finding	Worsening asthma was also recognised through changes in mood and behaviour (U)
Illustration	"Oh, he’s wheezy, coughin’, very arrig…., very bad mood he is, you can’t really talk to him, (right) really stroppy he is and then he’ll start on his brothers and sisters for no reason." Pg 188
Finding	Carers generally preferred their own subjective judgement to peak flow measurement (U)
Illustration	"It's a quantitative way of doing it, not a qualitative way of doing it....it's really hard for you know as the parents to see the wood for the trees....we just gauge it in a very simplistic way which is that he's not having prolonged bouts of it, he's having,err, short shallow bouts of it, that's tolerable for him." Pg 187
Finding	Watching over a child and allowing independence (U)
Illustration	"It's on your mind all the time, emm, day to day it's has he took his inhalers (yes) and kind of wanting to keep an eye on him without smothering him (yes), it's a balance." Pg 188
Finding	Physical symptoms were sometimes described in terms of their effects on other members of the family (U)
Illustration	"coughs were described as 'annoying', 'constant' and 'keep us up all night'. Pg 188
(62) Cashin GH, Small SP, Solberg SM. The lived experience of fathers who have children with asthma: a phenomenological study. Journal of paediatric nursing. 2008;23(5):372-85.	
Finding	The diagnosis of asthma was met with a sense of "relief." They all described a period before receiving the diagnosis during which their children experienced recurrent episodes of respiratory illness (U)
Illustration	"I felt relieved when a diagnosis was actually discovered because we had gone through so many years….of disturbed sleep, chronic coughing, and sniffling, and that [the diagnosis] made everything clear. It meant, okay, she is not just a child that has a lot of colds, and she is not just a child who coughs a lot for no reason…It made it clear to us as to the reasons why she was having the problems she was having." Pg 376
Finding	Once they knew that the diagnosis was asthma, the fathers went about what is best described as 'learning the ropes" of asthma management (U)
Illustration	"I had a basic understanding....of the asthma process...But you also need...information

	in regards to medication and other things which I did not have..." Pg 377
Finding	Fathers continued to learn by "picking the brains" of friends and others to get advice and practical information on dealing with asthma (U)
Illustration	"I've learned from talking to other people who have asthma and who have children with asthma…Things that have caused triggers for them you are now aware of and you watch for in your own child. Things that are beneficial for their children you may also try with your child." Pg 377
Finding	Fathers became "tuned in" to asthma. As a result, they zoned in on any information on asthma that they came upon in their day-to-day lives, such as newspaper and magazine articles as well as television and radio programs (U)
Illustration	"If I saw…an article about asthma..I read it. I wouldn't have before [child was diagnosed with asthma]." Pg 377
Finding	Consistency with the medication regimen required more effort than the fathers had thought. They had to learn to make it a part of their family's everyday routine. (U)
Illustration	"We had to be more regimented because…the medications that were prescribed for [daughter] were not part of our daily routine….It took some getting used to." Pg 377
Finding	Fathers learned about environmental strategies to control triggers (U)
Illustration	"I renovated the house. I took up all the old, dusty carpet and put down indoor-outdoor carpet that was easier to keep clean. We put in new windows and doors to get rid of the mold and mildew…It was that or move to some place else." Pg 377
Finding	Learned how to take a proactive approach to asthma treatment (U)
Illustration	"We learned that exercise…induces it….Now when she's playing soccer, for example…she will take her puffer 5 or 10 minutes before she starts playing…and she'll be all right." Pg 378
Finding	Able to recognize their child's symptoms (U)
Illustration	"There is a distinct asthma cough that you get used to." Pg 377
Finding	Fathers constantly looked out for their children and kept a watchful eye over them (U)
Illustration	"Sometimes just even in the ordinary interaction that you have…you sort of feel or hear or listen for a tightness in his chest. It has become a habit." Pg 378
Finding	Fathers wanted children to be vigilant as well (U)
Illustration	"We are trying to teach [son] that he must also be vigilant…and that it is not only us [who need to be vigilant]." Pg 378
Finding	Fathers were also alert to situations or activities in which the children could be exposed to asthma triggers (U)
Illustration	"You have to watch out for many things….like when he [son] wants to be around me….cleaning the car and stuff like that. I am fearful of atomized sprays that can trigger an attack." Pg 378
Finding	Asthma was always in the forefront when planning family activities and outings, so as to anticipate and avoid triggers (U)
Illustration	"There's a lot of forethought in planning activities. Vacations have to be well thought out." Pg 378
Finding	They wanted to shield their children from situations that could trigger an asthma episode while at the same time allow then to "lead as normal a life as possible." (U)
Illustration	"…so you try to compromise a little bit and you medicate them when they go, when they

	come home, and you monitor the amount of time that they are there….You can be as vigilant as you can, but..you want them to be like their friends." Pg 378
Finding	Fathers had a number of concerns that made them feel uneasy about some aspects of their children's asthma. Concerns emerged most predominantly when the children became acutely ill (U)
Illustration	"Your concerns are magnified when the children are not well; they are reduced when they get better. I think we have the tendency to feel very comfortable as to what we are doing when the children are responding and you become really aware of.them [concerns] when the children become ill." Pg 378
Finding	Foremost concern was with respect to their children being on medications during childhood, particularly oral and inhaled steroids (U)
Illustration	"I didn't want to see him on any type of steroid product, especially at his age…to put a child on steroids even a small dose, I was fearful that it would inhibit his long-term growth." Pg 378.
Finding	They were faced with the dilemma of complying with treatment that, on the one hand, was beneficial to their children but, on the other, could have a negative impact on their children's long-term health, and they tried to reconcile their concerns (U)
Illustration	"You read some studies that state uncontrolled asthma can lead to irreversibly damaged lungs that will not mature fully and that don't have their full capacity. So the untreated state seems worse than the side effects of the actual treated state." Pg 379
Finding	Concern about their children's safekeeping at school. Much of that concern centered on school policies pertaining to the use of medications. None of the schools that their children attended permitted students to carry medications on their person (U)
Illustration	For the most part, the fathers understood the need for the schools to have control over medications but felt that policies should be flexible regarding inhaled medications for children with asthma. The fathers were frustrated because they knew that if the child became symptomatic, he or she would need to use a bronchodilator right away. Pg 379
Finding	Concern relevant to the school setting was with respect to potential exposure to triggers (U)
Illustration	"….one day when it was cold and raining, he [son] was out at lunchtime That upset me…because that [the weather] causes his asthma to act up. So I phoned the school. The principal told me, 'Well, there's lots of children with asthma in the school and it doesn't seem to bother them." Pg 379
Finding	Concerns with the ongoing discomfort that their children experienced with asthma (U)
Illustration	"The chronic discomfort that the children go through, especially when they have exacerbations of their asthma, is a big concern for me. You know that they are not really at rest, whether it be sleeping or at play or just socializing with their siblings. There's like a constant irritation that they have and they are just not comfortable." Pg 379
Finding	Worried that asthma might become more severe in the future (U)
Illustration	"…first when he [son] had asthma….I wondered, 'How bad is this going to get? Is he going to be on medication for the rest of his life?..Now that his asthma is under control…it doesn't bother me as much as it did…but it still concerns me." Pg 380
Finding	Worried about how children would manage their asthma when they became teenagers (U)

Illustration	"And I can see that is going to be an increasing problem. I think that [son] is going to want to minimise it [his asthma] because it's not an adventure to go to the hospital anymore because it takes him away from other things that he'd rather be doing." Pg 380
Finding	Fathers felt "comfortable" in their ability to take charge and manage it on a day-to-day basis (U)
Illustration	"We feel quite comfortable, you know, in dealing with the situation now." Pg 380
Finding	Understanding the disease process, the medications, and the rationale for the treatment plan helped them appropriately carry out the activities involved in their children's care (U)
Illustration	"I think understanding the disease, understanding why you're doing what you're doing makes it a lot more comfortable to deal with..I think that is invaluable in your overall acceptance of it." Pg 380
Finding	As fathers gained experience in treating their children's asthma, they developed a clearer picture of the total situation and became more confident in their ability to manage it, especially when it came to dealing with acute episodes (U)
Illustration	"After you experience it [acute episode] a few times and saw that you knew how to deal with it, then you [became] more comfortable in dealing with it." Pg 380
Finding	The fathers' comfort level with asthma management increased as they saw their children respond favorably over the long term to the prescribed treatment plan (U)
Illustration	"After she [daughter] was diagnosed and after she was on medications for a while, she said one night, "You know, Daddy, it's like I can breathe again"….She could breathe again and things became a lot easier for her. That made it a lot easier for me." Pg 380
Finding	The men had supportive spousal relationships (U)
Illustration	"We are in this together. We lean on each other." Pg 380
Finding	Support from other family members and friends, particularly those who had personal experience with asthma (U)
Illustration	"I….used my sister as an example..She was doing a good job [in managing her son's asthma]…I just saw how she was taking care of her situation….I felt if she could do it, so could I. I didn't think it was a big job for her." Pg 380
Finding	They could easily access help if they needed it (U)
Illustration	"It takes the worry off me….The hospital is just down the road…[Paediatrician] even gave me his home phone number, so if we had any questions anytime whatsoever, [we could] give him a call." Pg 381
Finding	The fathers had confidence in the healthcare providers and were pleased with their children's care (U)
Illustration	"…the doctor and the nurses..We always felt very comfortable with how they were handling the situation and with the information they provided. That gives you more confidence in dealing with it. The way the staff dealt with it…they..put you at ease." Pg 381
Finding	Their attitude allowed them to see the positive aspects of their situation (U)
Illustration	"…it's a part of life. So you have to say, 'Fine. That's the cards that were dealt to me…" Pg 381
Finding	They all described a period before receiving the diagnosis during which their children experienced recurrent episodes of respiratory illness (C)

Illustration	"Well, I didn't know what was wrong at first...I thought she [daughter] had the flue or something...she wasn't eating and she was getting sick and tired all the time...She had no energy...In the nighttime when I used to check on her..she was just going [mimics noisy breathing] like she was trying to get her lungs filled up with air." Pg 376
Finding	It seemed to have taken longer to receive a diagnosis among the families with only one child with asthma and for the first child in the family of three children with asthma than it took for the subsequent two children (U)
Illustration	The father of the three children indicated that he and his wife were more tuned in to symptoms of asthma in the subsequent children and sought medical diagnosis in a more timely manner. Pg 376
Finding	Along with the diagnosis came a specific treatment plan. This contributed to the fathers' relief because they felt that they, as well as their wives, would be able to take action not only to alleviate the symptoms but also to improve their children's overall health, comfort level, and quality of life (U)
Illustration	"There was a sense of relief that at least now that we know what this is...there would be some possibility of managing it...there is a diagnosis and a treatment that goes along with this." Pg 376
Finding	Fathers were also relieved to learn that their children's symptoms were caused by asthma and not some other disease of a more serious nature (U)
Illustration	"With all the possible afflictions that one could have that might be life lasting, this didn't seem to be a terribly onerous one." Pg 377
Finding	They felt that by being watchful for symptoms of asthma in the siblings of the affected child, they would be able to seek medical attention in a more timely and informed manner than in the past, should the need arise (C)
Illustration	"Because of the older child [who had asthma], there are things that we would pick up on more quickly than before...There is a passive vigilance in that area." Pg 378
Finding	They felt there was a degree of uncertainty in the medical community about the effects of long-term use (U)
Illustration	"...I know they test them [inhaled steroids]...but the effect that something may have a 2- or 3-year period may be different than if it is over a 15- or 20-year period. I guess nobody knows the answers to these questions." Pg 379
Finding	Worried about how their children would manage their asthma when they became teenagers. Fathers dealt with that particular concern by endeavoring to educate their children about their asthma (U)
Illustration	"One of my biggest concerns...is to make sure that the children are armed with as much knowledge as possible to be able to cope with their asthma effectively when the are teenagers." Pg 380
Finding	Fathers, along with their wives, first learned about asthma from the healthcare professionals who were involved in their children's care, either an asthma educator or the child's paediatrician. Fathers were highly receptive to and satisfied with the education (U)
Illustration	"A lot was going through my mind....and it was nice to see that somebody was there to show us what to do because I really didn't know...She [asthma educator] showed us how to use the puffers and told us about them...She gave us a lot of pamphlets...She

	was a great help." Pg 377
(63)Kealoha MK. Malama na makua i na keiki me ka hano: Native Hawaiian parents caring for their children with asthma: University of Hawai'i at Manoa; 2012.	
Finding	The major antecedents of uncertainty were related to the variable nature of asthma symptom patterns before an asthma attack and during an asthma attack (C)
Illustration	"we noticed he get hard time breathing [had difficulty breathing] and his lips…turned bluish…the first episode….he was about three months and his lips turned blue and then his whole face…" Pg 73
Finding	Parents also had difficulty recognizing asthma symptoms of young children compared to older children because young children were unable to verbalize their discomfort (U)
Illustration	"He was screaming in his car seat, and…he never screams like that, so we took him out of his car seat and, we tried to calm him down and he wouldn't calm down…then I noticed his breath like he wasn't even breathing and he was just like hyperventilating…" Pg 74.
Finding	Parents with less asthma experience expressed and demonstrated more uncertainty recognizing asthma symptom patterns, identifying asthma triggers, and implementing asthma treatment (U)
Illustration	"…he was sleeping, it was the middle of the night. And I could hear him gasping for air, and when I looked into the crib his chest was caving in and I could hear him wheezing. I didn't know what it was…" Pg 75.
Finding	Past experiences with asthma that contributed to "event familiarity" status. Past experiences included having asthma or similar respiratory conditions and/or having two asthmatic children (U)
Illustration	"I think it is helpful that I have asthma. I am compassionate to his situation….I can literally sit there and know exactly….how he feels. I think…that helps me as a parent be able to help him in his situation." Pg 75
Finding	Unknown asthma triggers and unpredictable action of asthma triggers were recognized as strong antecedents of uncertainty. The participants learned how to recognize asthma triggers by watching their children react to various situations and objects (U)
Illustration	"And we live in Hawaii. There is [are] cockroaches everywhere so you know if my daughter has her asthma…."Oh no! We are not going [there]. There is [are] a lot of cockroaches. It is everything…especially living in Hawaii with the Kona winds and the vog and the weather changes drastically from sunny to rainy and just the steam that comes off the pavement after it rains or the flowers or perfume…." Pg 77
Finding	The initial hospital experience was difficult for many parents. (U)
Illustration	"So we ended up staying at….for like six, seven hours and he had to have like five breathing treatments…he was screaming and I didn't know what was wrong with him because you know, he is so little, he can't tell you what is wrong. So it was very nerve-wrecking…we ended back up at the hospital like four time since, before he turned one and a half, because of his breathing. It was traumatic." Pg 77
Finding	Participants expressed confidence in emergency room staff to provide superior medical treatment to their child when home therapy was ineffective (U)
Illustration	"After giving the nebulizer two, three times [at home], I ….rush [rushed] him [to the] hospital. Right away, the medicine that they gave him is instantly [effective], I mean,

	cures him right away. I guess they have a stronger medication, yeah?" Pg 78
Finding	When prescribed treatment proved to be ineffective (incongruent event), parents were responsible for deciding the next course of action (U)
Illustration	"…it's [nebulizer treatment] supposed to be lasting four hours, we are not even lasting two, we gotta go in [emergency room]!" Pg 78
Finding	Healthcare providers who primarily gave directions without specific and relevant explanation were considered to be unhelpful (C)
Illustration	One parent said that a doctor gave her "a bunch of medications" and told her to "call us if he doesn't get better." Pg 80
Finding	Social support assisted parents by decreasing their uncertainties about asthma symptom patterns and asthma management by providing information, service-related assistance, and emotional support (U)
Illustration	"What has also made it easy for me through the years is…my mother-in-law. She is severely…asthmatic. So she knows, as soon as the weather changes, she is calling us, "How is ---doing?" Because once she gets onto the nebulizer…then she knows that he is probably affected right now. So she is kind of our little warning sign…which is great! It's like….the alarm system…So she is really great and she has tought me a lot about how to care for him, yeah." Pg 82
Finding	Not all members of parents' social networks were sympathetic. (U)
Illustration	"My family didn't understand it [asthma]. They didn't know what it [asthma] was. They always just thought…like, 'Why is he sick again? What are you doing?" Pg 84.
Finding	In addition to providing emotional and social support to participants, many tutu and kapuna assisted parents with asthma care by performing traditional healing practices (C)
Illustration	"My mother-in-law is 75% Hawaiian. When the kids are sick, she just makes it all better…it is everything from clearing out their nose to rubbing their chest..she'll take just a warm compress and take them to bed with her and just lay down in bed with the warm compress on their chest…And I don't know if that is really just a Hawaiian thing versus her just being grandma. "Tutu". They call her….as soon as he gets into the house, the first thing he does is hugs and kisses grandma and she always asks about him…but there is definitely something….there. I think they have that bond, that asthmatic bond going on, yeah." Pg 82
Finding	Parents expressed their need to learn about the asthma condition. When information about asthma was unavailable, incomplete, unclear, or complicated, parents experienced uncertainty regarding basic aspects of asthma and asthma care (U)
Illustration	"I think, in the beginning, what made it harder was that I had no idea what asthma really was…I did't know it was the inflammation….I didn't understand how he got it or you know I didn't have it. I didn't know if he would ever grow out of it or…if this would be a life thing that I would constantly have to watch. I didn't know, could it get worse? The hardest thing was just not knowing exactly what it was." Pg 86
Finding	The inconsistent effects of triggers and the unpredictability of asthma exacerbations created a state of uncertainty for the parents (U)
Illustration	"One of the most difficult things, I think, is not knowing when it [exacerbation] is going to occur and if it occurs suddenly." Pg 87
Finding	All parents perceived asthma exacerbations to be 'scary;' and many felt 'fear' for their

	child (U)
Illustration	"…when my boy turned all blue…I was wondering [whether] he gonna make it or what [survive]…His lips turned blue." Pg 87
Finding	Parents expressed concern about chronic medication use (U)
Illustration	"My son took all these medicines and to me it did make him better, but I don't know about the long-term effects, the future, I don't know what it's going to do to his….chemistry or his brain, I don't know." Pg 87
Finding	Parents expressed confusion about complex aspects of asthma care (C)
Illustration	"And so I would take him to the doctor. They didn't quite say asthma, which I got a little confused about. Because you know…they give him all the albuterol and the prednisone." Pg 88
Finding	Ambiguity involved the difficulty parents experienced, when confronted with subtle, indistinct or confusing respiratory symptoms that appeared to be similar to asthma symptoms. Parents required the assistance of their healthcare provider to establish an accurate diagnosis and treatment plan for ambiguous symptoms (C)
Illustration	"He was really young and he had this crazy cough and I was convinced it was asthma. And then I started looking things up. Too him in [to hospital], and come to find out it was croup. That was scary!" Pg 89.
Finding	Participants applied vigilance as their foremost coping strategy against uncertain events (U)
Illustration	"Being really watchful. I always….have to be on the edge with him. Sometimes even the smell of things or eating certain things can trigger a bout [asthmatic episode]…but in the beginning not knowing exactly what would trigger him was a little difficult because they are not like every other kid; like with sports especially, you know, I can't just [say] "Go out and go play". You know, I have to stay there. I have to make sure that he is going to be able to last the whole game or…that he is not going to have an episode I between…." Pg 90.
Finding	Parents reported sleeping with young child during illness in order to monitor their breathing pattern (U)
Illustration	"I don't know when it's [asthma attack] going to happen. So he is always sleeping with he. He is my cuddle bunny. So then…I can hear him wheezing at night if he…has a hard time." Pg 90.
Finding	Monitoring also involved asking older children questions about their experience (U)
Illustration	"I am constantly on him. How [are] you feeling? How's your chest? Are you okay? Was that an allergy sneeze? Or It's just a tickle sneeze?" Pg 90.
Finding	"Being prepared" was consistently linked to monitoring (U)
Illustration	"But just to make sure you're prepared is the biggest thing. Because I would hate to be somewhere and not have the machine….and be like stuck with my baby who can't breathe." Pg 91.
Finding	They preferred learning by informally sitting with a small group of Native Hawaiian parents and "sharing stories." (U)
Illustration	"I think it is…good like all of us talking here. You know it makes you feel comfortable knowing I'm not the only one that does that….now you know these little home remedies that work for each other. You share it with each other and you find out what works." Pg

	93.
Finding	Many participants practiced other types of treatment outside of the medically prescribed plan. Three types of CAM therapies were identified and categorized by the research team: (a) comfort measures, (b) home remedies, and (c) Hawaiian cultural healing practices (U)
Illustration	"I think being Hawaiian and being a part of our culture you learn different things…out of the Western way, out of the medicine. Because you don't always want your kid on medicine. I don't want my daughter to be reliant on it [asthma medication]…if at all possible I would rather stick to natural resources and other mechanisms before I give her the albuterol and what-not. And I definitely will…do [CAM therapy]…first." Pg 94
Finding	Home remedies were described by one experienced asthmatic parent as "backyard style of doing things and...their own non-Western way of doing things and treating." (U)
Illustration	"used to put some Vicks in a pot of boiling water and you have to go over it and keep the towel over your head so that it keeps the steam in." Pg 95. "So if we are not at home and I don't have the medicine, I will give her a Pepsi. [Laughter] She'll slowly sip on it and it works for her. It works for us. So that is my quick escape…it'll last till we…come home." Pg 95.
Finding	Affect-management included methods of faith and comparing the patients condition to others who were more ill (U)
Illustration	"I know I need to have my faith and everything. Like he's gonna be okay." Another parents compared her child's asthma to a more serious medical situations as, "So as far as his illness goes, I am thankful that it is not something much more severe where he has to be hooked up to a machine 24/7." Pg 97
Finding	Participants identified themselves as the primary caretakers of the affected children and many fathers reportedly did not participate in asthma care. Although these mothers did not offer any concerns about fathers' lack of involvement or conflict about asthma management, they expressed the lack of sleep to be a serious concern (U)
Illustration	"Probably every winter…I'm up every night, every four hours, albuterol, prednisone for the inflammation, everything." Pg 101
Finding	A parent described her perspective and feelings while watching her child in respiratory distress and receiving nebulizer treatments (psychological difficulty) (U)
Illustration	"And I would cry because I feel so bad for him…he doesn't understand but I now he needs it, you know what I mean? And I have to just fight with him to keep it on and try to take it in. And sometimes when he is so bad and we go into [visit] the doctors, he doesn't take just one treatment, it is like two or three treatments…And he is sitting there just drained out because he has been fighting with us the whole time." Pg 101
Finding	Another participant explained the social difficulty many parents encounter when their children play in public places (social difficulty) (U)
Illustration	People are like, "Oh! Your kid is sick." "No, my kid is not sick. My kid has asthma"….they are not contagious and I feel like I'm constantly educating people. "She has…a chronic breathing problem. It is asthma. She is coughing because she is wheezing because she can't breathe." Pg 102
Finding	Securing reliable and knowledgeable babysitters was difficult (C)
Illustration	"But, it is hard because [grandmother]….never has given him a treatment. So if it

	actually comes down to it, I don't know if she'll remember what it is, cause [because] she is ….old and she is forgetful. But…I'm never that far away so if she does call me then….So it does feel like I can't leave him for very long." Pg 103
Finding	Finances directly and indirectly affected parents' adaptation challenges. Participants reported missing work and/or school to care for their ill children (U)
Illustration	"I told my job like I'm sorry if you guys choose to let me go because I'm taking care of my sick child, then do so, but I can't leave my sick son home to care for himself." Pg 103
Finding	Overall adaptation difficulty was experienced by three participants who had young children. They felt stressed and overwhelmed (U)
Illustration	"I don't know. Being a parent is already hard…to have school, work, taking care of the two boys…It's hard to constantly know what's going on with them when somebody else has them…when he does get it [asthma attack], it's so random…I'm not always there when it happens so it's just stressful." Pg 104
Finding	All parents were committed to caring for their asthmatic children and made many adjustments (U)
Illustration	"I mean it's not that hard once…you're forced to live with the situation…You gotta adapt and you realize like…okay." Pg 104
Finding	Another less experienced parent relied on the paediatrician for advice when faced with the uncertainty of an ineffective treatment situation (U)
Illustration	"I'll call [name of paediatrician]. 'He is showing these [symptoms], this [medication and treatment] didn't work. What are we gonna do?" Pg 78
Finding	A number of factors that may have adversely affected the parents' capacity to understand their children's asthma (process information) Factors included young age, developmental stage, work obligations, high school or college attendance, and raising more than one child (C)
Illustration	"It was just a little overwhelming for me, like just not being able to be there for him all the time. You know being at school and work, I can't think sometimes. I'm like oh my goodness what am I going to do?" Pg 79
Finding	In many other cases (5), relatives offered cultural remedies to assist children with asthma. The parents did not always understand the purpose of the remedies, but they nevertheless expressed appreciation for the relative's concern. The parents did not always share these practices or beliefs (U)
Illustration	"Like here, drink noni. I'm like, yeah right. I wouldn't even drink noni". The parents, however did not discourage tutu involvement because they recognized that their concerns were genuine. Rather, they accepted tutu remedies, applying some and storing others away. As one participant explained, "I do it just to..ot fight [argue]...I do it to satisfy them for a little bit." Pg 83
Finding	Healthcare providers were considered to be strong emotional supports for the majority of the parents (U)
Illustration	Five participants cited their physician as someone who "made caring for their child easier." Pg 84
Finding	Parents sought information about asthma, the nature of the disease, symptoms, triggers, purpose of medications, side-effects of medication, how to administer the nebulizer,

	purpose of the nebulizer, and other treatment strategies (C)
Illustration	"We had to learn a lot about what albuterol was compared to the steroid. You know, what is clearing out the mucus, what is keeping the lungs open, right?" Pg 91
Finding	Participants reported complications when administering some medicines and nebulizer treatment, especially to infants and young children (C)
Illustration	One parents reported difficulty administering prednisone by mouth to her young child because of its "yucky" taste. Most participants were concerned about the side effects of asthma medications, especially those that made the child "super-hyperactive," "jittery," "shaky," and eventually "drained." Pg 93
Finding	Comfort measures included stopping their child from running, having them sit and relax, asking them to take deep calming breaths, having them sit in a warm bathtub, "mist in tub," having them sit in an air conditioned (AC) car, and allowing their child to sleep upright on the mother's chest (U)
Illustration	"Where [when] he was struggling, I put him in the car, I started up the AC and we would sit there. In my driveway." Pg 95
Finding	Buffering strategies block the in-flow of information and included avoidance, denial, selective ignoring, and prioritization. Those parents who were not heavily engaged with their children's asthma care reportedly exercised more buffering coping strategies than the primary caregivers (U)
Illustration	"When I didn't know too much about it, I was like, 'Oh, okay. Everyone has asthma. Okay, we'll do some treatments whatever." Another participant also expressed her denial as, "I noticed that he was having a hard time breathing, but I didn't really think of anything because I didn't really think it was a possibility for him to have asthma since I didn't have it." Pg 98
Finding	Parents believed that physical activity would help their children "grow out of asthma." (U)
Illustration	A parent shared, "I like to keep ---active in things. So with sports or running or swimming at the beach...I like to keep---active to help [child] eventually [and] hopefully grow out of it....that would be my daily thing [activity]." Pg 98
Finding	Educating babysitters, teachers, coaches, and others who were responsible for the care of the child with asthma was a major undertaking (social difficulty) (U)
Illustration	"I would have to educate his...coaches on his condition...in case he does have an episode that they know...it is serious and that they can't keep pushing him. He needs to sit out...I guess....educating other people about his situation is a little difficult sometimes..." Pg 102
Finding	Parents with young children appeared to have difficulty understanding the asthma condition and the purposes of medications (C)
Illustration	"I guess when you are laying down...maybe it's how she is sleeping it's blocking her air or whatever it is I don't know. But yeah at night and in the mornings when she wakes up, her cough is bad." Pg 102
(64)Patrick DL. Description of Mothers' Experiences of Parenting their Children who have asthma. Anchorage, Alaska: University of Alaska Anchorage; 2001.	
Finding	Participants related experiences of caring for a child who was having difficulty breathing. All expressed feelings of fear and most reported uncertainty as well (U)
Illustration	"The times with asthma... the times it was hard, of course, was when he would have

	significant trouble breathing. It was mostly when he was younger And when he'd have trouble, he was real scared. And, of course, when he was real scared I was much more — I was his mother not his — nurse at all. I was afraid for him. And he actually came in one day from gym class, and he couldn 't speak. He was so [exhale sound]. His attack was so bad that he could not speak. And that really, really frightened me because I hadn’t - I ’d never seen him that bad. I had the nebulizer, so I was able to give him a treatment right away and take care of it. Had that been another child, not my own, I would have been calling the medics because it was that bad." Pg 25.
Finding	Mothers' experiences of seeking and finding medical care for their children. Feeling as though they were not being listened to and a lack of continuity of care created barriers for some mothers (U)
Illustration	"Whenever I'd bring him in with symptoms I knew he was because I knew the symptoms and I was staying up all night with him. But when I went in, he'd see somebody different. So they'd say, "Well, bring him back in. He's just got a virus," or "He's just got bronchitis," or "It's just a cold. Bring him back in." I'd say, "He's wheezing and he's drooling and he's up coughing all night." You know, forcefully coughing. So we just kind of bounced around a little bit." Pg 27
Finding	Uncertainty was the subcategory where mothers related experiences of not being sure, of not having a clear understanding of what the illness meant or what to do about it. They voiced feelings of not knowing what was normal (U)
Illustration	"Oh. and I finally took her to Dr .______ . She had pneumonia at that time, which I didn 't even know. Yeah, it was amazing what bad shape she was in.... I feel really bad. But the thing is, is that she was — all of her life she's been so bad and I didn 't — I just never knew. ... What was normal." Pg 27
Finding	This subcategory included mothers' experiences of what it was like when their children were diagnosed. Most described it as a time of relief, a sense of having the wherewithal to manage their children's illness (U)
Illustration	"I don't know what would have happened ...if I hadn’t gone to see him, if I hadn’t found him [Doctor]. She probably would have just — I don’t know how long they would have let it go without diagnosing asthma...and getting it under control." Pg 28
Finding	All mothers related their experiences of exhaustion as they cared for their ill children. They described what it was like to be up all night with a sick child and what it was like to continue for days on end battling with the asthma, trying to get it under control (U)
Illustration	"I stayed up with my baby every night when he had problems. I laid him down and he’d start coughing and wheezing, and then I’d have to lay with him propped up at 45 degrees. Otherwise he didn’t sleep. And then I never got any sleep because I was waking up every 20 minutes." Pg 29
Finding	All participants talked about receiving emotional support from family members and/or friends (U)
Illustration	"I think this is probably true with asthma as it is with other chronic illnesses that you seek out people that — you don 't really seek them out. It seems like you find each other. Like other parents that have children with asthma. You kind of gravitate towards them. They become part of your support group and you talk to them about what they [do]. Partly for me, the people that I know, they're also nurses. So it has been — it's nice to know that

	you're not alone and that — because sometimes you feel like, well, maybe I should have done this or whatever, and you talk to somebody else, and they can validate, "You know, what was wrong with that? That was fine." I think it's probably true with other illnesses, too, as it is with this. You seek that support and get it." Pg 30
Finding	After the time of medical diagnosis, mothers related how they acquired resources such as medications, information and medical supplies (U)
Illustration	"And the other thing is don't wait for information to come and land in your lap. It was hard to realize it wasn't going to. They gave us a little book for her to read called "You Have Asthma Now" or something like that. I don't remember what it was. And they gave us one little pamphlet. I'm like, "Hey, wait a minute. You want to pump my kid full of drugs, but you don't want to tell me about it?" That's why we got on the internet... And then there was — I don't even remember the name of the place. But there's an 800 number to call that we got from somewhere. I don't even remember what the 1800 number was for. I just remember I was trying to gather every little ounce of information I could." Pg 31
Finding	Keeping Track was a subcategory in which mothers maintain organization to keep track of asthma management. Some sense of order seemed to be needed to skillfully care for their children (U)
Illustration	"We had to take the Albuterol with the Atrovent every four hours. Albuterol with saline the hours in between. But the Flovent puff was once every third inhaling treatment. And the steroids you had to start at 15 cc's three times a day for a day or two and then you cut back to 10 three times a day for two or three days and then 5 cc's twice a day for so many days. That's why I made the Excel spread sheet. We'd write down the medications so we could keep track." Pg 31
Finding	The participants all related experiences throughout the child's lifetime when they closely observed their children. They carefully monitored behaviors and symptoms exhibited by their children. They paid attention to the child and to the environment of the child (U)
Illustration	"If we're paying attention, we can catch it before it becomes a full-blown attack. We certainly have to avoid the cold with him. The extreme cold, like when it's 20 or 30 below really seems to bother him. ...One time he went over to visit somebody who had a lot of cats and dogs and birds and everything. And we, as a precautionary, gave him a breathing treatment with the nebulizer before he left. Said, "I know you don't like this, but we're doing this just as a preventive." Off he went." Pg 33
Finding	Participants related their experiences of coming to know their children's behavior and symptoms in relation to activity, medications, climate changes, and seasons. Some mothers described this as being in tune with their kids. Additionally, they recognized environmental patterns (U)
Illustration	"And then over this last year, we were able to see better what times of the year she's more affected. She's definitely affected more in the fall... Uh-huh, when all the leaves and stuff are falling and rotting.... We just medicate her right off. When school starts, we just give her Singulair at night, and then we try to remember to give her Ceravent before she does running club." Pg 34
Finding	Trial and error type of experience as mothers found what actions and treatments were efficacious in the management of the asthma (U)

Illustration	"On the second attack, I had given him a treatment...at 2:00 in the afternoon, and I tested him at bedtime, and he was still hitting 330. His normal was about 260 to 280, is his normal peak flow ...I thought, "I'm not going to give him another treatment: he's obviously doing well." Well the next morning he was barely hitting 100. We took him into the doctor, and I explained that to her. She goes, "Well, why didn't you give him a treatment last night?" And I said, "Well this is why." And she goes, "Well that makes sense: I wouldn't have done it either." Pg 35
Finding	Mothers related experiences of feeling they had to give things up or put things on hold because of their children's illness (U)
Illustration	"So we've missed out on a lot of activities because he is sensitive to the cold. We definitely don't get to do many outdoor activities. Like seeing the ice sculptures would be out. Skiing or walking outside would be out. So we just end up doing a lot of indoor activities." Pg 36
Finding	Mothers' related a normalizing strategy to ensure their child lived a full and productive life despite having asthma. They did not want to treat their child differently than any other child (U)
Illustration	"We've never treated him like he's a kid with asthma. We always let him play as a normal kid. He goes out; plays in the dirt; runs up and down. Our child loves the great outdoors. You can't keep him in... I did notice when he was three that when he'd play in the dirt with his trucks, he'd always have bumps all over his hands. And he does have Eczema, too. Quite bad actually. Yeah. But, anyway, we have never stopped him from doing anything like that. Let him run and play; let him do all that. Just make him come in, take a bath, wash his hair, and keep him cleaned up that way. But we don't say, "Oh, you can't go out; you can't do this; you can't do that." Pg 37
Finding	The subcategory of Expert Mom was depicted by the participants as managing the asthma in their children (C)
Illustration	"We've gotten to the point, now, where if he's having a problem, we try and give him a treatment at home and see how he reacts. If he responds right away, we won't take him into emergency. When he doesn't respond, then we take him in. I feel like I definitely have a better handle on it now than I did." Pg 38
Finding	Participants related experiences of changes that took place during their children's adolescence. This was a time of relinquishing authority and letting go, not without fears and hesitations (C)
Illustration	"Actually she's [17 year old teenager] pretty' good about it._______[14 year old teenager] is the one that is real bad about it. Because he 's supposed to be on the same regime. He's supposed to be on Flovent and Singulair. And he just — unless I 'm right there giving it to him like when he was little, he doesn't take it at all." Pg 39
Finding	Participants related thoughts about what they felt was helpful during the parenting experiences of their child with asthma (U)
Illustration	"I think that one of the best things he [Doctor] did was give us that book to read. And he just -- he's willing to listen to all of our questions and everything. When we go in, _____[daughter] is his focus. He asks her questions and talks to her and listens to her and stuff." Pg 39
Finding	Participants related thoughts about what they felt was helpful during the parenting

	experiences of their child with asthma (U)
Illustration	"Whenever I go see the [Doctor], I just walk out like a weight's been lifted off like, "Yeah, I am doing a good job." It's always like, "Well, he's doing really good this time. He's not nearly as bad as when....Remember the other time when this happened?" Yeah, I think you need that pep talk. You don't need somebody to pat you on the back, say, "Good job." You just need somebody to let you know you're doing everything possible that you can for your child...you just need that reassurance." Pg 39
Finding	Helpful experiences with healthcare providers when her child was hospitalized. Of particular benefit was the information provided about her child's progress (U)
Illustration	"They kept me informed of what they were doing and how he was doing as his lab work got better....And so they said he really needs to be in the hospital and get some IV antibiotics. At first they thought, well, since I was a nurse I knew plenty...but then I said I really didn't know anything about babies with pneumonia....Not a thing. I told them I didn't know anything. So they did [hospitalize child]. They were very informative...they told me everything and how they were doing it and why they were doing it. They expected parents to stay and certainly never discouraged it all. There were parents everywhere...that was good." Pg 39-40

(65) Garcia MK. The Lived Experience of Mothers of Children with Asthma. Denton, Texas: Texas Woman's University; 1996.

Finding	The first element, ambiguous symptoms, caused the mothers to struggle in their attempts to make sense of their children's illnesses (U)
Illustration	"My experience mostly was with sick children and not knowing what was wrong with them. For several years, my oldest son always got coughs that would not go away…used every cough medicine and then the neb. He (physician) never used the word asthma." Pg 82
Finding	Children would be struggling to breathe at night, but have improved by the morning, the mothers began to doubt their own judgment (U)
Illustration	“It always happens in the middle of the night and by the time I bring him to the doctor’s (the next day), I think the doctor thinks I’m lying to him because he’s not even wheezing or he can just hear a little bit of a wheeze, and I just said, "You need to come home with me, I wish you were there at night when we need you." Because I don’t think he really understands." Pg 82
Finding	Mothers found asthma to be a subtle, and hidden disease; even family members and some healthcare providers were often inclined to discount the mothers' concerns (U)
Illustration	"The doctor said "Don’t baby her. You’re being over-protective. She’s not wheezing"……She was using her inhaler every 15 minutes….Same day, took her to another doctor and he admitted her to the hospital." Pg 83
Finding	The mothers struggled with the anxiety of never knowing when, where or why an asthma episode might occur (U)
Illustration	"….never knowing when it’s going to start up, that it could be any day. Is this just a typical runny nose and cough, or is this going to develop into another trip to the hospital? And when might it hit?" Pg 84
Finding	Night time caused the most concern (U)
Illustration	"You pretty much don’t know what’s going to happen. One day he could be fine and

	then….in fact, this happened recently, we put him to bed and he was fine and in the middle of the night he just couldn't breathe…." Pg 84.
Finding	The unpredictability of asthma episodes was a concern that never completely went away (U)
Illustration	"I know I can control the treatment a lot better, but I still can't control when it's going to happen or how bad it's going to be." Pg 84
Finding	Mothers struggled with their inability to determine the severity of each episode (U)
Illustration	"We're always at the point where should we take him to the emergency room? But by the time, it's like okay, one more breathing treatment, after this one, if he's not doing better….we're taking him in. Well, it always happens, because it's getting lighter in the morning and he starts doing better…" Pg 85
Finding	Worry being "paralyzing" (U)
Illustration	"There is nothing more frightening than trying to get to a hospital or doctor's office with a child who can't breathe in the back seat and then not knowing when that will happen again." Pg 85
Finding	The lack of information about diagnosis and severity was a major frustration (C)
Illustration	"Not knowing what I was dealing with, that's what I was dealing with…I thought I was going crazy, I thought I was losing my mind." Pg 85
Finding	Some of the mothers found the complexity, and uncertainty of treatment especially difficult when the healthcare providers gave them responsibility for treatment options (U)
Illustration	"I'm not a doctor and I don't know. But sometimes that is a pressure, did I make the right call? Should I give him .75 or is .5 going to be enough to get him through the night. She (the physician) gives us play with him because she feels like we can see it and we know. We try….if it's ever the wrong call, I feel it would be a real problem." Pg 87
Finding	Although the mothers readily admitted that their children needed the medications to breathe, the side-effects of the medications worried the informants (U)
Illustration	"Another major concern of ours is the steroid use. That is a real, real concern of ours….we read about what steroids can do…..but I'm afraid…Are we curing his asthma to give him cancer?" Pg 88
Finding	While the long term effects of steroids were usually the biggest concern, the Immediate side effects of some of the other medications were extremely troubling (U)
Illustration	"It's one thing for your child to be sick, but it's another thing when the medication that's supposed to help him is making him worse. He didn't know if he was coming or going. He was like an entirely different child, and it was so hard, because I'd try everything to get him to sleep." Pg 88
Finding	As the mothers learned the cues of an approaching asthma episode, they found themselves listening in a special way to their children with asthma (C)
Illustration	"When I hear him coughing, that's when I'll ask him are you okay? That's usually the sign that it is kicking in…." Pg 90
Finding	The mothers expressed concern about being alert to the earliest warning signs, so they could start treatment as soon as possible (C)
Illustration	"I could not come to bed at the end of the day without going upstairs and checking on the kids first to make sure that they were breathing or still alive or you know something like that. I couldn't do it. I could not even turn the intercom off at night…it's gotten a lot

	better…." Pg 90
Finding	Initially, the high degree of uncertainty regarding predictability, and severity, and the complex treatment regimens severely restricted and disrupted family relationships and any social life the informants might plan (U)
Illustration	"Now there has been a number of times where we have planned an evening out, where we have cancelled it, and not gone, because they have been sick, or come down with something….It limits you going, and being out as a couple." Pg 91
Finding	It was not unusual for the asthma, the medication, or the side effects to keep the mothers awake for much of the night (C)
Illustration	"It's worse than having a newborn baby, because not only are you monitoring, you've got to be awake enough to put the medication in. You'd have to be alert while you're doing it, and you're exhausted, but yet you're trying to stay up…" Pg 91
Finding	Mothers perceived that the healthy siblings frequently felt resentful (U)
Illustration	"….there's always been a little bit of jealousy there, because…he has told us that his brother always gets so much attention…" Pg 92
Finding	The marital relationship often showed the strain of the mother's increased focus on the child with asthma (U)
Illustration	"Last year was so difficult and traumatic, and even though my husband was really good it was a really big strain on our relationship and we're kind of trying to rebuild the relationship. Cause when you have a child between you in bed….." Pg 92
Finding	When the asthma was really uncontrolled, mothers talked about being consumed with the care of this child (U)
Illustration	"I just think of a black fog, I was just so worried about it. I couldn't even think or….wasn't even conscious of anything else in my life except that…." Pg 92
Finding	Most of the mothers were primary caretakers of their children (U)
Illustration	"I always end up having to deal with the sick things. I'm the healer. My husband just can't deal with it. I mean he tries, but it's me who has to be all strong. You end up taking care of the husband as another child, and you find yourself protecting the husband from dealing with certain aspects of the disease. You end up making the medical decisions….it was my responsibility, my burden…." Pg 93
Finding	To avoid emergency department visits or hospitalisationss, mothers were willing to be hypervigilant which meant round-the-clock monitoring of symptoms, administering breathing treatments, or doing whatever it took to keep their children out of hospital (U)
Illustration	"I don't sleep. I will stay up and listen to him breathe….when he's really bad…I can put him on the machine every two hours, and that is what has kept him out of the hospital…and I will put him on steroids if he is not responding to the machine." Pg 94
Finding	For some of the mothers, finances were a consideration in treatment options (U)
Illustration	"Financial strain is really difficult knowing what's the right thing to do. He really had a bad time in the middle of the night when he couldn't breathe and we didn't have any money or insurance cause my husband was laid off. So we did all those things (the doctor had told us last year), and we made it through the night, but by morning I was so scared, I should have taken him to the hospital. I know I'll never do that again." Pg 94
Finding	Initially, the mothers experienced a great deal of frustration in their dealings with healthcare professionals (U)

Illustration	"She (the physician) wouldn't listen to me….I kind of get the impression that she doesn't think your opinion counts." Pg 95
Finding	Mothers struggled for years without really knowing what was wrong with their children. When they did get the diagnosis, it was met with a mixture of guilt, sorrow and relief (U)
Illustration	"I think I knew, but I was hoping that wasn't what they were going to tell me. Yet, I was relieved in a sense because, I didn't know what was wrong with him." Pg 97
Finding	Some mothers felt guilty, especially if they had had childhood asthma (U)
Illustration	"And then having asthma myself, I felt a little bit guilty." Pg 98
Finding	Informants started talking to others about their experiences in an attempt to learn more and gain support. Many mothers felt very isolated going through this experience (U)
Illustration	"Even with a totally supportive family and husband, like I feel I have, you're still alone. I don't know whether it's fear. There's just this bond with your child. You want it to be okay. There is something about a child not being able to breathe that's probably the worst thing you can ever go through. Pain while it's terrible, you can comfort; you can get them to think about other things. Not being able to breathe is so basic and it's hard not to panic yourself. I think the feeling of aloneness would come no matter what. It has with me." Pg 100
Finding	Most of the spouses were not as available to the mothers as could have been hoped, either because they travelled or distanced themselves as way of coping (C)
Illustration	"My husband early on, I'd say was in denial….He didn't realise the intense severity, the life-threatening aspect of it until he saw how hunched over our child would get…unable to breathe…my husband was like freaked out." Pg 100
Finding	Most of the mothers did talk to their families about what was happening, and the rarely mentioned family history of respiratory problems, and sometimes deaths, started to be revealed (U)
Illustration	"It was a lot of sharing, networking with my sister-in-law, my sis, by this point there were other children in the family that were going through it. Anytime something would show up in the newspapers, or health magazines….just sharing that information. My sister went to a support group, when her child was diagnosed with it….that's when it really started coming together." Pg 101
Finding	Networking opened their eyes, and they began to understand the meaning of having and caring for a child with asthma. Networking offered them support and information and, in many instances, material assistance as well (U)
Illustration	"It was networking that really got me where I was. That was the key, in conjunction at the same time getting linked up with a good paediatrician and a good allergist. But the networking, mothers saying "this is how I deal with it, this is what I look for, this is what I do when this comes up." So it just all happened to fall in place at the same time." Pg 104
Finding	For almost every mother there seemed to be a demarcation or defining moment when it was the "final straw" or they just realised they needed to be assertive and persist in finding the best care for their children (U)
Illustration	"Finally, I got so fed up, I could not face another year of viruses, and sickness and ear infections and I couldn't do it anymore. I had also learned in the MA Report about asthma specialists…I found one….and I called him up and I interviewed him…." Pg 106

Finding	As the mothers doctor shopped and networked, they found the people who would listen to them and help them. At the same time, a transformation occurred as the mothers became people who would insist on being heard (U)
Illustration	"I've realised that if I don't stand up and ask these questions, nobody else will…And so many people are afraid or intimidated, by doctors….but you're the one who has to live with it day to day and if they make a decision and you either don't agree with or don't understand it. You're stuck. You're the one who has to live with it. They're not the ones who are sitting in your house dolling out the medicine, making the choices and doing all of these things." Pg 107
Finding	Achieving control was facilitated by finding a healthcare provider who would listen, acknowledge concerns, and include the mothers in the healthcare decision-making process (U)
Illustration	"He (MD) will admit, "you understand her better than I do….you get in touch with me or one of my partners at any time." I felt like I had a life line. I could get in touch with somebody who believed….I'm as much a part of the management team as he is." Pg 108
Finding	All of the mothers felt compelled to speak on behalf of their children, and this need extended beyond just being a voice for the children with the healthcare provider. The mothers advocated at the schools, so the best interests of their children would be taken into consideration (U)
Illustration	"I said, "Whatever you don't know, I will teach you (the school nurse)." And a bunch of us got together and bought a nebulizer for the school. It now belongs to the school, and she works very well with us." Pg 110
Finding	The informants were well aware that their children looked and acted normally, but when exposed to certain triggers, the children could become seriously ill very quickly. (C)
Illustration	"He spends the night I will usually ask him just take your sprays, take your medicine along with you. Just in case…." Pg 112
Finding	Informants did not try to hide their children's asthma from others, even if it limited their activities (U)
Illustration	"A lot of his friends' parents are concerned to take him, because when they take him places, you have to take a bag of medicine….I don't think he gets as many invitations to go overnight or on all day activities as he would if people didn't know he was sick." Pg 112
Finding	The mothers lived with uncertainty, but a way of feeling a sense of control was to develop routines (U)
Illustration	"We're just kind of in a routine….His type of asthma is extremely fatal and we just have to blank that part out. And we just deal with it from the start." Pg 113
Finding	When the children were sick, they would usually take medications without objection, but the mothers encountered resistance with maintenance medications (U)
Illustration	"My son says, "Oh, Mom, I don't want to do it." They hate it and I'm sure he hates me bugging him about it." Pg 114
Finding	Episodic denial, and wishful thinking were described (U)
Illustration	"I notice when we go off the medicine for a while, I go right back into denial. I go right back in thinking, gee, they're fine. I don't have to think about this anymore." Pg 114

	"maybe he'll outgrow it." Pg 114
Finding	Packing the drugstore was a form of taking precautions so that family activities could be maintained (U)
Illustration	"Any time we go anywhere for a day or two, I take a huge thing of, everything out of the medicine cabinet, and believe me, it has paid off over and over again…..people see me and they'll go….there's so and so with her drug cabinet under her arm, but I've gotten use to that. You just can't let it limit you, you just have to learn as much as you can and be as smart as you can and make everything as portable as you can and then just get out there and do it." Pg 115
Finding	While the uncertainty of asthma never goes away, most of the mothers had come to have more confidence in their ability to maintain some control (U)
Illustration	"I felt like as soon as I learned as much as I could learn about asthma and as soon as I felt that we had some sense of sanity or some sense of control over it, that's when I felt like I was coming out of the fog…" Pg 116
Finding	Being able to regularly attend school and participate in sports was a goal the mothers had for their children. To ensure attendance at school or daycare like other children, the mothers worked closely with the schools (U)
Illustration	"Each year…I would have to go to school and give my standard asthma spiel to the teacher to make sure she understood what he needed and when he needed it." Pg 117
Finding	Participation in Sports was a concern (U)
Illustration	"He's had a real hard time playing baseball and I will do everything I can to keep that child playing because that is his love in life. We're even going to try basketball….the doctors say "let him be like any normal child, he can do it," so we're going to try it." Pg 118
Finding	The informants often found themselves confused and ambivalent regarding the medications used to treat asthma (C)
Illustration	"One minute you feel like you know everything, and the next minute, I guess when you're trying everything and nothing seems like it's working...." Pg 87
Finding	For all of the mothers, the diagnosis of asthma was important in their attempt to deal with it (U)
Illustration	"But once we got a label, a name for what was wrong, and we were told it's not going to go away tomorrow, everything became a little bit easier. I was able to get information, but up to that point in time --it was just grasping at straws..." Pg 99
Finding	The mothers wanted their children to be children who happened to have asthma and not defined by their asthma (C)
Illustration	"I point out friends of mine who are adults that have asthma and we will see athletes on TV you know like in the Olympics and we'll say oh, yea they got a gold medal but did you know they have asthma?" Pg 119
(66) Clark B. Management of a Preschool Child's Asthma: The Parents' Perspective. Winnipeg, Manitoba: University of Manitoba; 1997.	
Finding	At diagnosis, parents expressed a variety of emotions and reactions to the label of asthma (U)
Illustration	"I remember when we brought him into emergency, and when we, had one mask and it wasn't enough, they had to mask him right away again, and he was, he was really in

	distress. And I remember the fear, just being terrified." Pg 64
Finding	Parents accepted or supported the idea that the disease that they saw in their child was in fact asthma, the diagnosis presented by the physician (U)
Illustration	"...you bring a limp baby. I knew before he even was limp by the wheezing and the rattling in his chest that it was asthma." Pg 64
Finding	Some parents did not accept the diagnosis (U)
Illustration	"I don't really think he has asthma. It only happens with colds. We give him the medications and it goes away." Pg 64
Finding	Parents prior experience with asthma affected the impression that the diagnosis left with them (U)
Illustration	"...my grandfather, he in fact died from complications with his asthma." Pg 65-66
Finding	Parents had to take their prior experience and come to some conclusions about that experience and the relationship between the prior knowledge and the knowledge they had of their child's diagnosis of asthma (C)
Illustration	"It wasn’t really scary for me because my dad has it, so I grew up with it and my husband had it, so he grew up with it." Pg 66
Finding	Parents related a variety of symptoms that they recognized in their child (U)
Illustration	"Wheezing, when his chest is so tight, it hurts. He starts running around, and he starts to choke, he starts to gasp."; "The coughing gets so bad, she can't get off the couch."; The wheezing the phlegm, just the sound he makes, you know. He looks grey, almost like a little old man, as opposed to a very vibrant young boy."; "The indrawing and...the no color in his mouth, he is always pale though." Pg 68
Finding	Parents needed to recognize that the symptoms that the child displayed were actually connected to the diagnosis of asthma. Because the symptoms have often been misdiagnosed several times before the diagnosis of asthma was made, the parents sometimes had trouble associating certain symptoms with the diagnosis (C)
Illustration	"...we thought it was just colds or pneumonia, like we didn’t think this could just be a breathing problem. Probably if we got on and treated it sooner..." Pg 69
Finding	Parents used strategies to work through the phase of ascribing meaning. Some parents used denial as their primary strategy. They were unable to acknowledge the diagnosis (U)
Illustration	"One mother denied ever being told of the diagnosis, did not relate the symptoms she described to asthma and related how her son’s illness was different from her sister’s, and therefore could not be asthma." Pg 70
Finding	Confronting is defined as taking a realistic look at the diagnosis and the impact that the disease had on their child and the rest of the family (U)
Illustration	"It meant restriction, my heart kind of sank a little bit because I thought he might not have the same kinds of opportunities at that moment [limp in emergency] that other kids might have... .it’s something you just have to control." Pg 72
Finding	Parents described the way that they observed the look of their child when he/she was having an asthma attack. They often described them as looking different than other children (C)
Illustration	One mother said that "he looked like an old man instead of a child. Each parent could identify the ways that their particular child reacted; coughing as soon as lie down at night

	was a common example that they related to the asthma; wheezing, the sound you never forget; "I listen to his chest, a friend that is a nurse gave me a stethoscope and taught me how to isten to his chest." " Pg 76
Finding	As parents were given medical prescriptions and recommendations from a variety of places and people, they needed to begin monitoring. Monitoring refers to the need to watch the effect of the medications and other treatments on the symptoms that they associated with asthma in their child (U)
Illustration	"We seem to know if she starts coughing, we start her on her blue inhaler, and she's on the brown inhaler all the time anyway, once a day... so right now, I bumped her to two brown puffs a day, like one in the morning, and one at night and I've been giving her blue inhaler...., before her brown inhaler,... and that seems to help her some." Pg 78
Finding	Medication side effects concerned most parents about asthma medications. The word steroid held a certain concern (U)
Illustration	"I know that all this medication is no good, because a lot of it is steroids. It seems every time we try and reduce them it flares up so we're back to the routine again." Pg 78
Finding	The other complaints about side effects came mainly from the use of Ventolin (U)
Illustration	"I know since we increased it he breathes better and he sleeps better, but he just doesn't sit still. What do you do?" Pg 79
Finding	The symptoms that parents associated with their child's asthma and the associated triggers had to be monitored (U)
Illustration	"I even noticed actually since the snow has started to melt that the mold is coming... that he is getting worse." Pg 79
Finding	Parents made choices about the part they felt they needed to play in their child's asthma care. Some described a sense of total responsibility to one of passively asking the physician every time there were any symptoms (C)
Illustration	"I don't know why it happens like that, but sometimes it's worse than others, or whatever, but I found that it's not necessarily the same dosage all the time...and I don't want to be giving him the dosage that he was on the last time if it's not going to be...., if it's not right this time." Pg 80
Finding	Other parents lacked trust in the physician and the healthcare providers' abilities to assist them (U)
Illustration	"I don't really think they know a lot I was at Wal-Mart one day and they had an asthma clinic set up there and my interest was, whether there were new medications out that could reduce some of his other medications. And she didn't even know what I was talking about. I knew more than the nurse there and the pharmacist knew." Pg 80
Finding	Parents had to learn the steps to prevent an asthma attack in their child. The prevention of asthmatic attacks included appropriate routine medication administration as well as making environmental changes in the home and the places where the child may encounter triggers (U)
Illustration	"We have this new home, we have no carpet, I don't use downy or pretty smelling things with clothes, I sometimes even have to double rinse the clothing." Pg 81
Finding	Some treatment knowledge was required to administer their child's medication at home. Parents described the ways they administered the medications, the frustrations with the actual use of the mask, as well as knowing when to give it (U)

Illustration	"It was always me that had to take him and grab hold of him and get his arm right behind my back, cross my legs and hold on to him while he would scream like hell when I had the mask on his face. I also learned, let him scream. If he is screaming he is taking deep breaths, if he is taking deep breaths the medication is getting way down in there where I want it to be." Pg 85
Finding	Parents needed to make choices about exposing their child to an environment that may endanger their health. Some parents tended to deny their smoking affected their child (U)
Illustration	"When he was small, I used to think why? Why my son? Why can't he breathe right? I blamed myself cause I smoke and I thought I did this to my baby but I really didn't I'm sure smoking doesn't help.... The smoking doesn't bother him ... .He doesn't like the smell of it but then neither do I and if I could quit I would you know, ..I just, I can't do'er. I am weak. You know, I know quitting for him would probably be the best gift I could give him. I just can't seem to get there, you know. I changed a lot of other habits, you know, but maybe someday." Pg 87
Finding	Other parents recognized the smoking threat and were very serious about limiting their child's exposure to it (U)
Illustration	"There is no smoking in the house, there is no smoking in the car, we don't even enter restaurants where there is smoking." Pg 87
Finding	Parents weighed the risk benefit ratio of the treatments, environmental changes and lifestyle choices with how they perceived their child's health. This meant that parents made choices that were not always what had been recommended by the literature or information that they received from healthcare professionals (U)
Illustration	"We had a cat before we had the kids, and they're very attached to her, and I didn't, I don't think that's fair that they have to do without her. Our 8 year old can't pick up the cat because it really bugs him, so we let him have a hamster... We catch a lot of flack for that, like having a cat and the hamster and things, but I don't think it's fair to kids to not have a pet If she [the cat] dies we won't get another one." Pg 89
Finding	Parental support needs varied based on a variety of factors. Some of the single parents tended to seek medical knowledge and psychological support that they needed, from their physician (U)
Illustration	"I always feel better once I've gone to the doctor's with her." Pg 90
Finding	The rest of the family was affected more when the health of the asthmatic child was more complicated. Often other children had their activity restricted because of the asthmatic sibling (U)
Illustration	"Like even the other kids, have said 'Oh well I guess we won't do anything today cause S is sick,' our whole life hinges on how S is feeling today." Pg 90
Finding	Some families identified relatives with previous experience as helpful in providing information or support in the environmental changes (U)
Illustration	"My mother-in-law brought all that— the pillow case cover and the mattress cover and a special quilt blanket for her bed... .She brought it because she knew about it but would I have done that?.. I don't know." Pg 91
Finding	Another way that family members were supportive included accompanying the parent on visits to healthcare providers (U)

Illustration	"He was getting worse and worse... so I went in there mad, and I took my team of sisters with me [laughter], and I said I wanted something done and then that's when we got the compressor." Pg 91
Finding	Parents said that if someone has not actually cared for a child with asthma they would not understand. Parents therefore felt very alone in learning to manage the disease (U)
Illustration	"I was just by myself... Everybody thought I was always exaggerating about it (crying)." Pg 92
Finding	The young age of the child and the need to provide medications on a regular basis meant that child care was a concern (U)
Illustration	"With day care it was hard... I never even knew if they would be giving him his mask if he needed it, and they'd say that he wouldn't need it at all and I'd pick him up and his voice would be hoarse from coughing and I knew that he needed it." Pg 92
Finding	The support that was initially required was the provision of some education about the disease, asthma. This was often done by healthcare professionals first met during illness episodes. Education that was provided to the parents and how the parents felt when they left the appointment often influenced other information seeking behaviours (U)
Illustration	"He (the doctor) gave me a lot of pamphlets and a lot of compassion. He is a very understanding doctor. He is the kind of doctor who genuinely cares about his kids, like every patient he has is like one of his kids, they're not just a number on a file and that makes a big difference.... Because of his attitude I guess he made me want to learn as much as I possibly could about it, so I could help S." Pg 93
Finding	If the parents believed that the physician had not attended to the symptoms that the parents were concerned about, they sought care elsewhere or become more assertive in their approach to the physician (U)
Illustration	"There was one time I wasn't getting through to the doctor, our eight year old has really bad coughing asthma, when his is acting up, and we'd go into the office and his lungs would be clear, there'd be no wheezing, no nothing. He'd walk out of the office, and he's coughing his lungs out, to the point where he pulled groin muscles. He burst vessels in his eyes, until then we got no where.... That was frustrating because I knew he needed prednisone, and I was really ticked off that they thought there was nothing wrong with him. It was difficult to explain how severe the coughing was. We ended up in emergency with a different doctor and we got it that way." Pg 93
Finding	Other support which was important to parents was the quality of the encounter with healthcare providers (U)
Illustration	"All I understood is that she has to take these inhalers, and when to go back to his office again, that's all he told me." Pg 93
Finding	There was also some uniquely rural issues raised. Some of the issues included field burning, exposure to large hog barns, and the lack of available healthcare (U)
Illustration	"In the rural area...there is not always a doctor,...it he comes down with an attack I either have to go to (next nearest bigger town) and his history is not as available to them... You rely on this family doctor and he is all of a sudden gone." Pg 94
Finding	There were also advantages to living in a small town (U)
Illustration	"And they get to know you, especially in a small town, the nurses would recognize you

	and if you came in they knew that he needed some oxygen... .and get it quickly." Pg 95
Finding	Financial burdens of the treatment of asthma created support needs for parents. Medications were often very costly (U)
Illustration	"I said well, I can't afford it, I said I can't cut anymore comers I was already going in the hole with bills,... I just started finding different ways to deal with it. I just bath him twice a week, the bath salts cost way too much." Pg 95
Finding	In the "Learning to Manage" phase, parents had to make some lifestyle choices that had an impact on their entire family. These have included issues such as: having pets in the home, smoking or allowing smoking in their child's immediate environment, the cleanliness of their home, or where they live, going out of the home to work and the way that they are available to their child, as well as the larger environmental exposures in the public (U)
Illustration	"It's easier now, it's second nature. It was hard to learn it, the what to do and how to do it but once I've learnt it, it's just do what you have to do not, it's not that panic situation any more.... You have to control asthma, you can't cure it, you have to maintain and control it. I control it by not giving him foods that are going to set off an allergic reaction., by not having animals, and by trying to keep the dust bunnies down." Pg 100
Finding	The need to anticipate the triggers was learned by parents during the "Learning to Manage" phase. (C)
Illustration	"The room [kindergarten] is fully carpeted. The sand tables area problem, there is a lot of dust." Pg 101
Finding	Parents identified that the knowledge base of others who had not been faced with an asthmatic child differed from their own child's experience required them to do some teaching (C)
Illustration	"My family's the only family in town and I mean they have no idea what asthma is, none of them will smoke around her, or if we go to their house, everybody will smoke outside, so it's just not my house that they have to smoke outside, they have all started to do that. They don't know about it, it just what' s happened with us, is all that they know." Pg 104
Finding	Negotiations had to take place with a child who was gaining more independence (U)
Illustration	"I tend to be a little paranoid. If I send him outside and it is summer and he is not at his friend's house and they decide to go somewhere else, yeah, I do panic, because then I don't know where he is and he disobeyed me and he went to the park.... Like nobody cares about his health or anything, it is just me.... Now we have an agreement, he has to have his medications all done before he goes outside." Pg 105
Finding	Parents were often relieved when the child could recognize themselves, the symptoms and anticipate the needed treatment (U)
Illustration	"...Now, if he's feeling crummy, he'll come and ask for it [medication], the first day that that happened, I thought this is wonderful. It just takes all the guessing out of all your wondering." Pg 105
Finding	Negotiations also had to take place with authority figures, in places where their child would be spending a larger part of his/her day. (U)
Illustration	"They (the school) told me that they didn't want children carrying their inhalers to and from school. I said none of that. So, she carries it with her in her pouch.... I had to finally

	get a note from the doctor to say that she needs to carry it on her person at all times, to convince them." Pg 106
Finding	Sustaining referred to changes in environmental controls or lifestyle choices that had been made by the parents and the need to continue them (C)
Illustration	"People have said to us, well you shouldn't keep him from going to these family dances. Well, are they going to be smoking?... Can people not just leave their cigarettes at home for one night? For three hours?" Pg 106
Finding	The parents were able to adjust the dosages of the medications to a level to sustain their child's health regardless of the situations encountered (U)
Illustration	"When he starts getting better, I switch him from the Pulmicort to the Intal. I make those decisions on my own, but often still get them checked, just pop into the doctors office and have it confirmed. I pretty much have a handle on it now." Pg 108
Finding	Some parents' reactions were more relaxed and unemotional. These children were usually the mild asthmatic cases (U)
Illustration	"it's no big deal to have asthma." Pg 64
Finding	Some parents had prior experience with older children with asthma (U)
Illustration	"My middle one we have had to go, oh he has had to have IV's quite often, we were in the hospital probably every four months with him..I knew before they diagnosed (this child) because it was all so similar." Pg 66
Finding	Some parents felt that the disease seen in their relatives was not the same as their child's (U)
Illustration	"my sister's asthma, she was in and out of the hospital,....he's not like that, I don't believe he has asthma." Pg 66
Finding	One mother described the idea of not knowing exactly what asthma was (U)
Illustration	"Well, I had no idea really what asthma was. I had never, nobody in my family ever had asthma, I didn't know, you know, that your tubes were inflamed and you couldn't breathe and cough, I don't know, I just didn't think that's what asthma was, I don't know. I never thought of it before, why would I need to?" Pg 67
Finding	Parents who were able to recognize some aspects of the disease, but were unable to act on the recognition tended to use the avoidance strategies (U)
Illustration	Parents of one child described having asthma as "no big deal." They talked about how the inhalers helped the colds their child repetitively developed. The father stated he also had asthma. The child reportedly coughed at night and had a runny nose frequently without fever. The parents acknowledged that their child had been diagnosed with asthma, but were reluctant to face any of the accompanying symptoms that their child displayed as being attributable to the disease asthma. Pg 71
Finding	Parents were not given information about the medication side effects and had to learn about the side effects in a trial and error method. They developed trust or distrust in certain healthcare professional's decisions about prescribing, based on the effects that they saw from the medications given to their child (U)
Illustration	"The side effects of the prednisone for her were awful,...he suggested (the prednisone) a few times and I keep reminding him and he goes 'oh, maybe not'....Really I don't think he knows what he is doing anymore. I know he doesn't know what he is doing! You know we try this it doesn't work, oh well, we will just try something else...I said I don't think she

	should be taking this much." Pg 86
Finding	Some parent's lack of prior intimate experience influenced the meaning that they attached to asthma (U)
Illustration	"So, it was scary, I thought oh no not my kid. You know, and all I could picture before me was these emergency trips to the hospital. Some are with oxygen tanks, it looks like you know, but it hasnt been like that." Pg 67
Finding	Another mother was more assertive in her approach to the medical treatment her child was receiving (U)
Illustration	"He was getting worse and worse, so I went in there mad, and I took my team of sisters with me, and I said I wanted something done, and then that's when we got the compressor and he started to get better." Pg 81
Finding	The strategies that parents used to learn to manage their child's asthma included information seeking; using the knowledge; and balancing. Information seeking referred to the need to gain knowledge (U)
Illustration	Parents obtained information from reading pamphlets, from healthcare professionals in one-on-one situations either in the doctors office or in the hospital, as well as from the occasional group session. Most parents received verbal information from their doctor at the initial diagnosis, especially if this was in the office setting. Many parents also identified a lack of information after the visit. Pg 83
Finding	Relationships that the parent was able to develop with other parents of asthmatic children, teachers, friends and family influenced the type of experience that they had. (U)
Illustration	For people seeking day care arrangements, the parents needed to feel secure that the care providers understood the effects of wearing perfume on their asthmatic child. One mother identified this to a worker after recently consulting a paediatrician and the day care worker immediately stopped wearing any perfume. The mother felt reassured and pleased with the day care worker's response. Pg 101-102
Finding	Some parents had learned that to think positively about the changes they had made (C)
Illustration	"They [the family] have all been pretty good..[parent quit job to be home with asthmatic child] if anybody needed a baby-sitter for an asthmatic child or child with allergies, I would fit just great." Pg 107
(67) Fleming S. Children with asthma and their carers' experience of hospital care: decision making at home and in the hospital clinic. Royal Holloway: University of London; 2010.	
Finding	Asthma caused disruption to their identity as the mother of a 'normal child' and the main carer in a 'normal' family social world (U)
Illustration	"That affects us, the fact that it's very difficult for me and my husband to get time together. Which sounds very selfish but it's also quite important. I do not really get any time to myself because I'm either in work or looking after them. It's even silly things like we can't organise to go out because you can bet your bottom dollar that would be the night that one or the other of them would decide they're going to be poorly. I think we went out last weekend. That is the first time we've been out in nearly a year because we've arranged to go out and then one or the other of them has got poorly and it just hasn't happened. If there's any doubt in my mind, I won't leave them." Pg 150

Finding	Uncertainty was one the main themes when the carers discussed their experience of managing their children's asthma. (U)
Illustration	SF: "You said that you went up to the hospital once a month?" Maddy: "Yeah. I mean you do it, I mean you just deal with it I mean I think the worst...the worst time was in the beginning when I knew nothing about asthma and it was just, the worst thing about asthma that I can say is that erm it's not black and white. You have this moggy grey area and it's not, she's this ill, she needs to be in hospital. It's all judgement." Pg 151
Finding	Many of the carers said they wanted their children to be treated as 'normal' children. (U)
Illustration	SF: "Does it have any restrictions on what he (Timothy) can do?" Susan: "No. We try not to let it have any affect at all and we address it as it comes up. I know I keep referring to Zara, but just to show you the way I respond to this sort of thing. She is severely allergic to horses but I still let her ride. I just give her anti-histamine. So I never restrict what….I will always try not to make asthma stop them doing anything; I try and get round it. Y'know if he (Timothy) wanted to run the marathon I'd try and get him lots of Ventolin. I'd try and meet him every 2 miles [laughter]. Rather than saying "Oh no, you can't do that you're an asthmatic". I've always tried to not let it stand in his way." Pg 152
Finding	Some carers, most with children with more severe asthma, said that their children were not 'normal'. (C)
Illustration	Karen: "Because I fetch him home every lunch time. I'm round the school 6 times a day (laughter). Because in the winter, like with his asthma I don't want him running around in the playground in the damp and wet. I don't know if I'm being over-sensitive but we've done this for about 3 years now. Since we had that bad period." SF: "Is that just in the winter or do you do that all year round?" Karen: "No just in the winter. But y'know he enjoys coming home and at least I know he eats his lunch. Whereas at school it's a quick bite of a sandwich and then out again playing." Pg 154
Finding	How having asthma themselves meant they have more empathy with their children's embodied experience of asthma and that they had trust in the effectiveness of medication (U)
Illustration	SF: "Do you think that there's any difference you having asthma?" Susan: "No. Except that you sort of know how it feels. I know how the tightening of the chest feels. And I appreciate the impact that ventolin makes. That's the only thing. I think because I've done it myself, I can appreciate how they feel." SF: "You were talking about having the confidence to put his pulmicort (steroid inhaler) down and up. Do you think it makes a difference with that?" Susan: "I think it probably does because I've done it on myself and I've seen how it works. And also I think it gives me a lot of confidence in the fact that I know that ventolin really does work. So when I'm not there, I feel reassured that he's got something with him that will sort it out. So it probably makes me not so worried about having asthmatic child, the fact that I've got it." Pg 158
Finding	A few carers stated that their children were very involved in family decision making for everyday decisions and the more major decisions (U)
Illustration	Maddy: I like them to have an opinion. I mean for example, my husband wanted to move and we were all unsure about moving so I made us all write a list of the reasons to move and the reasons to stay. Then we had a vote and it was three girls against one boy so we didn't move and we took the house off the market. So they are involved. I mean one

	example, we’d been on holiday for a week, we had a week left and we had eaten out at various restaurants. So we said we’d got 3 nights where we were going to eat out. So we voted as to which restaurants we wanted to eat in and the restaurants with the most votes we ate in so they really enjoyed being involved in that decision. But we like to involve them in making decisions, whether they’re earth shattering decisions or not.” Pg 167
Finding	For carers, using steroids to minimise the effects of an asthma attack was seen as a 'catch 22' situation. Most carers were aware that steroids had side effects but felt the benefits of having a child with less asthma symptoms outweighed the risks of giving the treatment (U)
Illustration	Carol: "But it's one of those…it's catch 22. You know if you don't take them you hit problems so you know if I think we can sort this out and then deal with the issues later. You know like they say about weight and everything. I just think if she is not on them, she's not well so you really haven't got much choice really." Pg 173
Finding	The concept of 'catching the asthma' early before the symptoms got too bad was echoed by many carers who kept a supply of steroid tablets at home, which meant that oral steroids could be given at the first signs of an attack or if their child had a cold which usually exacerbated asthma symptoms (C)
Illustration	Penny: "We’ve been to A&E but he’s stayed out...of being admitted and that’s because Jennifer Murphy (Doctor at the clinic) said "At the first hint of a cold give him a course of steroids." He’s still ended up ill but certainly not to the extent it was before...." Pg 174
Finding	A few carers were unconvinced about the effectiveness of steroid inhalers but still carried on giving it to their children (C)
Illustration	Sally: "And there is prednisolone. I have never been convinced that where they were taking green and brown or red preventatives (steroid inhalers) that they are preventing it at all. There is some evidence to say that in some people they're not. So the most important thing is that she feels that she is doing something about it by having her red puffer." Pg 175
Finding	Half of the carers said that they fully supervised their children's asthma management by watching their children take their medication (C)
Illustration	Elena (mother of Jeremy (7): "No, I give him all his medication....Sometimes I let him do it, but I am there because I think a seven year old has to have a grown-up around him." SF: "And when do you think that he should start doing more himself?" Elena: "When I trust him. He may say, 'I had it', and he didn't. So, I don't mind him doing it if he is in front of me. But not going into the kitchen and say, 'I had it', without making sure that he had it. And that is the responsibility of the parent." Pg 180
Finding	Half of the other carers said they shared asthma management with their children. Even though they shared care with their children, the carers still accepted that the ultimate responsibility for their children's health lay with them (U)
Illustration	Kay: "Now he's that little bit older I can say to him 'Take your inhalers' and he will go away and do it and I can trust him to do it. He would never say to me he has taken them when he hasn't...but Fabian mind you is only seven so...." Pg 183
Finding	Younger girls also were seen by carers to be responsible enough to be trusted to take their inhalers without supervision (C)

Illustration	Annabel: "Because it's not my body or my husband's body...and I think largely I do trust her and I think it has given her a sense of responsibility. I think to be that chronically ill for nearly, most part of her life. I think it's sad that someone has such a thing but I think it has made her quite sensible..." Pg 183
Finding	Children were not involved in decisions because it was considered in their best interests that carers decided for them (U)
Illustration	Elena: "We have to protect children. They are too young to be responsible for anything. He (Jeremy) can't even be responsible for his homework." Pg 167
(68)Wallace AS. Accessing asthma care: a case study of urban children: University of Colorado Health Sciences Center; 2006.	
Finding	Strong desire to be comfortable with the healthcare they access of behalf of their children (U)
Illustration	"The staff are nice. That's familiar to me. I like it. I'm comfortable there." Pg 82
Finding	Accepting of an ethnically and racially diverse clientele, with Medicaid or without insurance (U)
Illustration	"I mean even though the appointment thing's horrible, the, you know I live far from them, but I still do go to it because the reason why I like Denver Health is it's - how can I say this? When I moved to the Westminster area and I had, and you know had to move clinics for myself at that time - it's the way that they treat you. A lot of people, cause I know the people at Denver Health, so they, you know they're, I'm cool with them, I, you know, they're courteous. But if you go to the clinic and you just deal with different racial, you know races you know, different kind of people, there's a big difference... And if you have money or you don't have money, that's the difference. Denver Health will help you even if you don't have money." Pg 82
Finding	Of utmost importance is the feeling that health professionals are responding appropriately to their child's needs, in terms of attentiveness and quality treatment (U)
Illustration	"Every time I've ever came in there with an emergency with her [child] having an asthma attack or something, the people have been right on it. There's been like four or five people right on her. I can never complain about that. . .I've heard of other people go in with emergencies in other hospitals with their kids and have had asthma or breathing problems, and other hospitals I've heard of don't respond near as quick.. .In such force." Pg 83
Finding	Another significant aspect influencing parents' perceptions of the quality of healthcare administered to their children is the feeling that care providers respect their roles as parents (U)
Illustration	"I think I like most of the doctors. If you tell them something, they listen. Not like most doctors who know everything and know nothing. They at least explore the possibilities of what you're saying." Pg 84
Finding	Parents even believed that not having their concerns and assessments appropriately addressed by the care provider resulted in inaccurate diagnoses (U)
Illustration	"I know one time I was in and I was sure she was getting RSV, or whatever it was, and they told me, no, that she was fine. I brought her back the next day and "oh she has it." I knew that she had been in contact with it. I knew she had problems with asthma anyway." Pg 84

Finding	Feelings of not being heard by healthcare providers also undermines trust in the healthcare providers in general, placing parents in a defensive position during the healthcare interaction (C)
Illustration	" .. .Nobody knows your kids like you. You know I mean you can go into anybody, to any doctor and they . . .you know they need to, your kid needs this or that. You know you're a parent - as a parent you know your kids." Pg 85
Finding	Parents voiced concerns about the long term effects of asthma medications; however, these concerns usually focused on the long term effects of asthma medications, primarily steroids, and tailoring the regimen to their own child's condition (U)
Illustration	"Well, in some ways they [doctors] don't [know what's best] because well I'm always hesitant about medicines, you know, steroids or things like that. . .she's real sporadic and I don't think it's a good idea to put the kids on drugs or something long term." Pg 86
Finding	While parents generally endorsed the use of medications, they gave a wide range of responses when asked whether or not they actually felt like they had control of their child's asthma (U)
Illustration	"I think sometimes I have it under control" and "I have pretty good control over it." Pg 86
Finding	Asthma management becomes easier as children age, primarily because parents can start relying on the children to communicate their level of discomfort and concomitant needs (U)
Illustration	". . .it seems like as he's gotten older it's, as far as you know the breathing and all that, it seems like he's gotten better. So far as control, I would say about 70-80 % ... .when their little it's harder, so now it's easier cause I have my daughter to help me out with that, you know cause she's learned some." Pg 87
Finding	Some parents emphasized the struggle to administer medications to their children (U)
Illustration	"He's [the child] pretty good. When he, but when he's sick he's the kind of kid who don't like to take his medicine. .. .so then you're fighting with him for a week to take the medicine so then by [inaudiable] day when I'm there to see the Dr., he's pneumonia-like, you know what I mean?" Pg 87
Finding	All participants noted that this healthcare system provides quality services regardless of one's personal circumstances and ability to pay (U)
Illustration	"They don't make you feel like scum if you don't have the $25 copay." Pg 88
Finding	Medication costs appear to act as the most significant barrier when children are not covered by insurance, or when co-pays are more than families can afford (U)
Illustration	"Before I was on Medicaid, sometimes I would have trouble being able to pay for her medication." Pg 89
Finding	Parents who acknowledged accessing the system's urgent care clinic and/or emergency department stated that had do so only when their primary office is closed (U)
Illustration	"what happens is during the night he starts breathing heavy and it won't go, that's when I take him to the hospital." Pg 90
Finding	Parents reported going to urgent care or the emergency department when their child was in extreme respiratory distress (U)
Illustration	"Her lips were turning blue and everything else. So we had to go to the emergency department." Pg 90
Finding	As opposed to wait times, which seem to act more as a nuisance than a threat to

	access, the lack of appointments available in primary care clinics appears to have a significant impact on where parents seek care for their children in this health system (U)
Illustration	"Cause sometimes you don't you know, I mean if he doesn't, you know if he needs care - I mean if he needs to be seen and if I call and "You can't be seen 'til the next day," you know if he's sick that day I ain't going to sit there and try to make an appointment for the next day. If he needs to be seen he needs to be seen." Pg 91
Finding	It appears that those who feel they have ready access to their child's primary care providers feel it's convenient to receive care in their primary care office (U)
Illustration	"They've [the primary care clinic] been very accommodating, you know, when I call for an appointment they get me right in . . . " Pg 92
Finding	The ability to get appointments appears to be a benefit of having a continuing relationship with one healthcare provider and/or clinic (C)
Illustration	"Because he's dealt with him since he was a little boy, well since birth, we basically when I go in to see he always remembers who he is; he always knows exactly what to tell me he needs . . .I guess it's because I have been dealing with it so long that I know that if I call the clinic and he's [the doctor] is not there I can normally, they'll let me know when or if he'll be back in the office, into the clinic that week." Pg 92
Finding	Parents also feel as if their providers accommodate treatment to their needs while helping them overcome barriers while managing their child's asthma, especially in terms of getting medications refilled (U)
Illustration	"Like say for instance yesterday he was saying that his breathing was bothering him. He had used up his medicine that he had at school and I was able to call [her primary care provider], get the prescription refilled, and had him back on his medicine in 24 hours." Pg 93
Finding	Parents interviewed could not identify one person in the healthcare system from which they normally seek healthcare for their child (U)
Illustration	"I've just called and made the appointment and then who I see is who I see. They don't, I've never really specified this doctor I want to see." Pg 93
Finding	The minority of parents communicated that they lacked knowledge regarding their child's asthma diagnosis often attributed their knowledge deficits to a lack of education about the condition (U)
Illustration	" .. .you know at this point I don't understand what kind of asthma she has. I just don't know. I know that she's coughing a lot but she was coughing a lot and I didn't know but things like that - I just think needing to know." Pg 94
Finding	School based asthma education programs were helpful and informative for both children and parents (U)
Illustration	"They've [those in the school based asthma education program] explained to me about smoking inside the house, changing my clothes, even if I'm going to be smoking outside not wearing the same clothes inside. Keeping her away from things that I know that will make her react. All the things I should know." Pg 95
Finding	Services might be more informative and personal (U)
Illustration	Parent stating her desire that care providers explain asthma "to me instead of giving me pamphlets and telling me to read them." Pg 95
Finding	While participants often communicated that they can control their child's asthma, many

	communicated that exacerbations require immediate treatment (U)
Illustration	"We usually - well, when he’s having an asthma attack, I usually go to the urgent care. If his asthma gets that bad, it just can’t wait." Pg 96
Finding	It also appears that the level of accessibility of urgent care reinforces accessing these services for asthma exacerbations (U)
Illustration	"Because they [in the urgent care clinic] take care of him right away. I know that, when they know he’s having an asthma attack." Pg 96
Finding	Use of the urgent care clinic seems reinforced by whether or not parents feel there are barriers to gaining more immediate treatment in their primary care clinic (U)
Illustration	"Because they usually make us wait like a day for an appointment or they don’t have any available appointments. Or I could be sitting in their office all day waiting for him to be seen so they could fit him in versus just taking him to the Urgent Care and he can be seen and they can assess it. And if it’s you know not, I mean it’s, I don’t want to - time is not on his side you know? And that’s how I feel. And I mean he’s made me and Devon aware of you know on different occasions that you know you can pretty much die from it. So that’s where I’m at. I don’t, you know when he’s like constantly complaining or more than one day complaining then you know what, I just take him in." Pg 96
(69) Koenig KM. Living face to face with breathlessness: an interpretive study of low income families' management practices in Latino and African-American infants and toddlers with severe persistent asthma: University of California, San Francisco; 1999.	
Finding	Since symptoms began insidiously, usually with a benign 'cold', a runny nose and maybe a cough, parents found themselves dealing with asthma before they could reflect on what was happening (C)
Illustration	Freddie: "We just went with the flow. ... We do it because we had to do it because he's our son, he's sick and we have to deal with it period. And we have kids to take care of and we have to do it period. It's like you have to go to work. You don't think about it. ... You don't think about why. You just do it." Pg 109
Finding	Discovering one's child had asthma meant finding oneself within a threatening and largely unknown world (U)
Illustration	Lara: "You have to have it or your kid has to have it or someone very close to you that you love more than anything in the world before you could realize what asthma is. I thought asthma was just, oh you can't breathe. You know, you have a hard time breathing [for example] when they run. It's not even like that, it's, you can't breathe. You cannot breathe." Pg 110
Finding	Anna, who herself had been hospitalized with asthma as a child, suspected that 15 month old Araceli might have asthma when the first symptoms began. Anna understood how asthma felt from her own experience (U)
Illustration	Anna: "It's like after that, she was, just kept getting sick and then they diagnosed her, they said it was asthma. ... But I noticed it, like all the symptoms like I would get, like she would have wheezing, she would have coughing like her sides would pull in and you know I just, just could tell the way she felt, because like that's the way I get too when I get real bad." Pg 113
Finding	Anna helped a doctor establish the diagnosis (U)
Illustration	Anna: "... Like the reason why they diagnosed her with asthma because they said, cause

	I would tell them well maybe it's asthma. And they said, yeah maybe it is cause the same like symptoms and all that so. Like I probably wouldn't know if I looked at her and she was sick and I wouldn't know what was wrong with her if I didn't have it and ..." Pg 115
Finding	Lucy told what an earlier diagnosis of asthma would have meant (U)
Illustration	"Well if they [the doctors] think, I mean if it's asthma say it's asthma. Don't say that we don't want to say it's asthma. If it's asthma say it's asthma, don't just treat it. ... If you got one doctor saying it's not asthma, you got another doctor saying "we don't like to say it's asthma until he's 2 years old." . [S]ome of the doctors at [the children's hospital are] saying, "Yeah he has asthma." So I go back to the clinic. Well this doctor says he has asthma. ... That's what frustrated us the most,that nobody wanted to say it was asthma. ..." "If they had told us it was asthma, okay we know what's wrong with him. He has asthma. ... We would have looked up into it more. We would have asked more questions about it? We would have read up more on it." Pg 129
Finding	Asthma was frightening. She had learned from the media and from her mother that people die and may die suddenly from asthma (U)
Illustration	"Before I was like I didn't think asthma was that serious you know. But it's serious and I mean a lot of people have just died from that. I mean like even now that I hear more kids die from asthma. It's like you know, "Take asthma seriously." But a lot of people die from asthma. I guess cause I don't know a lot of people who have died from asthma, but a lot of people do die from asthma." Pg 116
Finding	When sick with asthma, Anna felt fearful and unsure of what crisis might lie waiting, and worried that she would not get better (U)
Illustration	"Like I'm like, gosh am I going to get better and you know? I'm just real worried." Pg 117
Finding	Asthma meant being vulnerable to protracted weakness (U)
Illustration	"It probably, it probably is that she has weak lungs or I don't know. They said that that could be it. They said she has sensitive lungs and she can get sick like that, real fast." Pg 117
Finding	Discovering asthma meant for Anna the rediscovery of her own helplessness, helplessness especially acute when she was alone as she struggled to breathe (U)
Illustration	"I mean seeing like my daughter sick ... I just think, I hope nothing happens to her. I just start thinking like, oh what if this happened and I just start crying and, but that's usually when I'm by myself [and] she's sick and I don't have nobody there with me. ... It's like, cause I just thinking stupid things. Like oh my gosh, I'll just think about like if she stops breathing. Oh God what am I going to do and stuff like that." Pg 119
Finding	The Search for a Helpful Explanation (U)
Illustration	"I don't even know. I don't even know why people get asthma. I don't know. ... I don't know why. Like I think once, I don't even know what asthma is. I mean I know what happens, like when she's having an asthma attack. I know how she gets when she you know, how she feels and stuff, but I mean I don't know what it is. I don't know why people have it." Pg 121
Finding	Anna continued the search for a reason that would give her a handle on preventing Araceli's symptoms (U)
Illustration	"Because I'm just, [don't] want her to get sick. You know I'll do anything just you know to

	prevent her from getting sick you know. But sometimes she just gets sick anyways. I mean if it's cold I take her and cover everything and have her covered up real good all the time and she just gets sick." Pg 122
Finding	Although Anna would "do anything" to spare Araceli's being sick, she believed that the severity of Araceli's asthma was largely out of her control (U)
Illustration	"Uh uh. It's just when it happens, it happens. And I just have to deal with it. Take care of it, take care of her, give her her medicine and ...." Pg 123
Finding	Freddie recalled his relative naivete about the illness at the time medications were first prescribed. From the vantage point of greater skill and experience with the disease he recalled his earlier lack of understanding with some fearfulness (U)
Illustration	"I had, I had no understanding of... when we, when he was first prescribed albuterol, the very first prescription of albuterol, I just thought when you gave it to him he's going to be fine and that's that. I had no idea,that he needed... I just assume when you take medicine that's that, you're better. But I had no idea that it was something y'd have to take ... every three hours, every four hours." Pg 129
Finding	Instead of accepting blame when they felt accused of doing something wrong, they were hurt and angry (U)
Illustration	"It's like you're treated as, "What are you doing wrong for him to be having these attacks." That's the attitude that I get." Int: Everywhere? Freddie: "So far. I mean, well, I mean I don't want to say everywhere, I mean well the clinic and the hospital. Are you giving him his medication right, as prescribed. Well, of course, I am. But just sometimes when they don't get well, and I know for a fact sometimes it don't work because my nieces [who also have asthma] still do that. They take their medication as prescribed and sometimes their attack is so bad that they have to get admitted." Pg 132
Finding	Once sure of the diagnosis, Lucy and Freddie were angry at those who provided inadequate management plans, incomplete, inaccurate diagnoses, and impeded their access to specialty care (U)
Illustration	"Well, we tell them [the doctors at the clinic], "Hey, he's already been in the hospital they already told us that he needs this kind of medication and he has more clinical visits than you can imagine. And we want to get to the bottom of this." And their, and his attitude was "who are you to tell me type." And when my mother-in-law says, "Hey, just refer us to a specialist we're getting tired of this, just refer the specialist I'll pay for it." And no he refused. Pg 134
Finding	Asthma can be controlled or prevented (U)
Illustration	"Back then I thought they could just stop it completely. ... I thought they could stop it completely or find out what was causing it so I could keep it away from him." Pg 140
Finding	Attentive to Reggie's everyday moods, appetite, and the subtle signs of breathing distress, Ruby became skilled in assessing his state of health (U)
Illustration	"I could figure out when he would have an attack before his attack would get too crucial. ... I could tell by his attitude. His attitude would totally change. He is a very happy friendly baby. If he just sat there, (to child) Yes baby. If he just sat there and he didn't want to be bothered, he didn't want to be played with, he was going to have an attack. When he was like 3 or 4 months. Even then cause he was a very happy baby. Very happy." Pg 141

Finding	Lost Voice and Scary Scream (U)
Illustration	"He cannot talk if he's having an asthma attack. It's like aak (demonstrates), in every, he's gasping in between every word. He cannot talk. He will scream, but he can't talk. ... [I]t sounds terrible. It's a scarylike scream. It's scary for me too if he gets really bad. It's scary for me too." Int: "What are you afraid of most?" Ruby: "Him not breathing at all no more. Him just not breathing at all." Pg 142
Finding	Ruby identified asthma as the biggest stress in her life (U)
Illustration	Ruby: "Yeah, it's hard because I have an asthmatic child, my mom's HIV positive, my dad has cirrhosis of the liver and it's just... oh God, I just take it day by day." Int: ... "You said you weren't [had not been] working for awhile." Ruby: "Oh God no. I was, I just went back to work in December. ... I had been off since, I had been unemployed since July, but I had to get back to work because the bills are closing in on me." D4.2 p. 25. Ruby: "I have to go to work to pay the bills, because AFDC gives me next to nothing. So I have to go to work to pay the bills, but I have to be there for Reggie if he has an attack so. If I don't go to work, I'll lose the car, lose the apartment. So it's like, I don't you know, it's a split... it's crazy." Int: "So you're torn?" Ruby: "Yeah. I have to go, I have to pay these bills and get clothes on their back and food on the table and I have to go to work. So. That's the only other stress I have besides his asthma." Pg 147
Finding	Feeling torn between wanting to support herself and her children and wanting to attend Reggie closely (U)
Illustration	"[Asthma is] a big problem to me all through the day. Even if I'm not around Reggie. Whoever has Reggie, I'm going to, I'm calling them constantly to make sure he's all right. I feel comfortable when he's with Franklin. Well, I feel comfortable when he's with grandma too, but grandma's a little older and she doesn't really understand a lot. Franklin, doesn't understand either, but Franklin knows what to do if this happens or that happens or if that happens. Franklin's, he watches so he kind of knows what to do." Int: "Without the support [you get] from your grandma and your boyfriend. That would be very difficult." Ruby: "I'd be; Oh! I'd die. I would be really stressed out then." Pg 147
Finding	Her questions about asthma primarily concerned how to assess a crisis and how to respond appropriately (U)
Illustration	"So the things I've asked about asthma is: How crucial is it? How long does he have to get to the hospital? When would I know when an attack is coming? That's how I know about the ribs. I asked the doctors that. And they say to keep him away from cigarette smoke, but I don't smoke cigarettes." Pg 149
Finding	No desire to understand the physiology of asthma (U)
Illustration	"Let me see. I don't have no understanding about asthma. I just know the things that I'm supposed to do to stop my son's asthma attacks and getting too crucial. I understand that it's a breathing disorder and I know the things that I'm supposed to do to stop it from happening." Pg 149
Finding	Because there had been no answers to reverse Reggie's unrelenting symptoms, Ruby felt let down (U)
Illustration	"Yeah, that's what getting me, that it's continuous. Now I thought it would be over with by now, but I guess. Not over with, but this they would some how be able to help me control it. And I'm not getting that. I'm not getting that at all. You guys don't understand what I go

	through. Nobody... Other parents might understand. I don't know if the doctors really understand or not, but its I want to figure it out. I wish I had them machines to do the testing. I'd figure it out myself. An allergy test or something." Pg 166
Finding	Doctors did not appreciate her knowledgeable attention to Reggie's asthma (U)
Illustration	Int: "You told me before the doctors don't seem to trust that you know what to do about the asthma." Ruby: "That's why I think they want to hospitalize him every time he goes, because they figure if I keep bringing him to the hospital, then I must not know. You know, which I do know, but I feel like the hospital can do a little more than I can. See if they have all those machines and all that stuff, you know." Int: "So they don't, they don't really know how much you know about asthma?" Ruby: "No, they don't. They think I'm just another young kid coming in there with an asthmatic child. But I've been, I've been paying attention." Pg 167
Finding	Ruby brought Reggie to the hospital knowing that she understood his asthma well, believing that hospital he would benefit from professional and technical care, and wanting reassurance because she feared Reggie might die in asthma crisis (U)
Illustration	"But I feel like the hospital, I feel like the people at the hospital know a little more what they're doing than I do. And I feel like if he's going to, if he's going to barely die they're the ones that can save his life. The hospital's the one. Sometimes I do know the things and I don't have to take Reggie to the hospital, but I have to have that second reassurance from the hospital that he's okay." Pg 168
Finding	She actively absorbed the caregiving practices that she could use at home (U)
Illustration	"When [Reggie] stayed two nights in the hospital it was me and my cousin. I think I left her two hours, came home showered and changed and I went back up there with my cousin. ... I want to know what they're going to do. I want to see what they're doing. I want to see because it, I feel like, if they're going to do something different I want to be there to see. So if I have to do it at home, I'll know what to do. So I like, when, if he's staying in the hospital, I like to be there myself. I don't want nobody to tell me what they did, I want to see it. If I have to do it at home, I can do it myself." Pg 168
Finding	Ruby believed the doctors could collaborate more with her in managing Reggie's care (U)
Illustration	"What I would really, really like from a doctor, I don't like running my kids to the hospital all the time when I know exactly what they need to get better. I would to be able to call that doctor and see if that doctor could call up for a prescription. Not saying that I would call everyday, every two weeks, every three for the same prescription, abusing you know the license of the woman or man or abusing the situation. Just when I know it's critical... Just to what I know is critical. They can call in the prescription for me. You understand?" Int: "So it sounds like you'd like a little more cooperation." Ruby: "Yeah. Yeah, I would. ... That's what I would like. For them to understand that I know what I'm talking about as well as they know what they're talking about. Cause I'm living this nightmare." Pg 171
Finding	All parents interviewed for this study wanted very much to avoid the possibility that their child might be hospitalized (U)
Illustration	"I would do everything I could to avoid going to the hospital." Pg 179
Finding	Emotional discomfort during breathing treatments was impossible to avoid (U)
Illustration	"Well ... in the beginning. She was like barely a baby. I'd have my brother help me. My

	older brother. He'd come and visit and I'd say, "Hold her down." Cause he’s a lot stronger cause. I said, "She might be small, but she can wiggle and move and..." So I'd have to have him hold her down, hold her hands back and put it on her face. Until she gives up and she has to sit there and cry and just take it." Pg 187
Finding	Resolve this conflict by omitting or delaying Susanna's breathing treatments altogether (U)
Illustration	"Sometimes I would feel so bad to give it to her, that I maybe skip." Pg 188
Finding	Feelings of defeat were clearly tied to what she wanted to do but could not do for Susanna. (U)
Illustration	"Well, it makes me feel bad that I can't do more to help her. That I have to take her to the hospital. Cause she does not like going to the hospital. She doesn't like the doctors. So it makes me feel bad that I can't do more. I can't help her out with you know, her breathing. I can't give her anything to make her feel better." Pg 188
Finding	Despite feeling defeated in needing to seek emergency care for Susanna, Maria had developed a certain level of confidence about being able to determine when Susanna needed to go the emergency room (U)
Illustration	"... I gave her the inhaler. Nothing was working, so I decided just to take her in. Usually when I take her in, they would give her stronger medicine and she would be okay. And I guess this time that I took her in, it was wasn't working. Her oxygen was low and they were giving her medicine after medicine and the doctor decided just to her leave in. And that was just her first time. I was surprised that she could actually... she didn't look so sick. I seen her worse. I've seen her worse than that. She never was hospitalized. Usually her medicine would kick in. This time I was surprised that she even stayed and she wasn't as sick I'd seen her before." Pg 190
Finding	Tonya, Maria, and Anna experienced a disconnection between their understanding of the medicines they were giving to control symptoms and the use of these medicines for management of asthma (U)
Illustration	Int: "Do you know what the different medicines do to help Araceli get that better?" Anna: "No there's a lot of them. I don’t really know but I know they make you get better. Like I know like the, when I do the nebulizer it helps her breathe better and that... what are these here called? The bottom ones, the yellow ones?" Int "The [brand name of non-steroid anti-inflammatory medicine?" Anna: "[Brand name of non-steroid anti-inflammatory medicine.] Those I guess they help open, take the swelling you know. These (albuterol) like, I don't know, like opens her bronchials up and help her breathe better. And the steroid syrup I guess just, I guess loosens her lungs up too. I don't know." Pg 191
Finding	During the first recognition of a breathing crisis, Lara was motivated to seek help (U)
Illustration	"I was just like, just shocked like, "God you know it’s taking her that much to breathe. She needs to go in. She needs help." When you're putting that much effort in to trying to breathe, you should, you're going to need oxygen. I didn't know what was wrong with her." Pg 219
Finding	Parents chose varied strategies to relieve asthma distress (U)
Illustration	"If it’s totally to where we know that it's bad, we'll take her to the emergency room, [children's hospital] emergency. Basically all we try to do is we catch her runny nose and

	we try to get medicine before it gets worse, and they [walk in clinic providers] don't give us the kind of medicine that she needs. It's always [over the counter antihistamine and decongestant]. So we'll just give her, her inhalers [left over from previous emergency visits] ourselves. We just give her inhalers before it gets worse." Pg 224
Finding	Remained actively attuned to asthma and learned to recognize the qualities that distinguished common symptoms as signals of asthma (U)
Illustration	"[W]e'll know if she's catching a cold, when she'll cough at night. Not now, but in the winter. That's how we know. Those coughs. And another thing we learned, is those coughs are asthma attacks. ... We thought that cough was a cough. A cough is a cold you know. For us people cough as a cold, but for asthmatics, a cough is an asthma attack. Especially during her sleep or during nap." Pg 225
Finding	Reverted to self-care practices until they felt there was a crisis requiring hospitalisations (C)
Illustration	"[I]f she's already coughing and stuff and breathing hard then, we take her to the emergency. That's how we make our decisions by her, what's wrong with her. We try to get her in before it's, it's too late. We try to get medicine before it's too much worse ...." Pg 225
Finding	Belief in the Importance of Meticulous Attention to Prevention (U)
Illustration	"I try to do as much as I can at home. My window sills, I go through maybe every three weeks, I [bleach] or I sterilize all my windows. And I clean all the mold off the windows in my rooms. And I really have to go through the house and really clean. Really good. And I try to do it as often as I can, but it's real hectic because it takes all day to get things because we talk mold, dust, anything could trigger it. But she's done so well, I don't know if it's because of the summer and that there's not, I don't know. The blooms are out and I've really watched her with the trees blooming and I thought that that would really get her." Pg 227
Finding	Wanted to avoid using steroids on a regular basis (U)
Illustration	"I really tried to keep Bette away from the steroid part and I try to do as much as I can at home." Pg 227
Finding	Strategy for preventing Carolina's exposure to cigarette smoke (C)
Illustration	Javier: "I always have to wash my hands. When I go outside and smoke a cigarette, all the time [I remember] to wash my hands when I touch her or pick her up. ..." Int: "And you've noticed that the smoke makes a difference." Javier: "Yeah, that's what the doctor said. ... So I had to stop doing that." Lara: "Well, he's always smoked outside though. I don't like the smell of cigarettes." Pg 230
Finding	Avoiding others who smoked was more complex (U)
Illustration	Lara: "Just last weekend, no the weekend before, me and her went to his aunt's house and they smoke. They smoke cigarettes and I didn't want her to be there because they smoke cigarettes. And they smoke in their house and we were watching TV and they were smoking, and I asked them to open the doors and windows and they did. And I gave her inhalers, but she was like, "Stop already." She told them like that. And so I took her into his cousin's room where nobody smoked or nothing. So me and her just stayed in there the whole time. Cause in that room there's no smoke." Pg 230
Finding	Carefully supervised Carolina's contact with other children (U)

Illustration	Lara: "Not really. We don't really want, I mean it's not that we don't want her around kids, it's just that you know kids have a lot of germs and with her asthma we get scared of her getting sick. So it's like "Don't touch her. Don't." So nobody never comes over that much. But I mean she does play with her cousins [who lived in Los Angeles and Oregon]." Javier: "When they're not sick." Lara: "When they're not sick." Pg 231
Finding	Parents restricted their children's outdoor play on windy days (U)
Illustration	Elena: "Yeah and I feel bad when these days are windy and she wants to cry and cry. She wants to go out. The air, you know it has too much pollen and that's what the doctor told me too, that it could be the air. When I see that it's sunny and it's not too much windy. I just let her go out. I let her go out all the day." Int: "... [W]hen she's inside all day instead of outside in the wind, have you seen that make a difference in her breathing?" Elena: "Yeah, when [there's] too much wind and it looks like it's going to rain, she's outside and she starts coughing. And she comes in she starts coughing a lot. So that's why I go, no that's, it's bad for her." Pg 231
Finding	Developed a level of confidence about when to take Issac to the hospital (U)
Illustration	Abby: "I can tell, I can tell, pretty much every time I knew that something was wrong with him, I was always right all the time. Maybe once or twice I was wrong and they'd send him home, but hardly ever am I wrong. Practically every time [he'd be hospitalized] unless it was just for an ear infection or something. You know mainly every time I take him in for his asthma and his wheezing, usually they admit him. Most of the time. 75 percent of the time." Pg 234
Finding	Emergency room procedures also challenged Abby's confidence (U)
Illustration	Abby: "They took his oxypulse, or whatever..." Int: "The pulse oxymeter they put that on his finger?" Abby: "Yeah. It was like 90/92,93. And that wasn't too good to them. They don't like that. And that's what scares me is because he could be home and I wouldn't notice and what if his oxygen was like 90 or 91. How am I going to know that kind of stuff? And that's really bad because they don't like the thought that it gets down that low and they automatically put him on oxygen. How am I going to know [when] it gets down that low?" Int: "So that number is really important to you?" Abby:"Yeah, to me because it is to them. As soon as that machine starts going off they come. I mean it scares me." Pg 235
Finding	Learning as much as she could was a priority (U)
Illustration	Abby: "I mean it's, [thinking about what I could do] just drove me nuts. It was like, it drove me nuts thinking about it all the time. It's like God. ... I would always sit there and while the therapist was giving him treatments. I would sit there a lot of the times and just talk to them. And why is he like, why is it, why, I would always ask him questions constantly. ... Look if you get tired of me asking you questions you can tell me to stop. And they're like no no, it's okay. I was always just wanting to learn something from what happened or why are you guys going to do this or just learn things so that I would know." Pg 236
Finding	She wanted professional guidance in a situation that was for her confusing and unfamiliar (C)
Illustration	Corrine: "I didn't want to come home, not that I didn't want to come home with the burden [but] because it's a problem that she has, but I didn't know enough about it. See,

	I felt more comfortable if I was there with the help and with the knowledge of these other people that knew what they were doing.... We'd been back to the ER 3 times already." Pg 238
Finding	the pros and cons of the decision to hospitalize (U)
Illustration	Corrine: "I wanted to bring her home because I didn't want her to have to go be terrified. [At the children's hospital], they make it, they try to make it the best, relaxed. They [don't] w ant the kids ... to be afraid of going back. But I knew they were going to have to poke her ...." Pg 238
Finding	worried that coming home might be detrimental (C)
Illustration	Corrine: "When you're at home with them you feel so sorry for them that when they cry and you're trying to give them a treatment that you let them take as much as you can take and then you let them rest. Where at the hospital, they don't do that. They know what they have to have. They know what's going to make them a lot better and a lot faster." Pg 239
Finding	Recovery might take much longer without suctioning and IV medication (U)
Illustration	Corrine: "[It] would have probably made it a little bit easier. ... To bring her home. But I felt that I wanted her well quick. Because she had suffered already for two or three days. ... [B]ecause they intravenously have her steroid in her and they're just constantly suctioning her so she could breathe and that muscle could open up in her lungs and I mean stuff that we couldn't do here. We couldn't do that here at home. I could have brought her home and it could have taken us three weeks for her to get well, when it took her five [days]. ..." Pg 239
Finding	Asthma's Undiminished Fearsomeness (U)
Illustration	Abby: "... [H]e would like he would be grunting for air sometimes. Like (she demonstrates gasping and grunting and then holding his breath), yeah and for a long period of time he would like (she demonstrates) and then ...hold it and then that's I jumped up out of bed and I grabbed him and took him to the hospital. That scared me. Cause he'd be like grunting and hold it like, (she demonstrates breathing) I could hear it. I could hear the way it was. It didn't sound good at all. ... That's when I just barely started to know all about this stuff. ... There was just a lot of times that he was just really really bad. Really really bad." Pg 245
Finding	relationships with asthma after long experience in dealing with crises (U)
Illustration	Maria: "And then she starts, you can see her, she starts breathing, you can see her veins from her neck." Int. "Oh, so she really struggles to breathe." Maria: "Yeah. A lot. When she talks she can, can't even hold a whole sentence because she has got to take a deep breath." Int: "How are you through all this? ..." Maria: "Well, it's been so long, already I'm used to it. So. I know more about it." Pg 246
Finding	Asthma Management Disrupted by Other Life Concerns (U)
Illustration	Vicki: "It's just another thing. It's just another one of problems in my life. It's, there's something else on the add-on. Do you know what I mean? Because it's like, my life's always been hard, [and] it's [asthma is] something else.... Sometimes it gets frustrating and I start thinking, you know all this is happening to me when, oh my son's in the hospital I'm thinking, this has happened to me, this has happened to me, and this has happened to me. Now look what's happening to me now, my son's in the hospital. And

	everything I tried to do good, it seems like it's going worse for me. I'll think that. And I'll think, now what do I do, I mean to get away from the situation. ... I see the bad things. I see all the bad things. So it's like you know, I try to just take it a day at a time. That's it, a day at a time and see what happens. But it's nothing easy, it's hard. It's hard." Pg 249
Finding	restraint is most terrifying (U)
Illustration	Jimmy: "Well she doesn't like to be like strapped down. Probably no kids like that." Corrine: "Confined." Jimmy: "You confine her she snaps." Pg 277
(70) Palmer EA. Family perspectives and experiences of having a school-age child with asthma: Duquesne University; 1999	
Finding	Many of the first asthma attacks occurred during the night and necessitated an ambulance trip to the emergency room. Families described this as extremely upsetting and frightening (C)
Illustration	"I was worried with the fact that I heard her coughing, then she was unable to get her breaths, so I hurried up put her in the shower, steamed up the room, and she coughed out like a plug. I called 911 emergency and she had like a little bit of wheezing and was brought to _______ hospital emergency room." Pg 75
Finding	Once the diagnosis of asthma was made, caregivers described a wide array of extreme negative emotions and feelings. These emotions ranged from anger and frustration to fear and devastation (U)
Illustration	"I was so upset when I first heard that word [asthma] because I mean before I knew about asthma, for me to hear "asthma", it was almost like hearing "cancer"...I actually got goosebumps.. .My child has a terrible thing." Pg 76
Finding	A few of the families had suspected something was wrong for a while and felt that they had not received the correct diagnosis at earlier sick visits (U)
Illustration	"So she had been treated twice in the doctor's office and twice in the emergency room and no one ever suggested the word asthma to me. I was actually ready for the diagnosis." Pg 77
Finding	This diagnosis phase was a period of insufficient knowledge on the part of the caregivers and high expectations from the healthcare delivery team (C)
Illustration	The paediatrician checked his lungs and they said to me, "He has asthma, here's an inhaler." Never showed Andrew how to use the inhaler, never told me what kind of asthma he had, never told me what he was even taking. I had no clue, I had no clue what I was doing." Pg 77
Finding	A few of the caregivers also admitted going into denial (C)
Illustration	"There's no asthma in our family." Ellen admitted to "pushing off the initial diagnosis." Pg 78
Finding	Repeated episodes often gave rise to feelings of guilt and blame (U)
Illustration	" I didn't know that, you know, that you couldn't have the sprays around him.. .and so, um, I blame myself it was, like, real guilty." Pg 79
Finding	Doctor frequently chastised her for apparent mismanagement of the asthma (U)
Illustration	"The doctor said "He's not making it; he's having all these hospitalisationss and he's having all these problems because things aren't being done properly." Pg 79
Finding	The lack of a diagnosis was a problem for many caregivers. They believed that perhaps if the child had visited a specialist earlier, the management of the asthma may have

	been undertaken or correctly prescribed sooner (U)
Illustration	"Andrew was on the inhalers...and he was having these attacks and I didn't know what was going on. There was something wrong, he kept wheezing, having these coughs and these colds, and I 'm thinking something's wrong, so I had to demand.. .to see a specialist.. .I just about had to stand on my head to get the referral." Pg 80
Finding	Poor support varied among subjects, but included the school, the participants' home, the physician, and the healthcare system (U)
Illustration	"It's like everybody throws their hands up and says, "Well, I'm not authorized to do this...." Pg 81
Finding	Parents identified a variety of conflicts within the context of school and the transition of the child from the home environment, where many of the parents had learned to control the environmental triggers of asthma, to the school environment where the parent or vigilant caregiver was not present (U)
Illustration	"If I'm on a regimen at home doing it every day the right way when he's home here why can't it be done in school? My son is allergic to roach faeces and his classroom is in the basement where the cafeteria was and he'd go into an attack." Pg 82
Finding	One of the most remarkable battles that arose for the caregivers in this study was the carrying and storage of the child's inhaler at school (U)
Illustration	"In elementary school you have to leave them [inhalers] with the nurse...I did it [sent it with her] I started doing it when she had a cold, and then I left it in there...I will step over the boundaries....You know, because it's stupid— You read too much of people that you know they wouldn't let their kids have their inhalers. And that's bull__" Pg 83
Finding	A final school battle reported by the caregivers was the transition from home to school. They had mastered the home care of their children's asthma, and when they then relinquished that care into the hands of the school, it was difficult (U)
Illustration	"The transition to school hit me in the face....We fight them constantly. We are tussling over the inhaler thing now..." Pg 86
Finding	Another incident that came up during the children's lives was the issue of transportation on the bus (U)
Illustration	"I was so mad, and I went right up, it happened on a Friday, and I saw one principal Friday night, and I was in the school at 7:30 Monday morning when they opened. I talked to everybody, the school nurse, the principal...And I said, "I don't know what it's going to take for you guys to say you don't put an asthmatic on the bus like this! You don't do it, you just don't do it." I told them, "I work 2 minutes from here for a reason. You call my work" .. .And I told Heather, "You don't just let them put you on the bus." You say, "I want to go to the nurse, my mother will get me..." Pg 87
Finding	Another area of battle for these families was related to issues of the mother working outside of the home. When the child had a difficult night, there were often conflicts with parents who needed to be with their sick child, and yet needed to be at work also (U)
Illustration	This woman found the role of working outside of the home to conflict with the need to vigilantly manage her son's asthma, so she quit the job that she had maintained for 20 years. She described this as very difficult: "It was the hardest thing, I didn't even speak to [the boss] when I left." Pg 87
Finding	Informal networking was frequently reported as a strategy for learning and acquiring

	knowledge about asthma (U)
Illustration	"Other mothers...I network...and at the bus stop we get into conversations because you'd be surprised at the children who are school-age who actually have asthma.. ..And some of the ladies I don't even know their names. There are about three of them up there, and we just talk about our children.. .."And he had an attack last week; he had to be hospitalized"...And you know and we'll start talking and then we just exchange notes you know, and that's how I really have had the support that I need and I really wish there was an asthma support group." Pg 90
Finding	Another method of acquiring knowledge was self-teaching (U)
Illustration	"But I myself went out, I researched it. I read books and I sort of became a self made expert because at that point I figured if they didn't even tell me at the hospital what was wrong with her I wasn't going to count on anybody to inform me." Pg 91
Finding	Respondents reported that formal education did take place, but they all felt that they did not receive enough teaching on asthma (C)
Illustration	"You have to pound your doctor for knowledge...I went beyond the call, you know what I mean, I learned about it. I [saw the ad for the] asthma [camp], I made the point to go, I went and asked the questions...we went to Camp Breathe E-Z." Pg 92
Finding	Caregivers stated that the first thing they do for the children at the emergency room is to give them nebulizer treatments, so many parents fought and acquired the knowledge and equipment to do this at home (U)
Illustration	"We've been able to treat her at home...because we have that nebulizer and the fact that that's the first treatment they give at the hospital....So we have that at home and we've always insisted on keeping it." Pg 94
Finding	Caregivers put extensive efforts or work into teaching everyone about the asthma (U)
Illustration	"Cindy's been going to all of the classes that the American Lung Association has. My husband and I we take her to the Breathe E-Z camps every year...I've given her books, and I've given her pamphlets. We practice what we would do if there was a breathing problem in school. My older daughter is also aware: have her lay down, take her breaths, make her calm, give her water....The older daughter knows: if I'm ever not home, or you're in school, they can't get a hold of me they're going to tell you. You get her on the floor, you lay down with her and you start the breathing with her 'til she's calm....And my older daughter knows how to get hold of us..." Pg 95
Finding	Families also engaged in teaching with the child's school by letter writing, meeting with teachers, and talking with the school nurse (U)
Illustration	"But when she was ready to go to school, we went up and we would talk to the teachers....And we've already had a conference with all the teachers. Every year we have gone in and talked to the teachers, explained, you know,...explained the asthma...We've gone to the principal's [office], we've gone to...I have no qualms with talking with the school superintendent if I have to. I have had to for other things and I said so now I just stand up for them... .The teachers took care of her, it's been real good, it really has." Pg 95
Finding	The parents expressed relief at finally finding a physician who would give them optimal treatment and care (C)
Illustration	"He [the specialist] did all the allergy things with him, he really got to the method of

	Andrew, really did..." Pg 96
Finding	Caregivers said that when they "took control", or became vigilant, this was a changing point for them (U)
Illustration	"I had to decide what was my priority and I decided it was for Edward to live. He's alive and much better now and I have succeeded at this." Pg 97
Finding	A final resolution strategy for Jackie was finding the positive in the asthma (U)
Illustration	"We've taken the negative and made it positive...we have found, too, that it encouraged me to strive harder to try and find a place of my own because at the time we were living with my parents, and Jennifer's grandmother smoked and also had carpet in that house and it made really difficult to try to manage with those factors there." Pg 100
Finding	One mother said that she did not believe that the school personnel realize the seriousness of the asthma (U)
Illustration	"I don't know what symptoms they need, when a child is saying she needs it....They should know more about how sick these children are...a dying child for breath that is serious!" Pg 85
Finding	An additional problem within the school environment is gym class (U)
Illustration	Respondents varied in the level of satisfaction they had with gym, but those who reported gym as a conflict stated that it was a case of the gym teacher having higher expectations for the child's physical endurance than the child was capable of doing. Pg 85
Finding	The issue of a school nurse not being present was a problem for the families, but one they could not remedy (U)
Illustration	"This sharing of a school nurse is a nightmare." Pg 85
Finding	There also were battles within families (U)
Illustration	Two caregivers reported that they were sometimes fighting with grandparents who could not understand why their grandchildren were always ill, which they felt guilty or upset about as it implied a feeling that the mother was doing something wrong. Pg 88
Finding	Caregivers also began to learn by trial and error and noticing what their children's triggers to asthma were (C)
Illustration	"A lot of this you have to read...pick up every pamphlet you see. I can see when her eyes is getting all watery, and she's getting coughy, and she's getting...I just can see it 'cause I've know it so long, I can see when it's really getting ready to trigger up something." Pg 91
Finding	Consequences of "not knowing" included mismanagement and may lead to increased dissatisfaction with caregiver's previous and future encounters with healthcare providers (U)
Illustration	"If you're going to your paediatrician, they should teach you and I that was my biggest fight when I called up there. They asked me why I left; I said, "Well, you give me an inhaler and my kid got, I don't know what he has, he has allergies he has all this stuff....you never said a thing." Pg 93
Finding	Part of taking control involved shifting of some of the responsibility of asthma management to the child (C)
Illustration	Brenda encouraged Betsy to speak up and communicate with her teachers, and Jackie felt that the best thing she could do for Jennifer was to get her to realize that no matter

	where she is, if she's in trouble, she has the right to inform someone. Pg 99
Finding	Interestingly, when the fathers had asthma, it was still the mother who became the primary vigliant monitor of the asthma (U)
Illustration	"Oh, he helps some, but never equal. That falls on me." Pg 100
(71)Wagner F, Steefel L. Beliefs Regarding Asthma Management Relating to Asthma Action Plans (AAPs) of African American Caregivers Residing in Newark, New Jersey Public Housing Communities. Journal of paediatric nursing. 2017;36:92-7.	
Finding	Participants recounted realities inherent in caring for a child with asthma in an urban environment, they included insurance instability, food insecurity, legacy of intergenerational asthma, and their involuntary reactions to these challenges (U)
Illustration	"I just throw it up to God, like I know that (seeing the doctor) needed to be done; just make the proper arrangements. I don't mind being behind on my bills because that's something that had to be done. I weigh my options. My babies need food. We're older. We know how to survive. We'll toast some bread. Put something in your stomach to help you stay strong enough." Pg 94
Finding	Asthma was described as intergenerational; caregivers handed down what they had lived and adhered to for asthma management (C)
Illustration	"I try to get her to stay healthy without being on medication all the time. I guess because of the experience with my mother who was on it. My mother had to walk around with a machine on her face all day long. Oxygen was over there in that corner. And she had this long cord to go all the way through the house. She walked through the house, but her machine was in the bedroom. My mother passed away from it." Pg 94
Finding	The preferred methods for controlling asthma consisted of restricting the child's outdoor activities, and using nebulizers, steam, and showers in lieu of administering daily controller medication (C)
Illustration	"Sometimes it depends on if he had gym or something that day, when he comes home from school, I say, take a treatment. I just try to avoid it. That's like a precaution instead. Stop it before it comes." Pg 95
Finding	Importance of maintaining vigilance (U)
Illustration	"If you pay attention to your babies, then you will know that something is wrong and they need to sit still versus just letting them rip and run, rip and run. Now when they come in the house, they're wheezing and it's going to take a minute. You have to catch it early." Pg 95
Finding	Respondents preferred to use non-medical approaches (U)
Illustration	"Besides the nebulizer - what do you call it? I don't like putting all that stuff on him. I have a thing where you filter the air. You put Vicks in the water and let it boil. The humidifier? Right, I don't have one right now. It's gone. But I put a little pot on the stove and we sit there in the kitchen because it circulates the air." Pg 95
Finding	Albuterol adopted as medical management (C)
Illustration	"I have so much albuterol in the house that I can sell it if I want to and still have enough for my children." Pg 95
Finding	Understanding of an AAP and the value obtained for its use (U)
Illustration	"It's a guide for you to know what to do when your child is having an asthma attack and looks like they can't breathe. It's just like a fire escape plan. It's something to have so

	you will know what to do in event of emergency. I keep it under the mattress so I won't lose it and the kids won't tear it up. When I attempted to use the plan, I felt good because I didn't have to go to the ER." Pg 95
Finding	Awareness of AAP, not attaching intrinsic value to its use (U)
Illustration	"I've seen that before. My daughter has all that stuff. I haven't really read it. When she gets a lot of information, she's like "Oh, Ma." and she'll tell me, but for me to actually look at the papers and stuff like that, I know this because I've lived with it all my life." Pg 95
Finding	Use of the ED (U)
Illustration	"Sometimes I use it (the medication). And other times? I just take them straight to the hospital?" Pg 95
Finding	Attentive attitudes of Healthcare Professionals important (U)
Illustration	"I love the attitude, their persona, the place of business where they chose to be at. It's never too crowded. They don't rush you. They want to make sure your child is okay. It ain't like, "Your child has asthma. Okay. Here's some more stuff for the nebulizer. Go." No, they check...." Pg 95
(72) Carrillo G, Perez-Patron MJ, Lucio RL, Cabrera L, Trevino A, Xu X, et al. The Benefits and Challenges of Managing Asthma in Hispanic Families in South Texas: A Mixed-Methods Study. Frontiers in public health. 2017;5:150.	
Finding	Lack of asthma knowledge - Parents learned about the disease when their children were diagnosed, usually after dealing with multiple respiratory illnesses and complications before a diagnosis was made (U)
Illustration	"I did not know what asthma was for a while. My daughter would start choking and I did not know why, I did not know it was asthma until the doctor told me it was because of the asthma." Pg 5
Finding	The asthma condition was defined in the way that it was experienced: by its symptoms, of which the most important was having difficulty or not being able to breathe (U)
Illustration	"Just whenever is really hot or really cold she had difficulty breathing, she's had this problem since pre-kindergarten." Pg 5
Finding	When asked about how asthma affected their children, parents immediately referred to limitations in their physical activity (U)
Illustration	"She loves to walk, she wants to do that like my other children when participates in running competitions at school, so it is hard for her not to be able to do that." Pg 5
Finding	Parents brought up that their children felt embarrassed by these limitations or by having to use medication like their inhalers at school (U)
Illustration	"My kid would hide to use the inhaler, he was ashamed. He would hide the pump to avoid bringing it to school." Pg 5
Finding	A common error acknowledged by parents in all the focus group discussions was that initially, they did not adhere to the consistent use of asthma medications or discontinued it when their children's symptoms seemed to decrease (U)
Illustration	"I used to do that, I will look at him doing well and wouldn't give him the medication and then he would get sick, but now I know." Pg 5
Finding	Stressful learning process (C)
Illustration	"My two sons have had asthma since they were little, and [being] without education is difficult. After the [asthma] education, it's different." Pg 5

Finding	Those who mentioned receiving asthma education emphasized how important learning to identify asthma triggers was for disease management (U)
Illustration	"I have received asthma education, and what I have learned is to change cleaning products to avoid chemicals." Pg 6
Finding	One of the main challenges to controlling their children's illness was identifying asthma triggers (U)
Illustration	Triggers mentioned during focus group interviews were smoke, chemicals, animals, dirt and dust, pollen, and stuffed animals. Cold weather and running or doing physical activity were also identified as risk factors for asthma attacks in their children. Once asthma triggers were identified, parents reported changes in their routine in order to help their children avoid asthma attacks. These newly adopted self-management behaviors included changes in their household cleaning habits, such as switching to asthma-friendly cleaning products, changing bed sheets often, removing carpets, avoiding animal contact, and not smoking or grilling inside the house. Pg 5
(73) Yamada J, Potestio ML, Cave AJ, Sharpe H, Johnson DW, Patey AM, et al. Using the theoretical domains framework to identify barriers and enablers to paediatric asthma management in primary care settings. The Journal of asthma: official journal of the Association for the Care of Asthma. 2017 Dec 20:1-14.	
Finding	There were conflicting reports from parents who indicated gaps in their understanding about the medications that were prescribed for their child in terms of the dose, frequency, and duration of administration of asthma medications (knowledge) (U)
Illustration	"But it is very confusing like with the Flovent being affective after two weeks comparing to being immediate. You just don't know when to take it. Should you take it after they cough for 20 minutes, should you take it before they start coughing" Pg 9
Finding	Some parents stated that they would benefit from additional training on how to use asthma medication devices (skills, behavioral regulation) (C)
Illustration	"To know how many puffs and how long the puffer stays in the mouth." Pg 9
Finding	Parents indicated that both parents (i.e., mother and father) were responsible for managing their child's asthma (U)
Illustration	"Who in the family is responsible to manage your daughter's asthma? Both myself and her dad." Pg 9
Finding	There may be long term effects from long term use of asthma medications (U)
Illustration	"I think long-term use, long-term chronic use. Because it's so mild that, you know, is it necessary to have the (medication) long term?" Pg 9
Finding	Instructions I receive about the course of treatment for my child is not clear (U)
Illustration	"I come back two years later and they're like oh, okay so why are you still doing that, like I didn't know there was a timeframe." Pg 9
Finding	All participants were concerned about logistic barriers, wait times, and delays in organizing follow-up appointments for parents (U)
Illustration	"We were referred back in June but I think, it's just the wait times in general, we couldn't get into the center closer to our home and the only way we could get in is if we came all the way here. Yeah, more available resources and just cut down on the wait time that it takes for your child to get in to see a specialist." Pg 9
Finding	Used strategies (e.g., placing inhaler next to toothbrush) to ensure their children

	received their asthma medications (behavioral regulation) (U)
Illustration	"Well, we leave his puffer by his toothbrush so every morning, ok before school, go brush your teeth and take your puffer and at bedtime you know obviously brush your teeth and take a puff, right?...We've tried calendars, we've tried notes on the mirror and that type of thing. It's you know, constant monitoring." Pg 9
Finding	They also expressed concern and worry about the long-term side effects of asthma medications such as their inhibition of their child's growth and development (emotions, beliefs about consequences) (U)
Illustration	"She has fears of the myths that lots of medications at a young age could cause liver damage, stunted growth, and so she is trying some other natural things such as mint oil or aromatherapy or whatnot, and at night time if he has a cold or something like that, a little Vicks VapoRub on his chest or between his toes. I mean certainly we know that that is going to help, but not on a daily basis. It's not enough." Pg 9
Finding	Physicians and nurses played an important role in educating parents about asthma control (social/professional role and identify) (U)
Illustration	"Whose role do you think it is to educate parents on how manage asthma? Healthcare doctors. Anyone else? Yeah, nurses." Pg 9
Finding	Parents also reported receiving inconsistent instructions about their child's treatment (environmental context and resources) (C)
Illustration	"I come back two years later and they're like oh, okay so why are you still doing that, like I didn't know there was a timeframe." Pg 10
Finding	Most parents were aware of their child's asthma triggers and asthma medications; however, there were conflicting reports from parents who indicated gaps in their understanding about the medications that were prescribed for their child in terms of the dose, frequency and duration of administration of asthma medications (knowledge) (U)
Illustration	"...it's just morning, night, like I just don't know how long we keep up with the two puffs in the morning like today she's well maybe we'll go to one puff a day so it's just, I don't know when to keep doing it or, and then you book appointments and your family doctor is like well why are you here, like I think I was told six months of this prescription, I don't know." Pg 9
Finding	Parents stated that they required more confidence in understanding their childs asthma triggers and medications (beliefs about capabilities, behavioural regulation) (C)
Illustration	"Because it's just, like I said, he's a bit overactive and has a tendency to hide it on his own, you know, and he doesn't necessarily come forward and tell us I'm feeling out of breath or anything like that, he's too busy just going, going, going right." Pg 9
Finding	Competing priorities and time constraints could interfere with managing their child's asthma (environmental context and resources) (U)
Illustration	"Ok, we need another 5 refills....we should probably drop everything and go and do it; however, work, sports, this type of stuff with the kids we can ok, squeeze it in on Saturday morning, right?" Pg 10
Finding	Parents reported that the cost of asthma medications was not an issue for them (environmental context and resources) (C)
Illustration	"If you're only getting your (medication) three months at a time, its $12, four times a year, plus you add the Singulair, plus you add the Ventolin, so the price of it does add

	up." Pg 10
(74) Lakhanpaul M, Culley L, Robertson N, Bird D, Hudson N, Johal N, et al. A qualitative study to identify parents' perceptions of and barriers to asthma management in children from South Asian and White British families. BMC pulmonary medicine. 2017 Sep;17.	
Finding	Cause of asthma was either not known or not identified (U)
Illustration	"...there's no sort of identifiable cause but it is very common becoming more common". (Mother, Indian Gujarati) P4
Finding	Families discussed the types of reactions they received when they had informed family members or others within their community about their child's asthma (C)
Illustration	"It might make a change because they blame me [My extended family] just say, tell me that I don't take care of her. That's what they say to me. [Laughter] I'm not taking care of her...that's what they think and then I just turn around and I say, what makes you think that? Is it because I'm working? Because I enjoy working? I'm not going to stop working because she's ill, because that ain't going to make her better. If I stop working, I can't sit down with her twenty-four seven and say, Oh you feeling better? I can't keep her from school and say Oh, don't go to school, you're going to get ill." (Mother Bangladeshi) Pg 5
Finding	Confusion related to the use of inhalers, in particular their function and when to administer them (C)
Illustration	"Because, when the nurse at the hospital said, "Has she got an inhaler?" and I said, "A blue one, we've been told twice a day," she didn't say, "Oh okay, well, actually you can use it up to ten times, and you might find that might be more helpful." It was "Oh for goodness' sake, that's that's just a waste of time, it's a waste of medication, that is." You know, and that made me feel like "Oh great, so the doctor's wasted my time and because of that, I'm here"...I don't, well, we don't know. So that would have been helpful. How we control it, and just, just consistent information about how often we should be using the blue inhaler." (Father Indian Punjabi) Pg 5
Finding	Unsure about whether inhaler technique was correct (U)
Illustration	"I don't know if we are still using it right. When he is doing his inhalers he is getting smoke coming out and I am saying to him you can't be doing it right because that shouldn't be happening." (Mother White British) Pg 5
Finding	Families discussed possible side effects deriving from asthma medication (U)
Illustration	"That stuff can actually, sort of [affect his] growth or his bones can be a bit thinner bones. We were more sort of thinking, that if he's going to have steroids, we were not worried about the pumps, giving steroids that pink tablets, which we were concerned about, because he was given that, let's say every 4 weekly, every 3 weekly...Because his body, immune system, would not work if you keep feeding him steroids and his immunity will be so broken down he'll have to rely on steroids for the rest of his life which I wouldn't want." Father Indian Gujarati Pg 6
Finding	Families talked about keeping their child's asthma under control (C)
Illustration	"I don't want to give him puffs all the time when he doesn't need it. So I'm rather hopeful as he grows up, he grows out of it so as long as he is getting better and you are giving him when he needs it and as he gets old he doesn't have this problem to just try and

	keep it in control." Mother Pakistani Pg 6
Finding	Parents related asthma control to the regular and appropriate use of asthma medications (U)
Illustration	"I think a lot of it is to do with the medication, if he came off his medication I think he would be quite a poorly child." (Father, white British) Pg 6
Finding	Multiple visits to the GP with recurring problems and delays in receiving a diagnosis engendered feelings of annoyance and anger (U)
Illustration	"It's just getting people to listen, that's what used to get me so angry because nobody would listen to me. When I used to take him doctors I used to mention my nephew had the same symptoms and now he is on all these inhalers. 'Because your nephew has got these symptoms don't mean to say that you have got the same thing, it's just chest infection it's just something it's just common to him', that's what I used to get. I used to go in there and come out upset all the time." Mother White British Pg 6
Finding	Families perceive the GP to be the first point of contact in managing their child's asthma (U)
Illustration	"I just went to my GP and say I'm seeing the same symptoms. They referred him to the hospital. And [we've] just been going from there." Mother Pakistani Pg 7
Finding	The ongoing management of a child's asthma often required that families interacted with HCPs regularly, usually through a regular or annual review with a practice nurse (C)
Illustration	"It's more a question and answer session as to how they have been, but that's not a review of their medication because it's the doctor surely who has to sanction any new or alternatives." Pg 7
Finding	Emotional impact on their families, such as the fear and worry caused by seeing their child ill or distressed (U)
Illustration	"It's quite shock....shocking really. I'm quite traumatised at times because it was....a couple of times we had to take her in and out, it wasn't just once. It was like coming....straight after she was diagnosed it was so difficult and, on occasion, every 2-3 months, this was a couple of times we went to the hospital. The first thing it was go to A&E and I don't think you're allowed to go to A&E now for such things unless it's really, really severe. Yeah, all we did for five hours in hospital or even longer, half the night in hospital we had to spend with her while she was on the bed and she 'crying and screaming and they put the nebulisers on...and it's quite.she's so small and tiny. Tiny little girl. Poor thing. She was screaming, she didn't like the mask thing on her face, it was happening all the time and she was getting scared of hospitals, was thinking 'what was going on?' Mother Bangladeshi Pg 7
Finding	Causes or origins of asthma (U)
Illustration	The most commonly mentioned causes across all families were environmental (e.g. the weather, damp, dust, pollen, pollution), and physiological and genetic (e.g. weak immune system, asthma being hereditary not breast feeding). Pg 4
Finding	Lack of information provision by healthcare professionals about their child's asthma (U)
Illustration	Many families (8 (57%) White British families and 19 (63%) South Asian families) reported wanting more information about asthma and its management. Pg 5
Finding	Seeking advice from other sources, such as pharmacists (U)
Illustration	Almost a third of South Asian families described accessing the pharmacist for advice

	about a child's asthma and medications to receive a second opinion, to gain additional information about asthma medicines, and, in some cases, the pharmacist demonstrated how to use inhalers or spacers. Pg 7
(75) Hook L. Understanding what really matters between families and providers caring for young children diagnosed with asthma. Dissertation Abstracts International: Section B: The Sciences and Engineering. 2018;78(11-B(E)).[112]	
Finding	Causes of asthma (U)
Illustration	"The weather gets cold and she gets congested. I think the cold started it and the cigarette smoke make it even worse." Pg 43
Finding	Causes of asthma (U)
Illustration	"I don't even know what caused it." Pg 43
Finding	Triggers of an asthma attack (U)
Illustration	"No I don't know what triggers the cough, maybe because he's outside sometimes. The cough gets worse at night and at school when he is napping." Pg 43
Finding	Triggers of an asthma attack (U)
Illustration	"The doctor told me it was the air and pollen, you know she did talk about it but it was the first time." Pg 44
Finding	Triggers of an asthma attack (U)
Illustration	"We tried to pay more attention to dust...not only for him but for everybody....just try to keep clean the dust where he sleeps and not expose him to cold weather." Pg 44
Finding	Daily controls for asthma (U)
Illustration	"Keep on giving the medicine in the morning and at nights...when we go to park give her inhaler before and just try to watch and I just ask her if she is ok." Pg 45
Finding	Daily controls for asthma (U)
Illustration	"They did an action plan with me, they explained it, and then put him on all the medications. But to me the medication they put him on, did not work like they should." Pg 45
Finding	Health outcome for asthma - "good control" (U)
Illustration	"The normal things that we do every day like eat well, healthy, exercise, and not forget about the medicine and be careful with the pollen." Pg 46
Finding	Overall course of asthma as disease (U)
Illustration	"I think he'll grow out of it but if he doesn't then we'll just have to continue controlling it." Pg 46
Finding	Overall course of asthma as disease (U)
Illustration	"I didn't believe it. I thought maybe they were wrong. I just did not believe it." Pg 46
Finding	Overall course of asthma as disease (U)
Illustration	"We must accept it. There is no way to reverse time. At the beginning, we were worried but now we start trusting the doctor, had classes and understand more about it." Pg 47
Finding	Asthma effects on daily living in the family and community (U)
Illustration	"I felt lost and I couldn't go to work and I could not process everything. My car is broken. I have to walk and take the bus...What if she has an episode in the middle of the street. I tend to do everything by myself because I'm always by myself." Pg 47
Finding	Asthma effects on daily living in the family and community (U)
Illustration	"I talk to the school nurse all the time. I call many days. I want to know how he is

	doing." Pg 48
Finding	Decision making between family member/caregiver and healthcare provider (C)
Illustration	"Well she's new to us. We didn't live here. I liked that doctor she was really good. She helped me, she understood me...I would tell her stuff, she'd be like "okay, well try this. The doctor now has only seen my child for four months. I got the AAP but it is at head start. She keeps trying to figure out the cough." Pg 48
Finding	Decision making between family member/caregiver and healthcare provider (C)
Illustration	"I'm trying to find a new doctor...we wait sometimes 30 minutes just so the doctor can walk in and walk out of the room in 10 minutes." Pg 49
Finding	Decision making between family member/caregiver and healthcare provider (C)
Illustration	"The emergency doctor went over the plan and told me a nurse would come to my house. My doctor told me to use the office rather than the emergency room. But that does not make sense for me to wait at home while my child is sick, the office does not open until 8.30am and they don't answer the phone till 9am. I have no car, I have to take the bus with my other children." Pg 50
Finding	Family member/caregiver attitude about healthcare relationship (U)
Illustration	"I want to look for one doctor. I don't want multiple doctors to talk to. I also want the doctor to explain things to me instead of just saying what it is and leaving. It makes me feel very uncomfortable." Pg 51
Finding	Family member/caregiver attitude about healthcare relationship (U)
Illustration	"I was angry because I was always in the emergency room, every three days. He was suffering. I was frustrated. I could not get answers." Pg 52
Finding	Family member/caregiver attitude about healthcare relationship (U)
Illustration	"I am a working mom I don't want to sit at the hospital wait for hours for you to judge me. The community should do more to help mothers understand. I had denial. I did not keep giving the medications. I need to understand." Pg 52
Finding	Caregivers voiced concerns about beliefs about inhaled corticosteroids (U)
Illustration	"We don't like to give the medicine all the time. In the beginning, we were super worried about the medicine." Pg 56
Finding	Each caregiver talked about dealing with asthma within the family dynamics of the setting, even isolating the child if the weather was bad or other children had been sick (C)
Illustration	"I could not go to work and I couldn't process everything...her being sick just got me spinning. A good day for us would be locked in this house, AC full blast, and movies all day because she can't go outside when it is hot." Pg 59
Finding	AAP not in caregiver's language of choice (U)
Illustration	"I made the mistake of giving him Qvar when he needed the Prevntil. I speak a little English but I need my instructions in Spanish." Pg 60
Finding	Mothers reported an asthma diagnosis as being part of the history and culture of the community, i.e., connection with themselves or other family members (C)
Illustration	"I have asthma. I just expect my child to have asthma. So, I was afraid when he had the first attack, but we all have asthma." Pg 58-59
(76) Abdullah Al Aloola NA, Nissen L, Alewairdhi HA, Al Faryan N, Saini B. Parents' asthma information needs and preferences for school-based asthma support. The Journal of asthma :	

official journal of the Association for the Care of Asthma. 2017 Nov;54(9):946-56.	
Finding	Children experienced difficulties using the inhalers, or mastering the skills required to use the inhalers (U)
Illustration	"I see that it is difficult to be used by children in correct way". Pg 949
Finding	The necessity of reminding children with asthma to take their medication (U)
Illustration	"Not easy to remember to take it by herself, I should remind her". Pg 949
Finding	Aesthetics of some asthma medication caused problems (U)
Illustration	"He did not like the taste and smell of the medication. " Pg 949
Finding	Complexity of prescribed regimen caused problems (U)
Illustration	"It is cumbersome for my son to use it in regular way." Pg 949
Finding	Children experienced side effects from the asthma medication (U)
Illustration	"With time, I notice that my son started limping. I took him to an orthopedic specialist. He made some examinations and he said that the laboratory tests showed that the cortisone had affected his [my son's] bone and he prescribed Vitamin D drops for him. In the mornings he [my son] complains about his feet, that he feels some pain." Pg 949
Finding	The high cost of asthma-friendly materials, and the issue related to availability of asthma-friendly materials (U)
Illustration	"Parents of children with asthma face a big challenge to find and buy such materials. I bought asthma pillow with 480 Sudi Riyals=150 Australian Dollars. As doctor told me to change his [child's] bed and pillow to cotton and asthma friendly materials, this was because he was having asthma attacks at night..." Pg 949
Finding	Strong concerns about their child's school environment (U)
Illustration	"Most of school teachers don't care about materials used in craft classes, as some materials have strong odours that trigger asthma...In addition, [on the] first day of school after holidays, the school is filled with dust that triggers asthma in children. Further, they clean the school during school holidays with materials that have strong odour [s]. Last week, they painted the whole school with new paint on Sunday. When my daughter go [went] to school, she could not stay in her building [as the smell of the paint affected her asthma], and she went to the high school building directly till her father took her back home". Pg 949
Finding	Children felt embarrassed taking their medication in front of their peers (U)
Illustration	"She feels embarrassed to use her inhaler in school and in front of her friends." Pg 950
Finding	Children were afraid to play at school, as they felt they would not be able to perform well in sports (U)
Illustration	"Asthma limits his physical activity, and actually my son is afraid to have an attack if he plays." Pg 950
Finding	Little confidence in the ability of the schools to manage their child's asthma, most participants chose to keep their child when their child's asthma was likely to flare up (U)
Illustration	"I am absolutely not confident about the school to take care of my child when he has asthma attacks. I forced him to absent himself from school for a week...even though he become better." Pg 950
Finding	Positive actions had been taken to care for their child when the child suffered an attack at school (U)
Illustration	"He [the child with asthma] was feeling faint one day, the school called the school nurse

	and she took him to the nearest clinic where they gave him a nebulizer. They [i.e. the clinic and the school nurse] thought he had a cardiac problem because he was pale and bluish in colour. When they took him to hospital and after examination they diagnosed him with asthma." Pg 950
Finding	Schools needed to adopt a stronger advocacy role in relation to issues such as asthma (U)
Illustration	"I think the most important need is education to children [students without asthma as well] inside schools regarding asthma." Pg 950
Finding	Participants indicated that their child's physician 'assumed' that the parents were knowledgeable about asthma due to their professional status (U)
Illustration	"No information of any type was given to me at diagnosis, as I am working in the hospital and when they see that I am wearing a lab coat, they assume I know everything." Pg 951
Finding	Participants indicated that their child's physician had verbally explained to them how to manage their child in the case of asthma attacks (U)
Illustration	"The doctor explained to me how to use inhaler, how to change the use of drug based on symptoms, and how to avoid triggers. He explained that verbally and showed me how to use inhaler. In addition, he provided me with written materials about asthma." Pg 951
Finding	Despite almost all of the participants noting a need for school-based asthma support, only one participant commented on parent-school communication (U)
Illustration	"...they care if parents inform them, and give them notice. I think the most important thing is parents' communication with the school." Pg 952
Finding	A child's family structure was another issue that affected the taking of medication (U)
Illustration	One mother indicated the care of her child had been fragmented following a divorce. She noted that she ensured her child took the medication when the child was with her, but was unsure of what occurred during the custodial changeover. Pg 949
Finding	Nearly all of the participants indicated that they still needed basic information on asthma (U)
Illustration	Participants listed a number of queries, including queries about: (1) basic concepts (i.e What is asthma? How does it develop? Is it genetic? Is it curable? and What are the signs, symptoms and triggers of the disease?); (2) treatment and prevention (i.e. How can asthma be prevented? How can inhalers be used correctly? How do asthma medications work? and what are the expected side effects of the medications? Pg 952

(77)Waters DM, Olson AM, Foushee N, Shelef DQ, Stewart L, Yadav K, et al. Perceptions of stress, coping, and intervention preferences among caregivers of disadvantaged children with asthma. Journal of Child and Family Studies. 2017 Jun;26(6):1622-34.

Finding	Asthma-Related Stress (U)
Illustration	"It can be scary, definitely scary. Because it's something that you can't control. And that's her health and you have to watch your child experience not breathing, that's like very scary. Seeing her going through it is really, really scary. And there's nothing you can do about it." Pg 1625
Finding	Chronic stress due to constant worrying about their children's well being (U)
Illustration	"You can be stressed out like losing your mind. You can be stressed out and be worried.

	You can be stressed out and be scared. So there's different levels. My stress level would be a little like in midway, nervous. I've researched asthma. And some people have asthma attacks and die. So I'll be nervous. I'll be scared. Because, like, what if my child has an asthma attack, and then up and dies? Like what parent wants to bury their child, especially a four-year-old?" Pg 1625
Finding	Stress increased when her daughter was ill (U)
Illustration	"I'm really stressed because when she's sick…When she's well, I don't worry as much, but when she's sick and she starts coughing, and when she starts coughing, well, I have to be ready, giving her the spray every four hours because if I don't give it to her, her symptoms get worse." Pg 1625
Finding	Work demands converged to create substantial stress (U)
Illustration	"You also have to be on the watch. I don't have work on Saturdays but apart from that, I'm always at work. I'm not allowed to use my phone at work, so I have to hide myself to call my mom and make sure that she's taking care of my son. I'm also on the watch. I know that I can take care of my child, but with someone else. It's hard to not be there. It's really stressful." Pg 1625
Finding	Accumulation of stressors from various sources (U)
Illustration	"You got stress upon stress upon stress—it's not just dealing with the asthma but you're also stressed through other personal issues." Pg 1625
Finding	Some parents resisted identifying their emotional experiences as stress (U)
Illustration	"I don't want to stress because I don't want him to feel me being stressed out because of it. I don't want him to think, like him having the asthma is like a burden to me, or what I need to accomplish for him, or anything like that. I don't want to call it stress… Well I'm stressed because my child has asthma. No, I'm not. I don't want to say-- My job is stressing me out, not my child. I don't want him to feel any type of way because he has asthma." Pg 1626
Finding	Parents had difficulty identifying how they coped with stress, asthma-related and otherwise (U)
Illustration	"I don't know. I honestly don't even know how I cope. That is a really good question. I don't know. I just have to do it. Like I just know it has to be done. It has to be done, or he will be back in the emergency room. And, like it's literally that simple for me. I have to give him his medication, because he's not going to tell me. He doesn't know. He's four." Pg 1626
Finding	Parents were able to identify a few coping strategies that they employed (U)
Illustration	"I definitely like to sleep and lounge and watch movies, order Chinese food, just be lazy, just do whatever I need to do. Wash clothes, whatever I can get done that needs to be done, I'll get it done. You know what I mean? Hang out with my friends a little bit. But you know, nothing major." Pg 1626
Finding	Need for caregivers who are knowledgeable about how to care for their children's asthma (U)
Illustration	"I get [to the daycare] and he's like really gasping for air, like trying to breathe. So I don't know what's going on…I was freaking out, panicking, like "Oh my god, my baby, my baby." And he's wheezing and gasping for air real bad…they never called an ambulance." Pg 1626

Finding	Putting children before themselves and their personal needs (U)
Illustration	"And you know the number one priority is taking care of your child. And then you start saying, "Well I can't get a minute in for me." And then, something comes up for the child again. So you get pushed down a little bit. And there's been days where, when you were talking about the bad, I want to chuckle, because there's been days I was scared to get in the shower. So I washed up in the sink when she was going through the [cough]. When I hear that, oh no, I can't be in the water. Turn the water on, wet the washcloth, turn the water off." Pg 1627
Finding	Little time to actively cope with her stress (U)
Illustration	"there isn't any time…I have work, then I come home and have to clean, wash the boy, etc. It's like a challenge. It costs a lot to have time for yourself when you have a child like this." Pg 1627
Finding	Parents' interest in learning deep breathing techniques, yoga, and using mindfulness (U)
Illustration	"How to eat right, exercise properly, even, you know, maybe some type of exercising that you could do with your child. I know they have like yoga and baby-type thing, you know, things like that, maybe something that you and your child could possibly do together, just to kind of maybe ease some of the stress or what have you. I think things like that would be definitely helpful…Deep breathing would be great. My child could use that. Maybe he'll calm down a little bit. But I would definitely do that." Pg 1627
Finding	Parents indicated a strong preference for face-to-face interactions for parental support (U)
Illustration	"I like that face-to-face kind of thing, because when there's text messages going back and forth, it lacks feeling for me…I don't get as much feeling as I would like to. Like when I'm sitting here with these parents today, I can kind of relate, you know. And we all have things in common here. And I think that's the best thing about it, for me, to exchange." Pg 1627
Finding	Parents overwhelmingly preferred group meetings to individual sessions (C)
Illustration	"A lot of times, people listen to what other people go through to make their situation better, or to work on their situation or stress. Like you can be stressing about one thing, I can be stressing about something totally different. But what you're stressing about—and we're talking about your stress-- it can help me with mine. I'm going with a different angle on stress and not being stressed." Pg 1628
Finding	Participants also saw the groups as an important opportunity to help other parents as well as providers learn about coping with paediatric asthma and stress (U)
Illustration	"I like [meeting with other parents]. I like to bounce ideas off of someone who, you know, who is going through a similar situation. You know, it might be something that they know that I don't, and vice-versa. So I would definitely love just a peer conversation would be great…We can just bounce ideas off of each other, bounce ideas and feelings and, you know, what happened this day with his asthma, this, that and a third. I would love that, oh yeah, for sure." Pg 1628
Finding	Resistance to communicating using technology (U)
Illustration	"I don't want to chat with you online. I don't want to text message the meeting leader. I don't want to have a phone conference. I want to sit down, and I want to smell your breath, and I want to know what happened to your child when they went to school last

	Friday, and you had to call the ambulance. I want to know how scared you were. I want to know how you dealt with it, so that if it happens." Pg 1628
Finding	Hispanic parents indicated that they had encountered linguistic barriers (U)
Illustration	"Especially in regards to your child's health…it's better to hear everything well, and that if you have any doubt you can ask and have it explained in your language." Pg 1628
Finding	Parental asthma-related stress arose from worry that their children may experience an asthma exacerbation (C)
Illustration	"I mean I make sure I don't forget, because if I miss one medication, I might as well say that's one day in the ER…It gets to the point that it gets stressful, because you know, I might be overworked, or I might be very tired. And sometimes I might be forgetful. If one of them is like really, really sick, it's like I can't juggle and be with this one, and this one is getting sick or like last time, I was admitting all three of them in the hospital…that was very stressful and it got to the point that I was getting in depression mode. But, you know, I had to keep myself strong for my kids." Pg 1629
Finding	Participants noted that enacting coping practices may be unrealistic due to conflicting work and caregiving demands (C)
Illustration	"I don't exercise when I'm calm. I don't know what makes these people think I'm going to exercise when I'm stressed. They said to walk until I'm calm; I said, 'Come on'." Pg 1629
Finding	Hispanic parents, however, preferred to communicate with intervention staff due to concerns about other parents' abilities to provide support and guidance (U)
Illustration	"It should be someone from the research study because that person can direct the conversation. If it were a parent, they'll probably talk about themselves and they won't direct the conversation very well. In addition to that, a professional can give more information about asthma." Pg 1630
Finding	Parents shared that they encountered communication difficulties when securing help for their children in several contexts - at school, at the pharmacy, and in medical settings (U)
Illustration	"It's like if you don't speak English, they ignore you. One time my son was really bad. He had symptoms and chest pain…I walked him to the clinic and my husband said, "Are you going to talk or do you want me to talk?" because if they don't understand us, we have to go back home. I spoke loudly and the doctor came in a second." Pg 1630

Appendix VI: Synthesised finding, included categories and supporting illustrations

Synthesised finding 1 - Negotiating the meaning of having a child with asthma

Findings	Categories	*Synthesised finding*
Families live in fear (U) During asthma attacks, parents often reported feeling scared or panicked (C) Fear and awe of asthma (U) These mothers' greatest concern was fear, "loss of the child" (U) Constant fear and anxiety even affected their own health (U) Mothers described the fear and panic of watching their child have an asthma attack, but all felt that an important part of 'managing it' was remaining sufficiently calm in order to avoid upsetting the child and potentially making the asthma worse (U) Fear, desperation and anxiety for the parents occurred when their child could not breathe (U) An even more upsetting event for the parents occurred when their child expressed fear of dying (U) Despite the fact that the fathers are confident, they also have feelings of anxiety (U) Sometimes I get scared too was a subtheme expressing caregivers' fears related to potentially losing their children	**Fear of asthma and the possibility of death**	**Negotiating the meaning of having a child with asthma** *Parents experience a range of emotions including fear of asthma and the possibility of death as a result. The unpredictable nature of asthma and the need for constant vigilance contributes to their anxiety. Some experience a sense of guilt and use denial as a coping strategy. Parents' existing knowledge and beliefs about asthma shape their approaches to management of the disease.*

due to the ill effects of asthma (U) All parents perceived asthma exacerbations to be 'scary;' and many felt 'fear' for their child (U) Participants related experiences of caring for a child who was having difficulty breathing. All expressed feelings of fear and most reported uncertainty as well (U) Worry being "paralyzing" (U) Asthma was frightening. She had learned from the media and from her mother that people die and may die suddenly from asthma (U) Lost Voice and Scary Scream (U) Almost all mothers reported that asthma is a dangerous disease because the child could die if not treated quickly (U) Mothers and family members were also very worried that their child could die from an asthma attack (U) Fear for their child's life (U) They were terrified by any suggestion of changing their child's treatment (U) Participants described how frightening it was for them when their children were so sick (U)		
Reactors - were more likely to see their children’s asthma as a mild form of the disease (U) Families experienced varying degrees of denial (U)	**Feelings of denial**	

Episodic denial, and wishful thinking were described (U) Parents used strategies to work through the phase of ascribing meaning. Some parents used denial as their primary strategy. They were unable to acknowledge the diagnosis (U) A few of the caregivers also admitted going into denial (C) Compensators - there was a sense of denial amongst some others as to the harmful potential of this exposure (U) Some families chose to deny the seriousness of asthma and instead shared perceptions of not being able to do anything to prevent an attack (U) Parents who were able to recognize some aspects of the disease, but were unable to act on the recognition tended to use the avoidance strategies (U) Buffering strategies block the in-flow of information and included avoidance, denial, selective ignoring, and prioritization. Those parents who were not heavily engaged with their children's asthma care reportedly exercised more buffering coping strategies than the primary caregivers (U) Parents rationalized their lack of prevention or planning by referring to a child as being tough or a trooper (U) Overall course of asthma as disease (U)		
Mothers' feelings - To feel guilty about not having	**Feelings of guilt**	

sufficient time for the healthy children in the family (C) Participants expressed some degree of guilt (U) Some mothers felt guilty, especially if they had had childhood asthma (U) Repeated episodes often gave rise to feelings of guilt and blame (U)		
Symptoms: The primary symptom mothers reported were shortness of breath, choking, coughing, chest tightness, wheezing, sneezing, restlessness, fatigue, and/or fainting (U) Asthma symptoms were commonly described as being a struggle for air resulting from air passages that were closed or constricted, obstructed, inflamed, or swollen. (U) The asthma condition was defined in the way that it was experienced: by its symptoms, of which the most important was having difficulty or not being able to breathe (U) Some parents' reactions were more relaxed and unemotional. These children were usually the mild asthmatic cases (U) A few mothers described asthma in clinical terms; as an inflammatory condition of the respiratory system (U)	**Parents' asthma knowledge and beliefs**	

Causes: Cause of asthma was either not known or not identified (U) Causes of asthma (U) Causes of asthma (U) Child's asthma was due to her use of antibiotics during pregnancy (C) Other causes listed were infections, activity and "vaccines" (U) Mothers were asked what they believed caused their child's asthma (U) Causes or origins of asthma (U) **Hereditary:** Hereditary explanation provided justification for mothers who had relatives with asthma (U) Extent of asthma in their family history (U) The majority of the mothers were uncertain about the cause of asthma. The most striking similarities among the mothers was that they seemed to know that asthma has a genetic component (U) Genetics were also mentioned (U) Mothers reported an asthma diagnosis as being part of the history and culture of the community, i.e., connection with themselves or other family members (C)		

Hereditary explanations provided justification for mothers who had relatives with asthma but puzzled others who did not (U) **Environmental:** Family Explanatory models for causality were primarily tied to environment exposure (U) The most commonly reported explanatory model for the aetiology of asthma held by these mothers was the rainy, damp Dutch climate (U) Other mothers believed that environmental exposures caused their child's asthma (U) **Prior and personal experience of asthma:** Parents had to take their prior experience and come to some conclusions about that experience and the relationship between the prior knowledge and the knowledge they had of their child's diagnosis of asthma (C) Parents prior experience with asthma affected the impression that the diagnosis left with them (U) Personal experiences strongly affected the parents' and caregivers' actions and assessments of their child's asthma (C) How having asthma themselves meant they have more empathy with their children's embodied experience of		

asthma and that they had trust in the effectiveness of medication (U) Past experiences with asthma that contributed to "event familiarity" status. Past experiences included having asthma or similar respiratory conditions and/or having two asthmatic children (U) Anna, who herself had been hospitalized with asthma as a child, suspected that 15 month old Araceli might have asthma when the first symptoms began. Anna understood how asthma felt from her own experience (U) Families described how prior asthma experiences helped them notice the difference between an asthma flare and what may turn into an emergent asthma attack (C) Asthma was described as intergenerational; caregivers handed down what they had lived and adhered to for asthma management (C) Siblings of the children who participated in this study often had histories of asthma or other chronic conditions and the family experiences associated with this influenced how the family currently manages the child with uncontrolled asthma (C) Some parents had prior experience with older children with asthma (U) Some parent's lack of prior intimate experience influenced the meaning that they attached to asthma (U) Some parents felt that the disease seen in their relatives was not the same as their child's (U)		

They felt that by being watchful for symptoms of asthma in the siblings of the affected child, they would be able to seek medical attention in a more timely and informed manner than in the past, should the need arise (C) **Beliefs** Some mothers believed their child could eventually outgrow their asthma (U) Overall course of asthma as disease (U) Parents believed that physical activity would help their children "grow out of asthma." (U) Caregivers shared several common beliefs about their teen's asthma such as a decline in symptoms of childhood asthma as the person grew older. (U) Most mothers believed there is no cure for asthma (U) Another mother believed her son's asthma will abate when (C) Beliefs about their teen's asthma (U)		
Religious belief also plays a role (U) Many mothers turned to prayer as part of their asthma care routine before and during their ED visits (U) "Generational faith" - faith of these mothers passed down from one generation to another (U) Cultural influences such as church (U)	**Religious beliefs**	

Affect-management included methods of faith and comparing the patient's condition to others who were more ill (U) Others who expressed hope for a cure referred to spiritual intervention (U)		
Unpredictable and frightening Mothers described their child's asthma as an illness that is unpredictable, dangerous, deceiving, and potentially life-threatening (U) Asthma's Undiminished Fearsomeness (U) The mothers struggled with the anxiety of never knowing when, where or why an asthma episode might occur (U) Uncertainty was one the main themes when the carers discussed their experience of managing their children's asthma. (U) Discovering one's child had asthma meant finding oneself within a threatening and largely unknown world (U) Latino limited English proficiency caregivers' encountered significant burdens related to their children's asthma care. Emotions centred on the inevitability of asthma attacks and on a collective fear that a lack of preparation and/or knowledge could render caregivers powerless to act. The dread of an asthma-related mortality event for the child was frequently mentioned (C) The majority of family caregivers described the unique	**Living with constant concern and worry due to the unpredictable nature of asthma**	

features of asthma that also were barriers to effective management of the illness. Flare-ups at night, seasonal changes, unexpected episodes, and the critical nature of the episodes are examples of condition-related barriers presented by asthma that typically created lack of predictability and an urgent need for care (U) Others described their children's asthma as unpredictable (U) The unpredictability of acute exacerbations was particularly worrisome (U) Fathers had a number of concerns that made them feel uneasy about some aspects of their children's asthma. Concerns emerged most predominantly when the children became acutely ill (U) Discovering asthma meant for Anna the rediscovery of her own helplessness, helplessness especially acute when she was alone as she struggled to breathe (U) Some parents found that the unpredictable nature of asthma made it difficult to be in control at all times which was frustrating and left them physically and emotionally taxed (C) Because there had been no answers to reverse Reggie's unrelenting symptoms, Ruby felt let down (U) The often unpredictable symptom pattern heightened the feelings of uncertainty (U) The unpredictability of asthma episodes was a concern that never completely went away (U)		

children's colds and coughs during the winter were always prolonged by asthma (U) As episodes continued to occur, mothers began asking more detailed questions about their children's symptoms, the prescribed medications, the expected outcomes, and explanations of possible causes (C) Mothers often worry whether their children will have sudden asthma symptoms that will endanger their lives, they also worry about whether teachers have the ability to handle such a situation. They instruct their child to call the family immediately if symptoms persist (U) Participants were worried because of the respiratory issues the children were faced with. They were afraid that the child might suffocate during one of these respiratory attacks (U) Uncertainty about how an asthma exacerbation would develop (U) The major antecedents of uncertainty were related to the variable nature of asthma symptom patterns before an asthma attack and during an asthma attack (C) The inconsistent effects of triggers and the unpredictability of asthma exacerbations created a state of uncertainty for the parents (U) Since symptoms began insidiously, usually with a benign 'cold', a runny nose and maybe a cough, parents found themselves dealing with asthma before they could reflect on what was happening (C)		

Fear and Worry Fear, worry and even desperation they experienced in caring for a child with asthma (U) Families expressed the impact of asthma in several different ways. They demonstrated chronic worrying (U) Parents described episodes of illness during which they had been frightened because their children were very ill (U) Participants expressed concerns about their child not being able to breathe properly. They described their fears that their child would die during an asthma attack (U) Mothers' feelings - Feeling anxious about the future (U) The fear experienced by these mothers was great. There was fear related to the responsibility of caring for an ill child (U) Parents reported several episodes of being afraid of what could happen if their child was unable to breathe properly. The child might wake up in the middle of the night, and the parents would sit at the bedside not knowing what to do. They described feelings of uncertainty, helplessness and being alone (C) Parents often cited feelings of nervousness, frustration, anxiety, fear, or anger concerning their child's asthma (U) Fear was integrated deeply in this part of the process of losing control (U)		

A parent described her perspective and feelings while watching her child in respiratory distress and receiving nebulizer treatments (psychological difficulty) (U) Overall adaptation difficulty was experienced by three participants who had young children. They felt stressed and overwhelmed (U) Emotional impact on their families, such as the fear and worry caused by seeing their child ill or distressed (U) Chronic stress due to constant worrying about their children’s well-being (U) When the asthma was really uncontrolled, mothers talked about being consumed with the care of this child (U) When sick with asthma, Anna felt fearful and unsure of what crisis might lie waiting, and worried that she would not get better (U) **Frustration, helplessness** Care-givers reported that asthma often left them feeling frustrated (U) Their inability to control the symptoms of the disease often resulted in feelings of sadness, anxiety, frustration, and powerlessness (U) Participants expressed feeling helpless (U) Parents expressed feelings of inadequacy and frustration when their child had exacerbations (U) Feeling of inadequacy in relation to seeing their child was		

ashamed of having asthma (U) Feelings of desperation or hopelessness (U) Feelings of defeat were clearly tied to what she wanted to do but could not do for Susanna (U)		
Vigilantly 'watching' the child during the acute asthma episode (U) They also described their constant vigilance about monitoring symptoms (U) Importance of maintaining vigilance (U) Participants applied vigilance as their foremost coping strategy against uncertain events (U) Becoming a vigilant caregiver. The vigilance described by these caregivers transcends all of the work and management required to take care of the child's asthma (C) Being the one accountable for managing their child's disease meant having to be vigilant and constantly reassessing their child's symptoms to ensure they did not miss anything (U) As symptoms persisted, the mothers became more and more vigilant (C) Mothers reported their desire to watch all of their child's activities during the day, because they were afraid of the worsening of the attacks (U) The speed at which symptoms could exacerbate and	**The need for constant vigilance**	

health deteriorated, contributed to caregiver's perception of the need for constant vigilance (U) The mothers expressed concern about being alert to the earliest warning signs, so they could start treatment as soon as possible (C) Parents' increased awareness of possible trigger events or precursor symptoms enabled them to intervene much earlier to prevent some asthma episodes and shorten the duration of other episodes (C) Remained actively attuned to asthma and learned to recognize the qualities that distinguished common symptoms as signals of asthma (U) Mothers' actions: Being on guard and constantly standing by always involves the responsibility, meticulous planning, and control of the child's daily life (U) Even though all these matters affected the lives of both parents and children, parents did not give up. (U) Monitoring their child's asthma symptoms and contexts that raise alarm for an exacerbation is an ever-present and demanding responsibility (U) Fathers constantly looked out for their children and kept a watchful eye over them (U) Fathers were also alert to situations or activities in which the children could be exposed to asthma triggers (U) The participants all related experiences throughout the child's lifetime when they closely observed their children. They carefully monitored behaviors and symptoms		

exhibited by their children. They paid attention to the child and to the environment of the (U) As the mothers learned the cues of an approaching asthma episode, they found themselves listening in a special way to their children with asthma (C) Participants demonstrated considerable courage in their determination to "do the best for our children" (U) Day-to-day experiences drove their ability to cope and intervene with their child's asthma symptoms, and they described having to be aware and flexible every moment (C) **Wanting children to be vigilant** Fathers wanted children to be vigilant as well (U) Monitoring also involved asking older children questions about their experience (U) **Wearing out due to vigiliance:** The need to be ever vigilant also contributed to wearing out (C) Maintained vigilance over symptoms by regularly interrupting her own sleep (U) I'll watch over you was expressed by caregivers as they talked about long nights spent watching over their children (U)		

U: uequivocal; C: credible

Synthesised finding 2 – Impact on Family Life

Findings	**Categories**	***Synthesised finding***
Managing work role demands was an important component of balancing demands. Time missed from work for the children's illnesses was generally viewed negatively by employers (U) Leaving their jobs at inopportune times to take care of their children when having an asthma attack (U) Caregiver could not leave work, but instructed daughter from home during asthmatic crisis (U) Difficulties being able to manage time off work in order to attend appointments (C) Some mothers reported the need to be available for support of their child's variable asthma exacerbations; this limited their employment opportunities (U) I'm never too busy for you was expressed by how caregivers made time in their lives to care for the asthma needs of their children. Working caregivers who took off from their jobs to care for their children during asthmatic crisis (U) Another area of battle for these families was related to issues of the mother working outside of the home. When the child had a difficult night, there were often conflicts with parents who needed to be with their sick child, and yet needed to be at work also (U)	Mothers managing multiple roles	**Impact on Family Life** *Family life and activities were restricted due to asthma and parents longed for a normal life. Mothers tended to be the primary caregivers and managed multiple roles including work, household activities and the demands of asthma management and as a result many suffered from stress and exhaustion. Some parents faced financial hardship with the costs of medications, equipment and transportation to hospital.*

Work demands converged to create substantial stress (U) Caring for a child with asthma often involved considerable disruption to the work of both the primary carers and their partners. Their children's health was more important than their work (U) Some participants also experience role strain when they had one child in the hospital and other children at home or when more than one child was sick with asthma (U) Asthma Management Disrupted by Other Life Concerns (U) Competing priorities and time constraints could interfere with managing their child's asthma (environmental context and resources) (U)		
Initially, the high degree of uncertainty regarding predictability, and severity, and the complex treatment regimens severely restricted and disrupted family relationships and any social life the informants might plan (U) Limitations on the child's activities and family lifestyle (U) Parents were highly conscious of the impact of asthma on the whole family (C) To strengthen a child's protection, the mothers adjusted their child's diet (U)	Feelings of having an unusual life	

They were saddened by the fact that they could not have a comfortable life like others and that they were affected by the stress concerning their child's illness (U) The dominant feeling for mothers was sadness (U) Asthma treatments affected both parents and children. (C) Carefully supervised Carolina's contact with other children (U) Both are longing for a relationship that is like the one between a mother and a healthy child, as well as a life with fewer restraints (U) The rest of the family was affected more when the health of the asthmatic child was more complicated. Often other children had their activity restricted because of the asthmatic sibling (U) Physical symptoms were sometimes described in terms of their effects on other members of the family (U) The child's illness represents a turning point in the family's life. Parents reported a change in their life perspective (U) Parents restricted their children's outdoor play on windy days (U) Asthma effects on daily living in the family and community (U)		

Sustaining referred to changes in environmental controls or lifestyle choices that had been made by the parents and the need to continue them (C) Three areas in which asthma disrupted or complicated activities: family holidays, the child's school camps and care-givers' work (U) Why me was one strong child subtheme that came from caregivers' perceptions of their children (U) Participants experienced increased levels of distress with a greater adverse impact on their own health and daily lives (U) Living on the edge of asthma is a constant balancing act that affects the entire family as well as the child with the asthma diagnosis (U) Children seemed to be 'sick all the time' (U) Asthma caused disruption to their identity as the mother of a 'normal child' and the main carer in a 'normal' family social world (U) Another participant explained the social difficulty many parents encounter when their children play in public places (social difficulty) (U) Mothers related experiences of feeling they had to give things up or put things on hold because of their children's illness (U)		

School absenteeism Some parents voiced that children had to miss school due to acute exacerbations of asthma (U) Some parents voiced that asthma affects their performance in class (U) **Inability to leave child** Many did not feel comfortable with leaving their child with someone who was not a family member (U) Caregivers purposively limited the child's social outings to contexts where adults have knowledge of asthma management (U) They worried that an asthma attack could happen at any time, and especially that they would not be available when the child had an asthma attack. Some parents were extremely reluctant to allow their child to be away from their supervision at all **(U)** Asking others to take on the caring role was described as difficult and parents did not feel that they could pass on the responsibility. (U) Securing reliable and knowledgeable babysitters was difficult (C) The young age of the child and the need to provide medications on a regular basis meant that child care was a concern (U) Parents found it hard to relinquish the responsibility of managing their child's health to others (U)		

Children being different The informants were well aware that their children looked and acted normally, but when exposed to certain triggers, the children could become seriously ill very quickly. (C) Informants did not try to hide their children's asthma from others, even if it limited their activities (U) Parents related a variety of symptoms that they recognized in their child (U) Confronting is defined as taking a realistic look at the diagnosis and the impact that the disease had on their child and the rest of the family (U) Some carers, most with children with more severe asthma, said that their children were not 'normal'. (C) To feel sorrow is grieving for the sick child's inability to do all the things that other children can do (U) Parents expressed concern about what their children were learning as a result of the entire asthma experience (U) **Concern about duration of the disease and on children's future** A remarkable similarity in all mothers was the concern about the duration of the disease (C) You Don't need to worry was an evident subtheme and was expressed by caregivers taking on multiple responsibilities for the care of their children's asthma		

(U) Uncertainty regarding child's future (U) Concerns with the ongoing discomfort that their children experienced with asthma (U) Worried that asthma might become more severe in the future (U) Worried about how children would manage their asthma when they became teenagers (U) Caregivers shared concerns and general health goals for their teens regarding exercise, other activities, diet and maintaining a healthy weight (U) Mothers were worried about their child's uncertain future, and thought that asthma could affect their educational, vocational and marital status in the future (U)		
Parents described the extra cleaning that they performed, washing window blinds, cleaning carpets, and trying in all possible ways to eliminate dust, pollen and other pollutants (U) Plagued by the labor intensiveness of dealing with asthma (U) Parents expressed confusion about complex aspects of asthma care (C) Mothers shared how monotonous and confining the day-to-day treatments were (U) Some of the mothers found the complexity, and	The labor intensiveness of asthma	

uncertainty of treatment especially difficult when the healthcare providers gave them responsibility for treatment options (U) Remembering or giving or taking medications on a daily basis was the most difficult aspect of asthma care (U) **Relationship with other siblings** The mothers' engagement in the care of the sick child affects the relations to the healthy sibling. The mothers are not at hand for the healthy child, and the child feels left out (U) Mothers perceived that the healthy siblings frequently felt resentful (U) Not telling her daughter or her siblings about their daughter's asthma diagnosis because she did not want to worry them (U) In order for the primary care giver to maintain their child's health, siblings often had to miss out emotionally and/or physically (U) In an asthma family it is sometimes difficult to understand the expectations and needs of the other. Sometimes it is hard for the healthy child to understand the mothers' laborious situation (U) **Marital relationship strain** The marital relationship often showed the strain of the mother's increased focus on the child with asthma (U) The mothers and the fathers have problems with		

spending time together. Living with a child with asthma reduces the time they have for each other (U)		
Asthma attacks were more frequent during the night and early hours of the morning. This led to sleepless nights and fatigue on the following day (U) Mothers undergo extreme stress while taking care of their children. They have experienced exhaustion during the management of the child's asthma (U) Families were also exhausted (U) Disruption in sleep patterns accompanied by the worry over the children's condition contributed to the mothers wearing out (U) Parents voiced concerns about their own quality of life and the constraints placed on them by having a child with asthma (C) Night time visits to the emergency department during winter months were even more difficult when families needed to find care for their other children or else take them along (U) Fatigue was constant and influenced many of the mother-healthcare professional interactions (U) Experiencing sleepless nights while sitting up with their children who had asthma (U) Parents reported sleeping with young child during illness in order to monitor their breathing pattern (U)	Stress and exhaustion	

Participants identified themselves as the primary caretakers of the affected children and many fathers reportedly did not participate in asthma care. Although these mothers did not offer any concerns about fathers' lack of involvement or conflict about asthma management, they expressed the lack of sleep to be a serious concern (U) Participants identified themselves as the primary caretakers of the with a sick child and what it was like to continue for days on end battling with the asthma, trying to get it under control (U) Children would be struggling to breathe at night, but have improved by the morning, the mothers began to doubt their own judgment (U) Night time caused the most concern (U) It was not unusual for the asthma, the medication, or the side effects to keep the mothers awake for much of the night (C) Mothers described an experience of staying up through the night while watching their child struggle to breathe. For most of the children this occurred relatively frequently at any time of the year (U) Asthma-Related Stress (U) Stress increased when her daughter was ill (U) Some parents resisted identifying their emotional experiences as stress (U) Parental asthma-related stress arose from worry that		

their children may experience an asthma Exacerbation (C) Putting children before themselves and their personal needs (U) Accumulation of stressors from various sources (U) Ruby identified asthma as the biggest stress in her life (U) Little time to actively cope with her stress (U)		
Cost of the recommended therapies (U) Even with subsidized medications and doctors' fees (bulk-billing), many families struggled to find the money needed to replenish medications on a fortnightly or monthly basis (U) Contextual barriers to using medications (U) Given that these drugs were necessary and perceived to be the "only option," parents believed that the monthly asthma drug expenditure was "money well spent" and represented good value (U) Respondents believed that they had no choice but to pay for the drugs or their children would suffer. Parents expressed a sense of helplessness regarding getting financial help to cover drug costs (U) A few parents indicated that when they were short of funds and two prescriptions were needed, they would purchase only one of the two prescribed medications	Financial Burden	

(U) The affordability of medicines and devices was a common concern raised by parents. Despite financial stress many parents reported willingness to spend money for medication if there were evident benefits to their child (U) Others used a spacer but found it to be expensive even though they had insurance(U) Cost of some supplies, like anti-mite sheets, was too expensive (U) The parents believed that hospitals in the cities or private hospitals could provide modern and effective treatments but it needed much money and accessing (U) A common theme identified by all parents was the negative impact on their standard of living compared with families with drug plans. Parents reported being stretched financially each month because of asthma medication purchases (U) Although parents believed the prescribed asthma medications were expensive, they understood and accepted the importance of maintaining a proper asthma medication regimen (C) Interviewees believed that government programs should pay for at least a portion of their drug costs (U) Perceptions of discrimination and indifference were mentioned as issues for parents of children receiving		

care insured by Medicaid (U) The financial hardship of raising a child with severe asthma (U) For some of the mothers, finances were a consideration in treatment options (U) Financial burdens of the treatment of asthma created support needs for parents. Medications were often very costly (U)) Accepting of an ethnically and racially diverse clientele, with Medicaid or without insurance (U) Medication costs appear to act as the most significant barrier when children are not covered by insurance, or when co-pays are more than families can afford (U) The high cost of asthma-friendly materials, and the issue related to availability of asthma-friendly materials (U) Participants reported facing economic hardship caused by expenditures on treatment and income losses (U) Satisfaction with prescribed medications (U) Parents reported that the cost of asthma medications was not an issue for them (environmental context and resources) (C) Finances directly and indirectly affected parents' adaptation challenges. Participants reported missing work and/or school to care for their ill children (U)		

Socio-economic factors One mother described a desperate situation in which her son almost died of an asthma attack because they had no transportation to take him to the hospital (C) Caregivers described socioeconomic barriers. Finding and paying for transportation to the hospital emergency room or the primary care clinic were a major concern (C) Participants recounted realities inherent in caring for a child with asthma in an urban environment, they included insurance instability, food insecurity, legacy of intergenerational asthma,, and their involuntary reactions to these challenges (U) Family poverty and housing instability left their child vulnerable to allergen exposures that were out of their control (U) Need for greater sensitivity to plight of raising children with high-risk asthma in context of poverty (U)**)** Neighbourhood violence not only limits children with asthma's time outside and exposure to outdoor air, but their participation in physical activity (U)		

U: unequivocal; C: credible

Synthesised finding 3: The process of getting a diagnosis and learning about asthma

Findings	Categories	*Synthesised finding*
Lack of a clear diagnosis / Never told child had asthma Family members felt confused and expressed that physicians did not give them a clear diagnosis (U) The uncertainty expressed by several was caused by not being able to understand the origin of their child's suffering, and the physician's limited capability to diagnose the problem (U) Never told their child had asthma (U) Not knowing the diagnosis left families in the limbo of worry for the child and shared suffering (U) Asthma controller medications being prescribed before they were told their child had asthma (U) Belief is that if they are not diagnosed with asthma, children should not be getting medicines for asthma (U) Parents felt more anxious and frustrated, so they tried to seek help from someone they believed in order to get a specific diagnosis and proper treatments (C) The difficulty with diagnosing asthma at a young age was brought up by all of the families. Many families discussed how, looking back, they now believe their child had asthma at quite a young age and how they would have liked more education on what symptoms may be associated with an asthma diagnosis (C) Healthcare professionals were reluctant to make a diagnosis	The process of getting a diagnosis of asthma	***The process of getting a diagnosis and learning about asthma*** *Parents expressed uncertainty in the period prior to their child being diagnosed with asthma due to lengthy delays in receiving a diagnosis, repeated hospitalizations and symptoms and feeling that health professionals did not take their concerns seriously. Many parents had suspected their child had asthma and for many, knowing the diagnosis brought a sense of relief. Armed with a diagnosis, parents focused on learning about asthma by networking with friends and colleagues and self-teaching due to a perceived lack of education provided by health professionals. Parents identified the need for formal asthma education at the time of diagnosis including information on symptoms, triggers, medications, side-effects and how to achieve good asthma control.*

(U) Some parents believed that physicians delayed diagnosis or diagnosed less severe asthma to “save the system money.” (U) Not having a diagnosis for their child's symptoms led to a great deal of uncertainty about how to proceed. Without an official 'label' of asthma, parents were unclear about whether to give medicines or how to manage symptoms (C) Lucy told what an earlier diagnosis of asthma would have meant (U) A few of the families had suspected something was wrong for a while and felt that they had not received the correct diagnosis at earlier sick visits (U) For a number of children, asthma is not a clearly defined illness. At the onset of the illness, parents revealed that they had been to the acute clinic several times without receiving help (C) The lack of a diagnosis was a problem for many caregivers. They believed that perhaps if the child had visited a specialist earlier, the management of the asthma may have been undertaken or correctly prescribed sooner (U) Multiple visits to the GP with recurring problems and delays in receiving a diagnosis engendered feelings of annoyance and anger (U) They all described a period before receiving the diagnosis during which their children experienced recurrent episodes of respiratory illness (C) It seemed to have taken longer to receive a diagnosis among		

the families with only one child with asthma and for the first child in the family of three children with asthma than it took for the subsequent two children (U) Caregivers dissatisfied with the asthma diagnostic process frequently described scenarios in which a diagnostic strategy was not communicated (U) Some caregivers suspected their child might have asthma soon after symptoms manifested. Caregivers were dissatisfied when they perceived concerns about asthma were not acknowledged by the medical provider (U) **Satisfaction / expectations around with diagnosis** Caregivers satisfied with the diagnostic process often conveyed that the child's primary doctor communicated a plan of action to diagnose asthma after the child first manifested respiratory symptoms (U) Caregivers who perceived their child as having more severe disease manifestations expected a more expedient asthma diagnosis. (U) In children with milder perceived illness, expectations were different. (C) When providers were perceived as responsive to their concerns, caregivers were satisfied with the diagnostic process.(U) **Making sense of symptoms** Parents experienced early symptoms of asthma and tried to find the meaning for these unexplained symptoms of their children (U)		

Many mothers could not make sense of the experience as they did not have any context for interpreting their experiences. The illness episodes had no recognizable pattern and reccurred frequently (U) Parents needed to recognize that the symptoms that the child displayed were actually connected to the diagnosis of asthma. Because the symptoms have often been misdiagnosed several times before the diagnosis of asthma was made, the parents sometimes had trouble associating certain symptoms with the diagnosis (C) Some parents reported seeking a deeper understanding of why their child became ill (C) Uncertainty was the subcategory where mothers related experiences of not being sure, of not having a clear understanding of what the illness meant or what to do about it. They voiced feelings of not knowing what was normal (U) The first element, ambiguous symptoms, caused the mothers to struggle in their attempts to make sense of their children's illnesses (U) Anna continued the search for a reason that would give her a handle on preventing Araceli's symptoms (U) Ambiguity involved the difficulty parents experienced, when confronted with subtle, indistinct or confusing respiratory symptoms that appeared to be similar to asthma symptoms. Parents required the assistance of their healthcare provider to establish an accurate diagnosis and treatment plan for ambiguous symptoms (C)		

Reaction on initial diagnosis The process begins with the diagnosis of asthma for the child. One mother recalled the diagnosis of her child as a very scary thing (U) At diagnosis, parents expressed a variety of emotions and reactions to the label of asthma (U) Many of the first asthma attacks occurred during the night and necessitated an ambulance trip to the emergency room. Families described this as extremely upsetting and frightening (C) Once the diagnosis of asthma was made, caregivers described a wide array of extreme negative emotions and feelings. These emotions ranged from anger and frustration to fear and devastation (U) Worry, concern and anxiety at the initial diagnosis (U) **Relief at knowing diagnosis** Relief at knowing the diagnosis clarified the problem as treatable condition with clearer prevention and management goals (U) Receiving an asthma diagnosis made some parent feel relief because they knew that it was not as dangerous as they had thought before. (U) The diagnosis of asthma was met with a sense of "relief." They all described a period before receiving the diagnosis during which their children experienced recurrent episodes of respiratory illness (U)		

This subcategory included mothers' experiences of what it was like when their children were diagnosed. Most described it as a time of relief, a sense of having the wherewithal to manage their children's illness (U) Mothers struggled for years without really knowing what was wrong with their children. When they did get the diagnosis, it was met with a mixture of guilt, sorrow and relief (U) Parents accepted or supported the idea that the disease that they saw in their child was in fact asthma, the diagnosis presented by the physician (U) Some parents did not accept the diagnosis (U) Many primary caregivers expressed difficulties with accepting the asthma diagnosis (C) Anna helped a doctor establish the diagnosis (U) Along with the diagnosis came a specific treatment plan. This contributed to the fathers' relief because they felt that they, as well as their wives, would be able to take action not only to alleviate the symptoms but also to improve their children's overall health, comfort level, and quality of life (U) Fathers were also relieved to learn that their children's symptoms were caused by asthma and not some other disease of a more serious nature (U) For all of the mothers, the diagnosis of asthma was important in their attempt to deal with it (U)		
Little knowledge about asthma	Educational needs at the time	

Respondents all indicated that they needed more help understanding the disease and knowing what to do (U) Little knowledge about asthma (U) One mother described the idea of not knowing exactly what asthma was (U) Lack of asthma knowledge - Parents learned about the disease when their children were diagnosed, usually after dealing with multiple respiratory illnesses and complications before a diagnosis was made (U) Many parents were unable to describe what many HCPs consider basic asthma knowledge (U) The challenges of differentiating asthma symptoms from other health concerns (U) Parents reported receiving little to no education at the time of diagnosis or during subsequent visits to the ED (U) Parents' perceived lack of knowledge compounded their problems and further escalated their fear and anxiety (U) Information that should have been provided by the healthcare team was absent or incomplete (U) Limited amount of information (U) Parents had less knowledge about asthma disease (C) Often the information which was provided by healthcare professionals was lacking or incomplete, and several mothers expressed dissatisfaction with the answers they received (U) Parents expressed that the doctors in primary care had educated them well at the time of diagnosis and discussed the	of diagnosis	

treatment plan (U) The minority of parents communicated that they lacked knowledge regarding their child’s asthma diagnosis often attributed their knowledge deficits to a lack of education about the condition (U) The Search for a Helpful Explanation (U) Parents' feelings of ignorance about their child's illness and their need for knowledge and information (U) Parents reported a desire for more information from ED providers (U) Information inconsistency was mentioned frequently by parents with limited literacy (U) Lack of accurate, consistent information (U) Mothers sought information from mutiple sources including books, nurses, and physicians. However, they did not always get the information they needed (U) Families often described a struggle between wanting information and not necessarily having access or the ability to clearly articulate their needs for the information (U) Some parents had not received any advice from practice staff and did not know about the health benefits of exercise (U) Difficulties managing their child's asthma-related healthcare, in terms of finding relevant information (U) Understanding the disease process, the medications, and the rationale for the treatment plan helped them appropriately carry out the activities involved in their children's care (U)		

What asthma does was described as (U) Parents expressed their need to learn about the asthma condition. When information about asthma was unavailable, incomplete, unclear, or complicated, parents experienced uncertainty regarding basic aspects of asthma and asthma care (U) The lack of information about diagnosis and severity was a major frustration (C) A number of factors that may have adversely affected the parents' capacity to understand their children's asthma (process information) Factors included young age, developmental stage, work obligations, high school or college attendance, and raising more than one child (C) Parents emphasized the need to know what to do for their child with asthma, including during emergency situations (U) Parents wanted to be given competent and understandable explanations of their child's condition and treatment, but about half of the parents were dissatisfied with the amount of information they were given (U) Parents had expectations to get repeated patient education in asthma care (U) Whether or not caregivers had received asthma education, they expressed a desire for continuous educational information on medications, asthma triggers, and symptoms (U) The most frequently mentioned provider barriers identified by family caregivers were related to the amount and quality of information that they received about asthma (U)		

Many caregivers identified the need for increased information and educational resources (U) Desire for lay language and simplified terms. Parents reported feeling uncomfortable with medical terminology and how that led to leaving the ED without full comprehension (U) Parents emphasized the importance of written information (U) Parents emphasized the importance of demonstration of medication administration and dosing (U) Information on accurate and easy to access online resources was also brought up as an important educational tool (U) Services might be more informative and personal (U) No desire to understand the physiology of asthma (U) Nearly all of the participants indicated that they still needed basic information on asthma (U) A few parents commented that they did not receive any formal education at the time of diagnosis (U) Lack of information provision by healthcare professionals about their child's asthma (U) Fathers expressed their desire to be more involved in taking care of their child's asthma. They would like more information about managing their child's asthma at the time of the emergency department visit (C) They reported initial explanations of medications being given, but even these seasoned parents said that they could benefit from review and reinforcement (C) Parents stated that they required more confidence in		

understanding their child's asthma triggers and medications (beliefs about capabilities, behavioural regulation) (C) Resistance to communicating using technology (U) **Received appropriate information** A few mothers did report receiving the information they needed (U) Parents who had received referrals to asthma clinics commented on the impact or quality of the education received (U) **Preference for education delivery / times** Participants had no preference for who provides informational sessions about asthma. Participants wanted a person who will be engaging and knowledgeable to deliver asthma education (C) Some participants did not mind having informational sessions on Saturdays, the majority preferred weekdays after work or early evenings (U) Parents indicated a strong preference for face-to-face interactions for parental support (U) Parents overwhelmingly preferred group meetings to individual sessions (C) Participants also saw the groups as an important opportunity to help other parents as well as providers learn about coping with paediatric asthma and stress (U)		
Learning about asthma	Learning the Ropes	

Experiences with asthma (U) Learning the Ropes began with the diagnosis of asthma in a child family member (U) Uncovering Asthma Patterns (U) Once they knew that the diagnosis was asthma, the fathers went about what is best described as 'learning the ropes" of asthma management (U) Parents described the way that they observed the look of their child when he/she was having an asthma attack. They often described them as looking different than other children (C) Some treatment knowledge was required to administer their child's medication at home. Parents described the ways they administered the medications, the frustrations with the actual use of the mask, as well as knowing when to give it (U) Another less experienced parent relied on the pediatrician for advice when faced with the uncertainty of an ineffective treatment situation (U) Parents sought information about asthma, the nature of the disease, symptoms, triggers, purpose of medications, side-effects of medication, how to administer the nebulizer, purpose of the nebulizer, and other treatment strategies (U) Parents' perceived gaps in knowledge might have resulted in part by what they learned from family and friends that may have differed from what they were told in acute care settings (U) After the time of medical diagnosis, mothers related how they acquired resources such as medications, information and medical supplies (U)		

She actively absorbed the caregiving practices that she could use at home (U) Learning as much as she could was a priority (U) This diagnosis phase was a period of insufficient knowledge on the part of the caregivers and high expectations from the healthcare delivery team (C) Stressful learning process (C) Hispanic parents, however, preferred to communicate with intervention staff due to concerns about other parents' abilities to provide support and guidance (U) The strategies that parents used to learn to manage their child's asthma included information seeking; using the knowledge; and balancing. Information seeking referred to the need to gain knowledge (U) Mothers not only 'calming the child' but also keeping themselves calm (U) Caregivers offered strategies that included some form of emotional component. Stress reduction and attempts to make the child feel like he or she is the same as other children (U) I may get excited or anxious was a theme that was identified specific to the girls when experiencing the effects of asthma (U)		
Networking Networking opened their eyes, and they began to understand the meaning of having and caring for a child with asthma. Networking offered them support and information and, in many	Sources of asthma knowledge	

instances, material assistance as well (U) Their desperation led parents to seek help from co-workers, other parents at their child's school, and from neighbours (U) Networks of care - "people obtain normative guidance by comparing their attitudes with those of a reference group of similar others." (U) Fathers continued to learn by "picking the brains" of friends and others to get advice and practical information on dealing with asthma (U) Caregivers reported that they did not receive enough information about asthma in the diagnosis phase and began seeking information on their own. Networking with other families who have children with asthma was an important strategy for gaining knowledge (U) Informal networking was frequently reported as a strategy for learning and acquiring knowledge about asthma (U) Learning occurred over time, with parents identifying multiple resources, such as asthma-based Web sites, the library, an asthma network and newsletter, family members who were nurses or who had asthma, and the pharmacist (C) Seeking advice from other sources, such as pharmacists (U) Preventer parents actively sought out information about asthma from a variety of sources (U) Fathers became "tuned in" to asthma. As a result, they zoned in on any information on asthma that they came upon in their day-to-day lives, such as newspaper and magazine articles as well as television and radio programs (U)		

Lay sources of asthma knowledge included: personal experience, relatives and friends, and the media (U) **Self-teaching** Self-teaching was described by mothers as reading everything they could get their hands on in order to gain some insights into asthma management (U) Even healthcare professionals have different opinions and parents reported that they received insufficient information from them. This prompted parents to seek information about the disease themselves (U) Another method of acquiring knowledge was self-teaching (U) Some mothers learned about asthma from internet sources (U) Respondents reported that formal education did take place, but they all felt that they did not receive enough teaching on asthma (C) They sought information only when they identified a gap (C) Lay knowledge also changed with caregiving over time (U) Parents named many sources of information about asthma, both professional and lay, and generally were confident about the adequacy of their knowledge (C) Strategies to resolve questions about medication (U)		
Difficulty recognising severity Severity was also determined by whether they could adequately treat their child at home or if they needed to go to the doctor of	Parents ability to recognize symptoms and determine severity	

emergency room – (U) Parents had difficulty interpreting the meaning and severity of asthma symptoms (U) Severity was also classified by the extent of their child's activity limitations (C) Use of the "machine" (nebulizer) was indicative of more severe illness (C) All but two of the parents portrayed their child's illness as very severe (U) Many parents avoided admitting that their child had moderate asthma (C) Assessment of asthma uncertain (U) Mothers struggled with their inability to determine the severity of each episode (U) Knowledge about asthma and its management appeared more likely if participants already had someone in the family with asthma (U) Parents also had difficulty recognizing asthma symptoms of young children compared to older children because young children were unable to verbalize their discomfort (U) Parents with less asthma experience expressed and demonstrated more uncertainty recognizing asthma symptom patterns, identifying asthma triggers, and implementing asthma treatment (U) **Moods and behaviour** Worsening asthma was also recognised through changes in		

mood and behaviour (U) Attentive to Reggie's everyday moods, appetite, and the subtle signs of breathing distress, Ruby became skilled in assessing his state of health (U) Her questions about asthma primarily concerned how to assess a crisis and how to respond appropriately (U) **Development of skills to determine severity** Despite feeling defeated in needing to seek emergency care for Susanna, Maria had developed a certain level of confidence about being able to determine when Susanna needed to go the emergency room (U) Mothers perceived illness severity by their child's symptoms, frequency and duration of symptoms (U) Some care-givers felt that they could tell when an asthma attack was beginning, and would watch it develop (C) Mothers developed skills to discern when their child was becoming ill (U)		
Triggers of asthma Another mother blamed her exposure to chemicals (U) Many of these mothers believed that the onset of asthma was related to a particular trigger (C) Triggers of an asthma attack (U) Triggers of an asthma attack (U) Triggers of an asthma attack (U)	Learning about asthma triggers and strategies for trigger minimization	

Cold foods or liquids were also identified as asthma triggers (U) Episodic nature of asthma based on seasons – (U) Accessing care for the child was also made difficult by winter weather (U) Children were symptomatic only during specific seasons of the year and mothers did not view the episodes as unusual. The children in these families were found to have asthma of less severity and frequency (U) Environmental exposures support the humoral balance theory of disease (U) Environmental exposures caused their child's asthma (U) **Physical activity as a trigger** **Limitations of physical activity** The first concern centred on the school experience. Parents emphasized the limitations of physical activity and the importance of medication (U) Children were afraid to play at school, as they felt they would not be able to perform well in sports (U) An additional problem within the school environment is gym class (U) Parents worried if their children wanted to participate in the school's sports program (U) Physical activity as a trigger for asthma (U) To avoid factors that induced asthma, mothers prohibited children with asthma from doing sports (U)		

These mothers' greatest concern was fear, "inability of the child to participate in sports" (C) When asked about how asthma affected their children, parents immediately referred to limitations in their physical activity (U) Preventers - This group of parents were also most likely to encourage their asthmatic child to be physically active to help build their strength and to try and prevent serious attacks (U) Parents were worried about the impact of physical activity restriction on their children. Many parents unnecessarily restricted physical activities based on lack of knowledge or misinterpretations of their doctors' advice.(U) Other parents did not restrict activities because they worried about the psychological impact of the restriction, but they were uncertain if this contributed to increased symptoms in their children (U) Another caregiver wanted her teen to know his limitations with exercise (U) Perceived effects of exercise on asthma symptoms (U) Many parents commented that GPs had encouraged their children to exercise and had stressed that asthma should not prevent the child from engaging in physical activities (U) What appeared to influence parents' support of physical activity, and the child's willingness to take part in it, was their beliefs about the child's physical 'capability ' and the 'safety' of exercising in the presence of perceived 'triggers' (U) Participation in Sports was a concern (U)		

Parents described their reluctance to make their children different from their peers by restricting activities, but some described this as necessary to avoid the risks of asthma (U) **Poverty and poor living conditions** Mould and dust in her living conditions made her child susceptible to asthma symptoms (U) Many parents report their homes contain mould, mice droppings, and cockroach allergens, therefore they frequently clean their home to reduce these indoor toxins, which trigger their children's asthma (U) Another mother depicted how her son was sick all of the time and her baby daughter was hospitalized largely owing to their poor living conditions (U) Many parents report that poor air quality within their inner-city homes challenge their ability to effectively manage their children's asthma. (U) Conflict about family pets (U) **Minimising asthma triggers** **Environmental factors** "Taking control" was extremely important for the caregivers, especially with symptom management (U) Parental recommendations for managing asthma (C) Day-to-day management of asthma (C) As to the environmental management, mothers would keep their home clean, dry the bedding, mop the floors, keep the children away from dust, burning incense and paint odours		

because these easily induced asthma (U) Caregivers agreed on general goals around environmental controls.(U) About environmental control, parents acknowledged the importance of it because it could be a trigger to cause an asthma attack (U) Families also suggested providing more information about environmental factors and how they affect asthma (U) Fathers learned about environmental strategies to control triggers (U) Changes in the environments to reduce the children's contacts with potential triggers (U) Seeking control included actions to change the environment (U) All parents described efforts made to lessen asthma triggers in the home or to decrease the child's chance of an asthma exacerbation (U) Managing the complex allergies experienced by their children was also identified as a significant caregiving responsibility (U) Belief in the Importance of Meticulous Attention to Prevention (U) Learned how to take a proactive approach to asthma treatment (U) Virtually all caregivers were aware of asthma triggers specific to their children and had developed strategies for avoiding them (U) Some caregivers used strategies that were developed on the		

basis of trial and error representing years of asthma management, others worked closely with their doctors to minimise the occurrence of asthma attacks (U) Families incorporated the newly learned information into actions demonstrated through actual lifestyle changes (U) Families incorporated the newly learned information into actions demonstrated through actual lifestyle changes (U) Those who mentioned receiving asthma education emphasized how important learning to identify asthma triggers was for disease management (U) Concern relevant to the school setting was with respect to potential exposure to triggers (U) Unknown asthma triggers and unpredictable action of asthma triggers were recognized as strong antecedents of uncertainty. The participants learned how to recognize asthma triggers by watching their children react to various situations and objects (U) The symptoms that parents associated with their child's asthma and the associated triggers had to be monitored (U) Parents had to learn the steps to prevent an asthma attack in their child. The prevention of asthmatic attacks included appropriate routine medication administration as well as making environmental changes in the home and the places where the child may encounter triggers (U) Caregivers described the process of identifying what triggers their attack (U) Practices regarding use of cleaning products (U)		

Caregivers described cleaning strategies (U) Effective intervention was the use of the hypoallergenic mattress and pillow covers (U) **Tobacco exposure** Tobacco exposure was another major concern (U) A major concern was the ways their children encountered second-hand smoke, even when smoking bans were in place for the home (U) To minimise or prevent their child from triggers, some stated that they asked family members or guests to smoke outside their home (U) The struggle between obtaining the cooperation of family members in needed interventions particularly limitation of smoking, while maintaining good family relationships (U) Avoiding others who smoked was more complex (U) Participants recognised the importance of reducing child exposure to triggers, smoking in particular (U) Strategy for preventing Carolina's exposure to cigarette smoke (C) Other parents recognized the smoking threat and were very serious about limiting their child's exposure to it (U) Another preventative measure was use of a smoking jacket (U) Caregivers mentioned avoiding triggers such as tobacco smoke and pets (U) Parents needed to make choices about exposing their child to		

an environment that may endanger their health. Some parents tended to deny their smoking affected their child (U) Caregivers smoked themselves and lacked insight to how smoker permeates the home dwelling (U)		
Parents weighed the risk benefit ratio of the treatments, environmental changes and lifestyle choices with how they perceived their child's health. This meant that parents made choices that were not always what had been recommended by the literature or information that they received from healthcare professionals (U) Challenges they all face when trying to identify causes of their child's asthma (C) One of the main challenges to controlling their children's illness was identifying asthma triggers (U) Some parents were aware of particular asthma triggers but did not prevent exposure to allergens or irritants, believing that a physical barrier, like a door, offered sufficient protection (C) Some parents who were aware of triggers to asthma exacerbations offered rationalizations for not eliminating them or identified incomplete efforts (U) Compensators - recognized the role of environmental triggers in general and triggers within the home environment in particular. However, rather than avoid recognized triggers such as smoking or keeping pets, they talked about compensatory activities (U) Lack of confidence in environmental controls (C)	Challenges in minimising triggers	

Although parents have learned methods to diminish the effects of environmental triggers, they continued to experience situations that were beyond their control (U) Mothers knew that by avoiding triggers they could reduce the risk of an asthma attack. But even with this understanding that asthma triggers should be avoided, in actual practice it appeared to be sometimes difficult to do so (U) Some parents were aware of the positive allergy but did not link home exposure to their child's symptoms (U) A feeling of helplessness in their efforts to reduce child exposure to allergens (U) There was a sense of preferring not to know too much about triggers (U) Taking preventative action helped them assume a sense of control over the situation. However, if their preventative action then failed it could leave them with a sense of personal failure (C)		

U: unequivocal; C: credible

Synthesised finding 4: Relationships with healthcare professionals and the emergency department experience

Findings	Categories	*Synthesised finding*
GP first point of contact Families perceive the GP to be the first point of contact in managing their child's asthma (U) Having to make quick decisions about whether to take her child to the primary care physician (C) Parents talked about where they sought care for their child (U) The ability to acquire knowledge about their local healthcare facilities was evident in the interviews. The parents often used this information in a strategic manner to achieve access to healthcare facilities (U) **Reasons parents went to ED** Asthma symptoms drove these mothers to make the decision to go to the ED (U) While participants often communicated that they can control their child's asthma, many communicated that exacerbations require immediate treatment (U) Parents reported going to urgent care or the emergency department when their child was in extreme respiratory distress (U) Parents took their child to the hospital or emergency department when they were unable to help their child recover from an asthma episode. Trips to the hospital	Emergency Department treatment and decisions to go to ED	**Relationships with Healthcare Professionals and the Emergency Department experience** *Parents and carers express varying levels of satisfaction with the healthcare professional's asthma knowledge levels and the quality of the encounter with the healthcare professional. Parents and carers are satisfied with their healthcare professional when they consider their opinions, provide high quality care, adequate time, respect, culturally appropriate information and resources, are available when they need them and address their medication concerns. Many parents and carers who are unsatisfied with information or care received seek a second opinion from a specialist. Parents and carers seek emergency department care for acute asthma attacks and some find the hospital experience to be a difficult one.*

often took place at night (U) She wanted professional guidance in a situation that was for her confusing and unfamiliar (C) It also appears that the level of accessibility of urgent care reinforces accessing these services for asthma exacerbations (U) Parents who acknowledged accessing the system's urgent care clinic and/or emergency department stated that had do so only when their primary office is closed (U) **Parents lacked confidence to manage acute exacerbations** Parents lacked confidence in their ability to manage acute exacerbations. They described not knowing what to do during an asthma attack, panicking in the moment, not having the inhaler on-hand (U) Lack of confidence and knowledge among participants regarding how to properly manage their child's asthma (U) Not knowing what to do was another fear (C) Fear and anxiety were the most common emotions participants felt during asthma emergencies (U) Fear of acute attacks (U) **The ED Experience** A sense of helplessness was expressed among participants unable to make their child feel better (C)		

Detailed depictions of striking physical changes observed during a child's asthma exacerbation were given. A discrepancy was noted between the caregiver's emotional burden and the urgency of subsequent interventions by healthcare providers (C) For mothers, their child's admission to hospital was a critical event, which they perceived as a life-threating crisis that they were not equipped to deal with. This was compounded by their lack of information and understanding, which brought with it great fear - the fear of the unknown (U) Their intense fear stemmed from their inability to comfort their child or understand what was happening and especially their fear that their child might die (U) Not knowing what was happening with her child in the emergency department (U) Parents also told stories of cold, rude treatment (U) The initial hospital experience was difficult for many parents. (U) Mothers described long ED waits (up to several hours) prior to diagnosis (C) Emotions expressed by mothers about their ED experience (C) Emotions expressed by mothers about their ED experience - The volume of people in the waiting room (U) Emotions expressed by mothers about their ED		

experience - Noise levels (U) Emergency room procedures also challenged Abby's confidence (U) restraint is most terrifying (U) The decision to seek emergency care at a hospital was not taken lightly (U) **Confidence in ED staff and health professionals** Feeling more comfortable having health professionals manage the acute care of asthma exacerbations (U) Most of them still preferred to hand over control to professionals and modern treatments when their children were having acute asthma attack (U) Other's taking control was described by families as feeling a sense of reprieve or relief by having healthcare professionals take over the care of their child experiencing an acute asthma attack (U) Being able to transfer responsibility to health professionals meant that they would no longer be responsible for the child's care which was comforting (U) Participants expressed confidence in emergency room staff to provide superior medical treatment to their child when home therapy was ineffective (U) Parents believed that an episode could only be conclusively treated in the ED, trying to control the symptoms at home with prescription medication was sometimes perceived to only "prolong the suffering" of		

the child (U) Parents insisted on taking their children to hospitals (C) Helpful experiences with healthcare providers when her child was hospitalized. Of particular benefit was the information provided about her child's progress (U) Ruby brought Reggie to the hospital knowing that she understood his asthma well, believing that hospital he would benefit from professional and technical care, and wanting reassurance because she feared Reggie might die in asthma crisis (U) **Parental involvement** Relationships with health professionals were also described as impacting negatively on parent's sense of self-efficacy. Parents talked about the pressure they felt from hospital staff to be fully responsible for the care of their child. (U) There was an expectation that because she was staying with her child in the hospital, that she should monitor her child and administer any treatments (U) Mothers stated that they were less involved with their child when he/she was receiving headbox oxygen therapy, which was described as a barrier that made them feel isolated (U) All mothers felt unable to assist their child in any constructive way and described this as either feeling helpless or having no control (U) All mothers agreed that it is instinctive to want to hold		

their child close to comfort and care for them. They wanted to not only be involved in their child's care but have their child physically close to them (U) Participants were unified in their perception that high-flow nasal prong oxygen therapy provided a more positive method of treating the children (U) Retaining one's hold is sometimes difficult when the child's asthma is so serious that the mothers are forced to leave the child in care of medical providers (C) **The decision to go** The decision of when to go for help was a difficult decision at first (C) When prescribed treatment proved to be ineffective (incongruent event), parents were responsible for deciding the next course of action (U) Symptoms did not follow the typical asthmatic presentation (U) the pros and cons of the decision to hospitalize (U) worried that coming home might be detrimental (C) Recovery might take much longer without suctioning and IV medication (U) Managed anxiety with a clearly structured plan to access emergency care base on the frequency of Albuterol treatments (U) The process of 'Making the Call'. This was the decision-making process mothers went through to decide when a		

phone contact or visit to a health professional was needed (U) One of the more stressful and difficult aspects of 'managing it', described by the mothers, was the process of 'making the call'. It was extremely important for mothers that they could justify their choice even if, as one mother described, this choice may have resulted in the child's death (U) ‘making the call’ was something that the mothers felt was their primary responsibility (U) Balancing is how families manoeuvred through the asthma experience with their child prior to the final decision to seek immediate medical care through a hospital or ED visit (C) Making judgment refers to the part of the balancing process where families begin to question the severity of the acute attack (U) Losing control can be described as the moment when the families realized that the asthma attack has become severe enough that medical attention must be sought. (U) Point of no return means that the severe symptoms have been identified by the family and child, and there is no longer a way to help control the asthma attack (U) Developed a level of confidence about when to take Issac to the hospital (U) To become knowledgeable of when to seek emergency		

care for their child. Most participants admitted that they waited too long to seek help from providers (U) Deciding when asthma exacerbations warranted emergency services. Those with older children, described a shared decision-making approach (U) During the first recognition of a breathing crisis, Lara was motivated to seek help (U) Parents chose varied strategies to relieve asthma distress (U) Reverted to self-care practices until they felt there was a crisis requiring hospitalization (C) Use of the ED (U) **Avoiding the ED** To avoid emergency department visits or hospitalizations, mothers were willing to be hypervigilant which meant round-the-clock monitoring of symptoms, administering breathing treatments, or doing whatever it took to keep their children out of hospital (U) All parents interviewed for this study wanted very much to avoid the possibility that their child might be hospitalized (U) Experienced managers of asthma reported that initially they would go to the ED all the time, but when they were more confident, they would 'try to ride it out' at home. (C) Caregivers stated that the first thing they do for the children at the emergency room is to give them		

nebulizer treatments, so many parents fought and acquired the knowledge and equipment to do this at home (U) Parents made choices about the part they felt they needed to play in their child's asthma care. Some described a sense of total responsibility to one of passively asking the physician every time there were any symptoms (C)		
Communication issues Conscious about the words and expressions that she used in the conversation with the doctor (U) Struggle and communicate well to get staff in healthcare to understand his child's needs (U) Ineffective communication with healthcare providers was commonly described. This occurred when an LEP caregiver was unable to get his or her message across well and/or felt dissatisfied or frustrated with an exchange (U) Mothers learned a way of communicating with the healthcare system that was not always positive. This communication was viewed positively by the mothers since it allowed them feelings of control and it served to allay fears (U) The emotional toll that seemingly routine asthma treatments imparted for LEP caregivers was also expressed. The caregiver's emotional burden was linked	Communication issues with health professionals	

to their struggle with cumbersome and/or absent communication with the child's health provider (U) Some parents became aware that they needed to direct their interactions with HCPs or specifically ask for more information (U) During situations in which a barrier to good communication was present, a spectrum of advocacy responses was observed. Individual emotional responses seemed to play a significant role. Emotional responses spanned a vast range, including shame, anxiety, helplessness, and anger (U) **Parents being assertive and demanding** Parents had to be very assertive (U) Another mother was more assertive in her approach to the medical treatment her child was receiving (U) Mothers began demanding attention by demanding a change to treatment plan, seeking referral to experts, or finding another paediatrician to coordinate their children's healthcare (U) As the mothers doctor shopped and networked, they found the people who would listen to them and help them. At the same time, a transformation occurred as the mothers became people who would insist on being heard (U)		
Unable to explain what they thought was wrong with their child because of a language barrier (U)	Language barriers	

Hispanic parents indicated that they had encountered linguistic barriers (U) Parents shared that they encountered communication difficulties when securing help for their children in several contexts - at school, at the pharmacy, and in medical settings (U) Some thought there was a lack of cultural understanding of American Indian families when, for example, providers did not understand the importance of the extended family/kinship network (U) **Seeking out GP or pharmacist who could speak their language** Parents used strategies such as seeking out GPs who could speak the same language (U) Parents used strategies such as choosing to access a local pharmacist who was often of the same cultural background or could offer advice in a language other than English (U) A preference for language-concordant healthcare providers was mentioned (U) **Use of interpreters / interpreter availability** Caregivers discussed issues related to trustworthiness (or lack thereof) placed on unfamiliar interpreters (U) Several factors that related to experiences with professional healthcare interpreters seemed to perpetuate ineffective communication. Mothers reflected on experiences with interpreter availability (U)		

Preference to rely on family members or children to interpret Often, caregivers relied on family members or even children to interpret because they were viewed as reliable and capable (U) **Importance of asthma action plan in their language and asthma education opportunities** Importance of having a language-concordant plan and how a self-administered language-concordant plan might be ineffective if the words used are difficult to comprehend (U) There was an overwhelming, unified desire to expand asthma-education opportunities for LEP caregivers (U) Caregivers indicated that language barriers were contributing to existing asthma support gaps (U) AAP not in caregiver's language of choice (U) Participants also shared their experiences with language-discordant written transactions (U)		
Participants perceived, and were sometimes told that there was "no time" for them (U) Judgmental attitudes of providers toward people from lower socioeconomic or minority backgrounds (U) Almost all of the family members described personal barriers to effective management of their child's asthma. Two described feeling inadequate or inferior in the	Concern about provider judgement	

presence of healthcare providers. Although half expressed having a lack of understanding about asthma, a few were reluctant to ask questions or felt afraid to ask questions without other family members present (U) Another participant felt that a parent's fear could be misunderstood by care providers (U) Concerns about being judged by providers (C) Doctor frequently chastised her for apparent mismanagement of the asthma (U)		
Expectations of health professionals Parents had expectations to be treated by a competent healthcare professional which did not always occur. Parents felt it had taken too long to achieve the asthma diagnosis for their child (C) Quality of care – credibility of professionals was crucially dependent on their ability to demonstrate adequate and consistent clinical knowledge (U) Of utmost importance is the feeling that health professionals are responding appropriately to their child's needs, in terms of attentiveness and quality treatment (U) Almost all parents stated that trusting their provider was paramount to receiving quality care. Factors that adversely affected the relationship of parents with their child's provider were: 1) healthcare providers distrust of parents' knowledge and familiarity with their child and	Parents and carers dissatisfaction with the knowledge and quality of the encounter with the healthcare professional	

child's disease (C) Mothers who do not succeed in having their concerns heard satisfactorily (or do not raise their concerns) tend to look for complementary and alternative treatment solutions (U) **Continuity of care and regular follow-up** Parents emphasised the need for careful monitoring, continuity and for the condition to be taken seriously (C) Parents emphasised the need for careful monitoring (U) Parents reported that after the initial visits to the healthcare provider, during which a diagnosis was made and maintenance medication was prescribed, they did not receive regular follow-up appointments (U) **.Criticism of health professionals** **High Expectations from health professionals** Once the diagnosis was made, caregivers described the beginning of high expectations from healthcare delivery team. This was viewed by the families in a negative fashion. (C) Once the diagnosis was made, parents described high expectations created by healthcare providers (U) **Lack of information provided** The reported lack of education by HCPs hampered parents' ability to identify their information deficits (U) Knowledge derived from HCPs about asthma was limited for many mothers (U)		

Participants indicated that their child's physician 'assumed' that the parents were knowledgeable about asthma due to their professional status (U) Consequences of "not knowing" included mismanagement and may lead to increased dissatisfaction with caregiver's previous and future encounters with healthcare providers (U) **Lack of trust** Many parents expressed strong criticism about healthcare providers in primary care (U) Reactors - often demonstrated a lack of trust in the advice available (C) Other parents lacked trust in the physician and the healthcare providers' abilities to assist them (U) Parents' lack of trust in nursing staff. The mothers felt that they needed to have a strong trust in the nurses before they felt comfortable with the care they were providing for their child (U) Outside of established relationships with the primary care physician or specialist, one third of the parents expressed distrust in professional management (U) **Lack of respect – did not recognise parents expertise** Family caregivers also described experiences in which they felt mistreated or misunderstood by providers. One third of the participants described what they perceived as prejudice, in which they felt that providers were		

insulting or talking down to them, as well as not listening to them. (U) Some parents reported a lack of respect on the part of healthcare professionals, who trusted neither in the parents' competence or their assessment of the situation (U) Instead of accepting blame when they felt accused of doing something wrong, they were hurt and angry (U) Self-advocacy in encounters with healthcare systems. Some providers do not value parents as experts on their child's life (U) Doctors did not appreciate her knowledgeable attention to Reggie's asthma (U) Mothers found asthma to be a subtle, and hidden disease; even family members and some healthcare providers were often inclined to discount the mothers' concerns (U) Some participants thought that providers did not recognize their knowledge and expertise regarding their own children. Being told to wait while their child was in respiratory distress was particularly stressful (U) Mothers did not feel that they were supported in their search for answers (C) Mothers felt that they were being labelled as demanding and obtrusive (U) **Unclear treatment decisions - Health professionals require additional education**		

Although doctors are acknowledged as asthma support providers, many caregivers feel they would benefit from additional education (U) Healthcare providers who primarily gave directions without specific and relevant explanation were considered to be unhelpful (C) Unclear decisions about management, and ambiguous advice about symptoms from healthcare professionals, could have a negative effect on experiences (U) Reactors - reported mixed messages from professionals (U) Healthcare Professionals used different inhaler techniques (U) Parents also reported receiving inconsistent instructions about their child's treatment (environmental context and resources) – (C) Instructions I receive about the course of treatment for my child is not clear (U) Misconceptions about asthma were prevalent and at times reinforced by HCPs (U) Initially, the mothers experienced a great deal of frustration in their dealings with healthcare professionals (U) Other support which was important to parents was the quality of the encounter with healthcare providers (U) Parents felt health professionals were not interested in		

being involved in issues of transfer or responsibilities (U) **Having concerns and being heard by health providers / being a partner** Parents even believed that not having their concerns and assessments appropriately addressed by the care provider resulted in inaccurate diagnoses (U) Feelings of not being heard by healthcare providers also undermines trust in the healthcare providers in general, placing parents in a defensive position during the healthcare interaction (C) Ruby believed the doctors could collaborate more with her in managing Reggie's care (U) The ongoing management of a child's asthma often required that families interacted with HCPs regularly, usually through a regular or annual review with a practice nurse (C) Decision making between family member/caregiver and healthcare provider (C) Decision making between family member/caregiver and healthcare provider (C) Family member/caregiver attitude about healthcare relationship (U) Family member/caregiver attitude about healthcare relationship (U) Family member/caregiver attitude about healthcare relationship (U)		

System barriers were mentioned (U) **Specialist care** In specialist care, all children received regular follow-up (U)		
Culturally competent healthcare providers Desire for culturally competent healthcare providers, including personally knowing the mother and her child (U) **Shared decision making** In specialist care, their opinion changing the medication dosage was a shared decision between parents and the medical team (U) Outcomes of care - Parents saw health services as a resource in maintaining control over asthma and judged the success of health services in achieving this outcome (C) Some parents were keen that health professionals include their child in consultations (U) Achieving control was facilitated by finding a healthcare providers who would listen, acknowledge concerns, and include the mothers in the healthcare decision-making process (U) The mothers spoke of how they wanted to be considered a member of the healthcare team but that efforts to fulfil this desire were not always welcomed.	Parents and carers satisfaction with healthcare professionals	

The mothers were appreciative when their knowledge level, daily experiences, and daily monitoring were recognized (U) Decision making between family member/caregiver and healthcare provider (C) **Access to appointments** Access to appointments in primary care as an important issue. Ease of access was very highly valued (U) Access to health professionals was perceived as readily available and a strong relationship existed, parents felt supported (U) They could easily access help if they needed it (U) **Mothers wanted healthcare provider to listen to them and support them** Mothers wanted to feel that the healthcare provider was listening to them (U) Mothers negotiated with health professionals to get the best treatment plan for their child. In some instances this meant that recommended medical treatment be deferred in response to the mother's expert knowledge about her child (U) Mothers' experiences of seeking and finding medical care for their children. Feeling as though they were not being listened to and a lack of continuity of care created barriers for some mothers (U) Healthcare professionals should understand and		

support them (U) Mothers' ability to convince their care provider about the seriousness of their concerns mattered greatly for the treatment plans they followed (C) Parents reported that they believed they had access to satisfactory medical care, and they appeared to be comfortable with their physician and the care their children received (C) Both negative as well as positive evaluations of their encounters with health professionals (U) Caregivers were generally happy with the level of care that they received from their GP and/or paediatrician (U) The fathers had confidence in the healthcare providers and were pleased with their children's care (U) Some had more involvement from their child's primary care providers than others. Despite provider support, Lisa was often conflicted about accessing emergency care (C) Parents preferred healthcare providers take a more holistic approach to managing their child’s asthma, including both physical and mental well-being of their children. (U) Another important element in the management of asthma, according to all the mothers and children, is their relationship with their doctors. The most frequently heard reasons for being satisfied with the care were the doctor taking enough time for the visit, listening to the		

complaint and taking it seriously, and being easily accessible and friendly (U) **Continuity of care** Caregivers sought to maintain continuity of care for their adolescent through relationships with medical providers and pharmacist.(U) Parents emphasized the importance of protected time and space for discharge communication (U) **Good communication skills / time** Caregivers noted the importance of physician verbal and nonverbal communication skills. Good relationships were those in which medical providers were characterized as good listeners and educators, willing to spend time with both the caregiver and child with asthma (C) Any healthcare provider was expected to have the skills to engage individuals in a conversation about health (C) There were also advantages to living in a small town (U) Strong desire to be comfortable with the healthcare they access of behalf of their children (U) Another significant aspect influencing parents' perceptions of the quality of healthcare administered to their children is the feeling that care providers respect their roles as parents (U) Attentive attitudes of Healthcare Professionals important (U)		

Participants indicated that their child's physician had verbally explained to them how to manage their child in the case of asthma attacks (U) Parents also wanted what they could bring to the consultation, in the form of their unique knowledge of their child, to be valued by health professionals (U) Fathers, along with their wives, first learned about asthma from the healthcare professionals who were involved in their children's care, either an asthma educator or the child's paediatrician. Fathers were highly receptive to and satisfied with the education (U) Comments about service delivery within usual care were generally favourable, especially in relation to the children's hospital (C) Parents wanted to be acknowledged for their own assessments, knowledge, and evaluation of previous therapies (C) Participants related thoughts about what they felt was helpful during the parenting experiences of their child with asthma (U) Healthcare providers were considered to be strong emotional supports for the majority of the parents (U) **Respiratory nurses** Parents expressed confidence in the consultants and appreciated the contact with the respiratory nurses (C) Fostering a relationship with a specialist respiratory nurse was described as providing them with the support		

they needed to manage their child's condition (U) Practice nurses dedicated to asthma care were felt to provide 'navigational assistance'. They often had more dedicated time and focus than GPs to spend with a family (U) Support received from the asthma nurse at the Child Outpatient Clinic (U)		
Seeking out alternative sources of care (U) Many caregivers had strong opinions that families should be referred to asthma specialists to provide answers about their child's illness and manage their child's care (U) Following the diagnosis, the caregivers moved into a phase of conflict or battle. Caregivers described instances of having to fight with their children's physicians to get a referral (U) If the parents believed that the physician had not attended to the symptoms that the parents were concerned about, they sought care elsewhere or become more assertive in their approach to the physician (U) Parents tried to shop around to find a second opinion and better treatments. (U) For almost every mother there seemed to be a demarcation or defining moment when it was the "final straw" or they just realised they needed to be assertive and persist in finding the best care for their children (U)	Seeking out alternative sources of care	

Once sure of the diagnosis, Lucy and Freddie were angry at those who provided inadequate management plans, incomplete, inaccurate diagnoses, and impeded their access to specialty care (U) The parents expressed relief at finally finding a physician who would give them optimal treatment and care (C) All participants were concerned about logistic barriers, wait times, and delays in organizing follow-up appointments for parents (U) They regularly referred to the doctor in order for the child to be under medical supervision (U)		

U: unequivocal; C: credible

Synthesised finding 5: Medication beliefs, concerns and management strategies

Findings	Categories	*Synthesised finding*
Health and treatment beliefs The interviews revealed a number of health and treatment beliefs that influenced caregivers' use of asthma medications (U) Parents described their child's asthma using a chronic explanatory model. Parents understood asthma as something that children had all the time, regardless of whether they were actively symptomatic (U) Parents described an intermittent model of asthma. Asthma was viewed as an acute illness something that "comes and goes," and does not exist in between episodes when triggers "bring the asthma on" (U) Carers' beliefs about what constituted ‘tolerable’ asthma (U) Asthma meant being vulnerable to protracted weakness (U) **Misuse of medication and lack of understanding of medication** Albuterol was frequently misused (U) Albuterol adopted as medical management (C) Misconception regarding when to use an inhaled	Confusion over the action of medications and understanding of asthma control leads to asthma management driven by parental beliefs	**Medication beliefs, concerns and management strategies** *Parents were concerned about side-effects of asthma medications, in particular cortico-steroids. They were confused over the actions of the medications and used a variety of strategies to manage asthma according to their beliefs about medications. Some understood the necessity of regular inhaled cortico-steroids and others did not adhere to medication regimens preferring to use complementaryand alternative medicine.*

corticosteroid and when to use a beta2-agonist (C) Some parents had difficulties differentiating the anti-inflammatory and bronchodilator (U) Most of the parents appeared to be confused over the purpose and classification of asthma medications, i.e. how a reliever or a preventer works (C) Parents who had children with long-standing asthma expressed a lack of understanding or confusion about how medications worked (U) Tonya, Maria, and Anna experienced a disconnection between their understanding of the medicines they were giving to control symptoms and the use of these medicines for management of asthma (U) There were conflicting reports from parents who indicated gaps in their understanding about the medications that were prescribed for heir child in terms of the dose, frequency, and duration of administration of asthma medications (knowledge) (U) Confusion between the names, appearance, and the type of medication that were given to their child was a concern (C) Most parents were aware of their child's asthma triggers and asthma medications; however, there were conflicting reports from parents who indicated gaps in their understanding about the medications that were prescribed for their child in terms of the		

dose, frequency and duration of administration of asthma medications (knowledge) (U) The informants often found themselves confused and ambivalent regarding the medications used to treat asthma (C) Parents with young children appeared to have difficulty understanding the asthma condition and the purposes of medications (C) Confusion related to the use of inhalers, in particular their function and when to administer them (C) Reactors - were more likely than others to rely on the use of reliever medication and were often confused about what the “brown” preventer inhaler was for: (C) **Management strategies** Management of symptoms for their child with asthma in a "moment-by-moment" fashion. (C) Parents who did not know what to do in case of an asthma exacerbation generally did not know how to prevent exacerbations either (C) As soon as asthma symptoms became apparent to immediately give the inhaler device to their children so they not became more impaired and needed to go to the emergency ward (U) The concept of 'catching the asthma' early before the symptoms got too bad was echoed by many carers who kept a supply of steroid tablets at home, which meant that oral steroids could be given at the first		

signs of an attack or if their child had a cold which usually exacerbated asthma symptoms (C) Ignoring symptoms, only going to the doctor when the child was sick, or dealing with symptoms once they expressed themselves (U) Reactors were most likely to wait until an asthma attack occurred before taking action to minimise its effects. (C) Freddie recalled his relative naivete about the illness at the time medications were first prescribed. From the vantage point of greater skill and experience with the disease he recalled his earlier lack of understanding with some fearfulness (U) Daily controls for asthma (U) Daily controls for asthma (U) Each caregiver talked about dealing with asthma within the family dynamics of the setting, even isolating the child if the weather was bad or other children had been sick (C) Effective interventions (U) Parents check counters on inhalers to confirm dosages and frequently prompt their children to take medicine (U) Used strategies (e.g., placing inhaler next to toothbrush) to ensure their children received their asthma medications (behavioral regulation) (U) An additional barrier to ensuring good asthma care		

for children was the limitations set on refills by insurance (U) **Use of Peak Flow meters** Carers generally preferred their own subjective judgement to peak flow measurement (U) Lack of use of peak flow meter (U) Another treatment strategy among parents was to use the Peak Expiratory Flow (PEF) to check their child's asthma symptoms (U) **Understanding of asthma control** While parents generally endorsed the use of medications, they gave a wide range of responses when asked whether or not they actually felt like they had control of their child's asthma (U) Asthma can be controlled or prevented (U) Parents also struggled to describe what "well-controlled" asthma means and how it is achieved (U) Families talked about keeping their child's asthma under control (C) Parents related asthma control to the regular and appropriate use of asthma medications (U)		
Concerns over steroid use, long term effects and medication addiction Mothers worried about their child becoming addicted	Caregiver concerns over medication side effects	

(U) Concerns about their child taking too much medication (U) Long-term effects of asthma medication use were also a concern (U) Another reason behind their decisions to sometimes not give the medication was that the Dutch mothers also worry about long-term side effects of ICSs (U) Mothers worry about the long-term and possible harmful effects of asthma medications (U) Many participants expressed concern about the impact of the side effects of asthma (e.g., reactions to drugs, rejection of medication, and the impact of the disease on normal childhood learning) (U) Possible long-term effects of newer medication on her daughter's lungs (U) Possible side-effects of inhaled corticosteroids was a concern (U) Concern of the side effects of the medicine the child uses (U) Fear of steroids (U) Resistence against medicines in general (U) Mothers worried about potential long-term effects of taking drugs for lengthy periods at such a young, developmental age (C) Parents expressed hesitations about asthma		

medications. Parents specifically feared that their child would become dependent on asthma medications (U) Some family members expressed their concerns about long-term use of medications, especially steroids, to treat their child's asthma (U) Parents had many concerns about both classes of medications (U) Caregiver concerns related to medication dependency and adverse side effects (C) When we asked more specifically about the proper use of ICSs as maintenance therapy, all mothers, with the exception of the Surinamese, expressed reservations in some form or another.(U) Refused to administer daily medications due to concerns about potential side effects (U) Concerns about long-term use of steroids (U) Foremost concern was with respect to their children being on medications during childhood, particularly oral and inhaled steroids (U) Parents expressed concern about chronic medication use (U) Although the mothers readily admitted that their children needed the medications to breathe, the side-effects of the medications worried the informants (U) While the long term effects of steroids were usually the biggest concern, the Immediate side effects of		

some of the other medications were extremely troubling (U) Medication side effects concerned most parents about asthma medications. The word steroid held a certain concern (U) Parents voiced concerns about the long term effects of asthma medications; however, these concerns usually focused on the long term effects of asthma medications, primarily steroids, and tailoring the regimen to their own child's condition (U) Wanted to avoid using steroids on a regular basis (U) There may be long term effects from long term use of asthma medications (U) They also expressed concern and worry about the long-term side effects of asthma medications such as their inhibition of their child's growth and development (emotions, beliefs about consequences) (U) Families discussed possible side effects deriving from asthma medication (U) Caregivers voiced concerns about beliefs about inhaled corticosteroids (U) They felt there was a degree of uncertainty in the medical community about the effects of long-term use (U) Corticosteroid prednisone was a great concern because of familiar side and long-term effects (U)		

Another source of concern was the efficacy of the drug (U) Parents revealed concerns about potential side effects of oral and inhaled corticosteroids (U) Participants discussed many concerns about the oral anti-inflammatory medication prednisone (U) Parents were not given information about the medication side effects and had to learn about the side effects in a trial and error method. They developed trust or distrust in certain healthcare professional's decisions about prescribing, based on the effects that they saw from the medications given to their child (U) **Side effects of Ventolin** The other complaints about side effects came mainly from the use of Ventolin (U) Quick relief bronchodilator also caused concern (U)		
If parents were convinced of the necessity of using ICS, this was mostly because they had observed an improvement of their child's symptoms after starting ICS (U) The mother's decision to rely on alternative medicine depended primarily on her satisfaction with prescribed medications (U) Many parents did not like giving medications but saw improvement with medication (U)	Medication issues – Adherence	

Mothers reported using controller medications daily as prescribed by their HCP (U) Many parents viewed daily medications as necessary (U) Satisfaction with prescribed medications (U) The mother's decision to rely on alternative medicine depended primarily on her satisfaction with prescribed medications (U) Conventional medication helped to control the asthma, at least to an extent, most of the time (C) Parents described concordance - using controller medication the way the clinician recommended (C) Biomedicine-only pattern - If a mother who was satisfied with prescribed drugs had few friends or relatives familiar with alternative medicine, she tended to stick with what the physician prescribed (U) Mothers may rely on biomedicine by default but desire other treatments (U) Coming to Know Medications (U) Parents' actively evaluated the effectiveness of medications administered (U) The majority of the Surinamese mothers had the idea that, although their children would be affected by asthma their entire lives, they could live with it and manage the disease (U) They were faced with the dilemma of complying with		

treatment that, on the one hand, was beneficial to their children but, on the other, could have a negative impact on their children's long-term health, and they tried to reconcile their concerns (U) For carers, using steroids to minimise the effects of an asthma attack was seen as a 'catch 22' situation. Most carers were aware that steroids had side effects but felt the benefits of having a child with less asthma symptoms outweighed the risks of giving the treatment (U)		
Intermittent use Those who did not give their child controller medications as prescribed explained they only used it when the child had symptoms (U) Intentional non-concordance - Parents stated that they intentionally did not give their child controller medications as recommended (U) Some parents would use ICS only intermittently or stop using it altogether (U) Asthma goes in bursts: does so the use of medication (U) Intermittent use of medications (U) They stopped preventer medication when their child appeared well and asymptomatic (U) Parents described unplanned non-concordance. These parents reported that although they intended	Medication Issues - non adherence	

to give controller medications daily as directed, they were unable to do so (U) Parents deliberately deviated from the paediatrician's advice. They adjusted the ICS dose according to what they thought was the desired level of asthma control in their child (U) Lacking the drive to achieve good adherence (U) Some parents were hesitant to administer medications on a daily basis. They believed children would develop an addiction or become dependent on the medication, become immune or tolerant to the medication, or experience side effects (U) Children were given a single daily ICS dose instead of the recommended two (U) Dutch mothers reported performing a detailed self-assessment of the state of their children's asthma before deciding whether or not to administer their ICSs. (U) A few carers were unconvinced about the effectiveness of steroid inhalers but still carried on giving it to their children (C) Doubt about effectiveness (C) **Challenges in administration of medication** Many parents said they often "forgot" aspects of their children's asthma management, such as to take rescue inhalers with them on walks (U)		

simply forgetting giving the medication altogether (C) Consistently administering daily preventative medications such as inhaled corticosteroids was even more challenging for parents and particularly so during periods of symptoms remission (U) Parents described unintentional non-concordance - they reported following the clinicians recommendation, but their description differed from the clinician's instructions given during the audiotaped visit (U) Unintentional nonadherence to preventer medications (U) Children 8-10 years of age were given full responsibility for taking their own medication, without parental supervision. (U) Parents were astonished to find out that adherence rates recorded for a year turned out to be much lower than they had expected (U) Ineffective ways of solving problems (C) Contextual barriers to using medications (U) Mothers unwilling to confront their care providers or unsuccessful in such a confrontation but with a knowledge of complementary and alternative medicine will incorporate alternative medicine in their treatment plans (U)		

Unaware of how to use inhalers or spacers Parents reported that at some point since diagnosis they had not known when or how to properly use an inhaler (U) Some participants did not use a spacer (U) Not sure if their child inhaled in the correct way (C) Parents commented on their child's inhaler and spacer technique and care, suggesting that confusion over use may be attributed to issues with information delivery from the healthcare professionals (C) Some parents stated that they would benefit from additional training on how to use asthma medication devices (skills, behavioural regulation) (C) Unsure about whether inhaler technique was correct (U) Parents felt that they would have benefited from hands-on learning with HCPs (C) Need for procedural knowledge about asthma care (e.g. how to use an inhaler) (C) **Children’s resistance of medications** Children were perceived to resist medications (U) Parents described initial struggles with their children who resisted taking medication (U) When the children were sick, they would usually take medications without objection, but the mothers encountered resistance with maintenance		

medications (U) Child raising issues, were found to be important barriers, parents would skip a dose when children refused the use of their inhaler simply to avoid upsetting their child (U) Some parents emphasized the struggle to administer medications to their children (U) Emotional discomfort during breathing treatments was impossible to avoid (U) Resolve this conflict by omitting or delaying Susanna's breathing treatments altogether (U) I get annoyed and frustrated was the way caregivers described their children responding to having to perform the daily regimen of asthma care (U) Participants reported complications when administering some medicines and nebulizer treatment, especially to infants and young children (C) Complexity of prescribed regimen caused problems (U) Children experienced difficulties using the inhalers, or mastering the skills required to use the inhalers (U) Aesthetics of some asthma medication caused problems (U) Most had problems taking medication due to the aesthetics, including taste or smell (U)		

Children experienced side effects from the asthma medication (U) **Medication preferences** 4 parents preferred the nebulizer to the metered dose inhaler, stating that, with the nebulizer, they were sure that the child received the entire dose of medication (C) Nearly half of the parents preferred oral to the inhaled delivery of medication (U) One parent preferred inhaled delivery to oral medication because pills gave her child a stomach ache (U) The preferred methods for controlling asthma consisted of restricting the child's outdoor activities, and using nebulizers, steam, and showers in lieu of administering daily controller medication (C)		
Not using complementary and alternative treatment Mothers who discussed use of herbs denied their use and deferred to the doctor for asthma treatments (U) All families described treatment in terms of western medicine, including home treatments that reflected knowledge about standard asthma guidelines (U) Pragmatic pluralist pattern - Mothers satisfied with prescribed medication but considering adding complementary and alternative treatments greatly relied on the knowledge, advice, and support from	Complementary and alternative medicine	

their networks of care (C) In many other cases (5), relatives offered cultural remedies to assist children with asthma. The parents did not always understand the purpose of the remedies, but they nevertheless expressed appreciation for the relative's concern. The parents did not always share these practices or beliefs (U) Mothers explicitly rejected the use of complementary and alternative medicine (U) **Decisions to try alternative medicines** Family members also had concerns about providers' approaches to diagnosis and treatment of their child's asthma. Some felt that physicians over-relied on drugs to treat their children and were not willing to explore alternative treatments (U) Mothers, fathers, and grandparents all demonstrated strong beliefs in the use of folk medicines and natural remedies to treat asthma (U) Use of traditional healing with regard to treating and caring for their child with asthma (U) Parents tended to use alternative treatments and traditional Chinese medicine and not to use the Western asthma medications until the child had an acute attack, when they started looking into Western medical care (C) Respondents preferred to use non-medical approaches (U)		

They try alternative treatment and hyposensitization treatment to improve child's health (U) After experiencing homeopathy plus usual care package, six of the nine families thought that there had been an improvement in the child's asthma symptoms (U) Mothers tried various other remedies (U) Parents/carers reported the use of CAM for their child's asthma. Most reported using herbal medicines, vitamins and steam therapy (U) The ones who succeeded with modern treatment, continued to use it, but the ones who did not, tried to use alternative methods to accommodate their prevention and child health (U) **Home remedies, comfort remedies and cultural healing practices** In addition to providing emotional and social support to participants, many tutu and kapuna assisted parents with asthma care by performing traditional healing practices (C) Many participants practiced other types of treatment outside of the medically prescribed plan. Three types of CAM therapies were identified and categorized by the research team: (a) comfort measures, (b) home remedies, and (c) Hawaiian cultural healing practices (U) Home remedies were described by one experienced		

asthmatic parent as "backyard style of doing things and...their own non-Western way of doing things and treating." (U) Mothers who spoke of a cure referred to natural remedies that are commonly used in Mexico (U) All mothers using complementary and alternative medicine preferred natural herbal products (U) Familiar with complementary and alternative medicine and used it selectively to complement prescribed biomedical treatments (U) Another mother recounted her experience of following suggested family and 'folk' cures (U) Homeopathic treatment was also perceived to have brought about broader quality of life benefits for some of the children (U) Comfort measures included stopping their child from running, having them sit and relax, asking them to take deep calming breaths, having them sit in a warm bathtub, "mist in tub," having them sit in an air conditioned (AC) car, and allowing their child to sleep upright on the mother's chest (U)		
Issues The asthma action plan was thought to be too generic (U) The asthma action plan was not understood (U)	Use of an Asthma Action Plan	

Awareness of AAP, not attaching intrinsic value to its use (U) While most of the families knew what an asthma action plan was, many were unclear about where it was located or how to follow the plan (U) **Advantages** Many caregivers who reported using an action plan described a series of intrinsic benefits to having a home treatment plan (U) The plan was used as a motivational instrument for all family members to learn when the primary caregiver was not available (U) Some families clearly felt empowered by the asthma action plan and knew how to follow each step without hesitation (U) Understanding of an AAP and the value obtained for its use (U) Parents reported that they had a written action plan (WAAP). Most felt that the WAAP was easy to follow and improved their child's care (U)		

U: unequivocal; C: credible

Synthesised finding 6: With time, parents and carers became more comfortable managing their child's asthma

Findings	**Categories**	***Synthesised finding***
Parents described a number of strategies that they used for coping with asthma, such as accepting it (resigned acceptance), social support and, less often, positive reappraisal and religion (U) Fathers described feelings related to acceptance. Having trust in other people's knowledge and ability to take care of your child, and daring to relax when other people have taken over responsibility are all important factors in being confident (U) Parents were able to identify a few coping strategies that they employed (U) Parents' interest in learning deep breathing techniques, yoga, and using mindfulness (U) Adapted to caring for and living with a child with asthma (U) Parents expressed that they needed to adapt to their child's everyday life so the children could participate in the same activities as children without asthma. This adaptation could sometimes result in infections for the child (U) Parents engaged in an appraisal process whereby they would weigh the risks and benefits in each situation to arrive at a sound decision to optimize their children's healthy or normal childhood experiences (U)	Adaptation and coping strategies	**With time, parents and carers became more comfortable managing their child's asthma** *With time, parents and carers become more comfortable managing their child's asthma and they use their initiative to change medications based on symptoms. Parents and carers accept asthma into their everyday life and establish routines, plan ahead with family activities and encourage children to self-manage their condition.*

In the "Learning to Manage" phase, parents had to make some lifestyle choices that had an impact on their entire family. These have included issues such as: having pets in the home, smoking or allowing smoking in their child's immediate environment, the cleanliness of their home, or where they live, going out of the home to work and the way that they are available to their child, as well as the larger environmental exposures in the public (U) Caregivers used other activities to improve their adolescents' asthma. (U) Transforming can be described as the point in the process where families began to absorb the new information they had been exposed to, made lifestyle changes, and proposed and implemented ideas for prevention of future asthma attacks.(U) All parents were committed to caring for their asthmatic children and made many adjustments (U) Fathers' feelings - To feel hope (U) Their attitude allowed them to see the positive aspects of their situation (U) Some parents had learned that to think positively about the changes they had made (C) A final resolution strategy for Jackie was finding the positive in the asthma (U) Fathers' feelings - Adjust to life's situation (U) Fathers' actions. To be action-aimed also involves an attempt to clear up difficult situations (C)		

Parents had difficulty identifying how they coped with stress, asthma-related and otherwise (U) Although Anna would "do anything" to spare Araceli's being sick, she believed that the severity of Araceli's asthma was largely out of her control (U) Participants noted that enacting coping practices may be unrealistic due to conflicting work and caregiving demands (C)		
It gets easier Caring for a child with asthma 'gets easier' (U) Predictability of asthma symptoms (U) Seeking control also included the concept of taking care of it. Taking care of it covers how families and children with asthma decide to accept and know asthma (U) Asthma management becomes easier as children age, primarily because parents can start relying on the children to communicate their level of discomfort and concomitant needs (U) relationships with asthma after long experience in dealing with crises (U) Caregivers said that when they "took control", or became vigilant, this was a changing point for them (U) A common error acknowledged by parents in all the focus group discussions was that initially, they did not adhere to the consistent use of asthma medications or	Becoming experienced at managing asthma	

discontinued it when their children's symptoms seemed to decrease (U) Health outcome for asthma - "good control" (U) **It took time** Parents who either had to deal with a child who required continuous asthma care or those who had cared for a child with asthma for a longer period of time appeared to have better mastered their fears (U) It took time to learn these management strategies (U) **Feeling comfortable and becoming more confident** All participants were quite sure of the provoking triggers and the following onset of symptoms (C) Able to recognize their child’s symptoms (U) Fathers felt "comfortable" in their ability to take charge and manage it on a day-to-day basis (U) As fathers gained experience in treating their children's asthma, they developed a clearer picture of the total situation and became more confident in their ability to manage it, especially when it came to dealing with acute episodes (U) While the uncertainty of asthma never goes away, most of the mothers had come to have more confidence in their ability to maintain some control (U) The fathers' comfort level with asthma management increased as they saw their children respond favorably over the long term to the prescribed treatment plan (U)		

The experience of assessing and managing symptoms, and making choices about how and when to access care helped them feel more confident about what to expect and what to do (C) **Being in tune and knowing their children** Mothers repeated throughout the interview the importance of "knowing their child". (U) Participants related their experiences of coming to know their children's behaviour and symptoms in relation to activity, medications, climate changes, and seasons. Some mothers described this as being in tune with their kids. Additionally, they recognized environmental patterns (U) The subcategory of Expert Mom was depicted by the participants as managing the asthma in their children (C)		
'Timing' the response to treatment (U) Reactor parents developed coping strategies through a process of trial and error (C) Weaning the child off the added medication given to manage the asthma attack. It is an uncertain and stressful time (U) Families stepped up treatment before or with the early onset of presenting symptoms (U) Once they were comfortable with asthma management, parents assumed the primary role of initiating or	Trial and Error	

changing asthma therapy based on symptoms. Over time, parents believed that they became more confident in this role through 'trial and error." (U) Because they received insufficient or unsuitable information, the parents mastered what was effective and what was not by trial and error. (U) When parents use the trying out strategy, they learn new things about managing their child's asthma. They can try out medicine or treatment, what they should avoid or can participate in, or what the child is able to manage in terms of allergens (U) Trial and error played an important part in decisions about asthma management. Professional advice was tested and adapted to fit with carers' own understanding, developed from experiences of each child's asthma (U) Whether the child was experiencing acute attacks was an important component of tolerable asthma (C) Trial and error type of experience as mothers found what actions and treatments were efficacious in the management of the asthma (U) As parents were given medical prescriptions and recommendations from a variety of places and people, they needed to begin monitoring. Monitoring refers to the need to watch the effect of the medications and other treatments on the symptoms that they associated with asthma in their child (U) The parents were able to adjust the dosages of the medications to a level to sustain their child's health		

regardless of the situations encountered (U) Some care-givers modified instructions from their healthcare provider in order to reduce the amount of medication that their child was taking, especially when their child was well (U) Through a trial-and-error process, parents came to learn which preparations were beneficial and which had untoward effects (U) Caregivers also began to learn by trial and error and noticing what their children's triggers to asthma were (C)		
Wanting children to self-manage Mothers would teach their children to identify the symptoms of discomfort and asthma, to understand the importance of medication and to know when to take medication (U) Importance of repeating information to children in a way the can understand it (U) Teaching the child about asthma (U) Worried about how their children would manage their asthma when they became teenagers. Fathers dealt with that particular concern by endeavouring to educate their children about their asthma (U) Children’s knowledge of their illness played a major role in enabling them to accept their treatment and increase their level of responsibility in self-care. (U)	Children and self-management	

Families also discussed how their children had learned from the acute asthma attack experience (U) Mothers of teenagers stated that their children understood the reasons for medications; in fact, they also stated that experiential learning for teenagers helped them with adherence to daily therapy (U) As children grow, there is an expectation by health professionals and parents that they become the primary managers of their illness and treatment. Parents believed that their ability to transfer responsibility relied on their own degree of control and the individual characteristics of their child (C) Caregivers identified goals that related to the desire for the adolescents to become more independent and responsible for controlling their asthma. (U) Caregivers wanted their teens to be able to verbally express their asthma symptoms and needs to others (U) Caregivers described their sons as having limited verbalization regarding their experience with asthma (U) Caregivers agreed on the need to have youth take preventive measures by avoiding triggers.(U) One caregiver tried role playing to influence her teen's behavior (U) I get scared was a child subtheme described by caregivers regarding their children when experiencing asthma effects (U)		

Responsibility given to child Responsibility to administer albuterol was given to child (U) Children had responsibility for taking their own medications (U) One mother was outspoken in her opinion that children should be actively encouraged to take responsibility for themselves and their actions, both in their everyday lives and in relation to their asthma (U) Many parents report that their children who are responsible for asthma management on the school bus are also independent with medication use at home. Reasons include parental work schedules, competing priorities, beliefs that children who are independent with medication use on the school bus, should demonstrate their independence at home, and perceptions that children's independence with medication is a "freeing" experience (U) Parents were often relieved when the child could recognize themselves, the symptoms and anticipate the needed treatment (U) As children matured and demonstrated proficiency in asthma self-care, parents were able to focus on meeting some of their own needs (U) Caregivers of daughters often stated that their daughters were required to be responsible for aspects of their asthma, such as locating their emergency inhalers (U)		

Younger girls also were seen by carers to be responsible enough to be trusted to take their inhalers without supervision (C) Many parents report they teach their young children to self-administer asthma medication because they are often on a school bus without an adult who is knowledgeable about asthma management (C) Caregivers were concerned that in their absence, teens needed to know how to respond to an asthma 'crisis' and that if they did not respond themselves, others might take inappropriate actions that were unwarranted (U) A few carers stated that their children were very involved in family decision making for everyday decisions and the more major decisions (U) **Parents playing a supervisory role** Parental concern was most likely to be caused by children's adherence to using 'preventer' medication as prescribed and it was in this domain that parents were most likely to continue to play a supervisory role, reminding and often 'nagging' children to use their inhalers (C) Parents reported their shock at discovering daily examples of coughing and chest-pain, which one child shrugged off as 'just normal' (C) Parents perceived that their school-aged children needed reminders so that they could be spared the negative consequences of not taking their medication		

(U) The necessity of reminding children with asthma to take their medication (U) Children were not involved in decisions because it was considered in their best interests that carers decided for them (U) One parent even articulated that she had no concerns about asthma medication, now that her daughter was young and she was controlling the medications (U) Mothers of a child with asthma consider themselves as controllers and the child thereby feels as though he or she is being controlled (U) Half of the carers said that they fully supervised their children's asthma management by watching their children take their medication (C) The mother at time diminishes the control (U) Wanting their child to become more autonomous in asthma self-management. Yet, they acknowledged the need for continued supervision and oversight in asthma care. (U) Participants related experiences of changes that took place during their children's adolescence. This was a time of relinquishing authority and letting go, not without fears and hesitations (C) Watching over a child and allowing independence (U) Negotiations had to take place with a child who was		

gaining more independence (U) **Parents and children working together** Parents described how they worked together in the management of the young person's medication (U) Part of taking control involved shifting of some of the responsibility of asthma management to the child (C) Half of the other carers said they shared asthma management with their children. Even though they shared care with their children, the carers still accepted that the ultimate responsibility for their children's health lay with them (U) Older children evaluated the effectiveness of measures taken and discussed their interpretations with their parents (U) Transfer of responsibilities from the parent to the young person was reported most commonly as being without prior planning but as a response to specific occasions or circumstances (U)		
Caregivers identified strategies they had taken to help the teen take their medications. The most common strategy was the establishment of routines (U) Keeping Track was a subcategory in which mothers maintain organization to keep track of asthma management. Some sense of order seemed to be needed to skilfully care for their children (U) Good use of medications (U)	Establishing routines with medications	

A method of medication management offered spontaneously was the use of devices, charts, and systems that organize medication administration (U) Consistency with the medication regimen required more effort than the fathers had thought. They had to learn to make it a part of their family's everyday routine (U) Caregivers developed goals for having an adequate supply of medication available. (U) Strategies to ensure that medications do not unexpectedly run short (U) The mothers lived with uncertainty, but a way of feeling a sense of control was to develop routines (U)		
Mothers' related a normalising strategy to ensure their child lived a full and productive life despite having asthma. They did not want to treat their child differently than any other child (U) Maintaining normal family life (C) Many of the carers said they wanted their children to be treated as 'normal' children (U). Parents talked about things they did for their children so the children would believe that they were living a normal life (U) The mothers wanted their children to be children who happened to have asthma and not defined by their asthma (C) Mothers do not wish their children to use asthma as an	Normalising	

excuse to refuse to do something or as a way of obtaining special treatment (U) They wanted to shield their children from situations that could trigger an asthma episode while at the same time allow then to "lead as normal a life as possible." (U) Limiting Rewards (C) Deciding on appropriate discipline to be used was another issue each family confronted (U)		
Caregivers offered strategies that included some form of planning ahead. Thinking ahead with regard to management activities including making appointments with health-care professionals, organizing the household through the use of reminders such as charts and journals, filling medications ahead of time, and cleaning ahead of time when the child is not present so he or she is not exposed to extra dust or cleaning supplies (C) Asthma was always in the forefront when planning family activities and outings, so as to anticipate and avoid triggers (U) Packing the drugstore was a form of taking precautions so that family activities could be maintained (U) "Being prepared" was consistently linked to monitoring (U)	Planning ahead	

U: unequivocal; C: credible

Synthesised finding 7: The need for support

Findings	**Categories**	***Synthesised finding***
Managing alone All mothers in this study had to manage the asthma alone. In addition to maintaining household activities and their office work, they also had to accommodate the added role of asthma manager (C) Hispanic mothers of children with asthma say that they often have to deal with a crisis situation on their own (U) Most of the mothers were primary caretakers of their children (U) Parents described full accountability for their child's health and well-being as the responsibility of only one parent within the family (U) Inability/reluctance of second parent to assume greater responsibility in managing their child's disease was described as a lack of confidence in managing the disease (U) Interestingly, when the fathers had asthma, it was still the mother who became the primary vigilant monitor of the asthma (U) Most of the spouses were not as available to the mothers as could have been hoped, either because they travelled or distanced themselves as way of coping (C) Burden of care was not distributed equally (U)	The need for support from family members, the community and health professionals	**The need for support** *Mothers are predominantly the primary caregivers for children and many feel alone in managing the burden of asthma. They rely on family members, healthcare professionals, education setting staff and other networks for support.*

The primary carer often struggled with the overall responsibility and other family members did not know how, or could not alleviate, the responsibility; (U) Overall sense of responsibility pervaded most aspects of their life (U) Mothers' actions: To retain one's hold is to hesitate to leave the care of the child to someone else (C) Universally, in two-parent families, the mother controlled asthma management including medication administration, healthcare provider visits, management and communication with school and day care, and other activities outside of the home. Mothers assigned the role of caretaker, as needed, to other family members with whom she felt comfortable.(U) Because no other family members helped the mothers, they left all the responsibilities to mothers. Lack of support from healthcare providers and family members increased the stress of the mothers, and, in turn, affected the children's and family's life (U) There are tight bonds between the mother and child with asthma (U) I've got your back means that caregivers were willing to do whatever was reuired to help their child who had asthma. This was demonstrated by minority caregivers communicating in assuring ways with their children during asthmatic crisis (U) Taking the blame for changing medications that appeared to exacerbate an asthma attack, even at		

recommendation of a physician (U) Informants started talking to others about their experiences in an attempt to learn more and gain support. Many mothers felt very isolated going through this experience (U) Parents said that if someone has not actually cared for a child with asthma they would not understand. Parents therefore felt very alone in learning to manage the disease (U) Poor support varied among subjects, but included the school, the participants' home, the physician, and the healthcare system (U) **Both parents managing asthma** Parents indicated that both parents (i.e., mother and father) were responsible for managing their child's asthma (U) Fathers state that they play an active role in caring for their child experiencing an episode of acute asthma (C) **Need for community level asthma support** Caregivers reported a lack of community-level asthma support resources (U) Not only did caregivers want astha education for themselves and their children; they also wanted the community to be better informed. Caregivers considered community education and provision of resources that promote community-wide understanding of asthma a priority (U)		

Parents identified that the knowledge base of others who had not been faced with an asthmatic child differed from their own child's experience required them to do some teaching (C) Caregivers also expressed a strong desire for support groups in their community (U) They preferred learning by informally sitting with a small group of Native Hawaiian parents and "sharing stories." (U) Mothers unanimously stated that there is a lack of an adequate social support system for immigrant mothers of a child with asthma (C) **Family support** Caregivers offered strategies that included some form of social collaboration such as involving other family members and maintaining positive relationships (C) All participants talked about receiving emotional support from family members and/or friends (U) Fathers' actions were mostly related to liberating. To be action-aimed is to care about the child in a somewhat tougher way (C) Grandparents are very involved in taking care of their grandchildren's asthma and the proximity of living arrangements is a significant factor in the type of role they play (U) Mothers often rely on others to assist in the management of asthma symptoms (U)		

Support from partners and immediate family was highly valued, on both an emotional and a practical level (C) Mothers emphasized that they would be unable to adequately manage unforeseen and critical situations caused by their child's illness without their spouses' help (U) Caregivers rely on family members to provide them with the support they need to manage the demands of raising a child with asthma. Often these family members have direct experience raising their own child with asthma (U) As well as the way the family organised itself to undertake the new roles, the quality of relationships within the family were identified as an important component of effective management of the illness (C) Involving the family as a support system for their adolescent, especially as it related to medication management (U) The sibling of a child with asthma supported the family's work of managing the environment (U) Multi-layered web of family and friends who are likewise engaged in monitoring and managing their child's asthma (U) Advice was often given by relatives and close friends (U) The men had supportive spousal relationships (U) Support from other family members and friends, particularly those who had personal experience with asthma (U)		

Some families identified relatives with previous experience as helpful in providing information or support in the environmental changes (U) Social support assisted parents by decreasing their uncertainties about asthma symptom patterns and asthma management by providing information, service-related assistance, and emotional support (U) Most of the mothers did talk to their families about what was happening, and the rarely mentioned family history of respiratory problems, and sometimes deaths, started to be revealed (U) Another way that family members were supportive included accompanying the parent on visits to healthcare providers (U) Caregivers put extensive efforts or work into teaching everyone about the asthma (U) Cultural influences such as community were an important part of day-to-day living (U) **The need to look after self** The importance of taking time to care for self was expressed by many parents (U) Feeling torn between wanting to support herself and her children and wanting to attend Reggie closely (U) **Family / friend difficulties** Difficulties in preventing other family members from overreacting to the children's asthma (U)		

Parents relied on their own mothers for help with the children, especially when a child was ill. Yet, sometimes this caused additional problems (C) A final battle reported was that of family conflicts (U) Lack of understanding between the mothers and the fathers is also described. The mothers take the greatest responsibility for care of the sick child and feel that the fathers do not understand how laborious and hard this can be (U) Participants reported that there were disagreements regarding the proper approach to patient care, care options and the proper approach to handle a patient who refuses treatment (C) Families discussed the types of reactions they received when they had informed family members or others within their community about their child's asthma (C) Relations between mother and friends often are disturbed because of the friend's lck of understanding of the child's disease (U) Not all members of parents' social networks were sympathetic (U) A child's family structure was another issue that affected the taking of medication (U) There also were battles within families (U) **Support from health professionals** An essential part of a doctor or nurse's role was to		

'confirm the call' made by the mother and offer reassurance and affirmation that the mother was indeed 'managing it' (U) Trusting the doctor and asking for his/her help in controlling the illness (U) The support that was initially required was the provision of some education about the disease, asthma. This was often done by healthcare professionals first met during illness episodes. Education that was provided to the parents and how the parents felt when they left the appointment often influenced other information seeking behaviours (U) Parental support needs varied based on a variety of factors. Some of the single parents tended to seek medical knowledge and psychological support that they needed, from their physician (U) Physicians and nurses played an important role in educating parents about asthma control (social/professional role and identify) (U) **Issues around support from health professionals** **Medication barriers** Barriers that impacted asthma management - Difficulties fulfilling prescriptions when inhalers are empty or lost (C) Parents also feel as if their providers accommodate treatment to their needs while helping them overcome barriers while managing their child's asthma, especially in terms of getting medications refilled (U)		

Access to doctor / continuity of care As opposed to wait times, which seem to act more as a nuisance than a threat to access, the lack of appointments available in primary care clinics appears to have a significant impact on where parents seek care for their children in this health system (U) The ability to get appointments appears to be a benefit of having a continuing relationship with one healthcare provider and/or clinic (C) It appears that those who feel they have ready access to their child's primary care providers feel it's convenient to receive care in their primary care office (U) Use of the urgent care clinic seems reinforced by whether or not parents feel there are barriers to gaining more immediate treatment in their primary care clinic (U) Parents interviewed could not identify one person in the healthcare system from which they normally seek healthcare for their child (U) In primary health setting lack of continuity of staff and availability of appointments impact negatively on sense of support. (U) All participants noted that this healthcare system provides quality services regardless of one's personal circumstances and ability to pay (U) **Community / Rural issues** There was also some uniquely rural issues raised. Some of the issues included field burning, exposure to		

large hog barns, and the lack of available healthcare (U)		
Prohibitions about children carrying medication / school policy issues School prohibitions about children carrying medication with them (U) Parents identified a variety of conflicts within the context of school. One of the most remarkable battles that arose for the caregivers was the carrying and storage of the child's inhaler at school (U) Several parents report that their children who attend inner-city public elementary schools are required to keep their asthma medication in the nurse's office. Yet the children do not always have timely access to their asthma medication because the nurses in these particular schools spend limited time in one school building, and when present, have multiple responsibilities within the school that draw them out of their office (U) School policy created access barriers to asthma medications (U) Anxieties regarding policies were commonly expressed (U) Caregivers voiced concerns about a lack of asthma-friendly school policies (U) Concern about their children's safekeeping at school. Much of that concern centred on school policies	The need for support from school / childcare	

pertaining to the use of medications. None of the schools that their children attended permitted students to carry medications on their person (U) One of the most remarkable battles that arose for the caregivers in this study was the carrying and storage of the child’s inhaler at school (U) Caregivers shared experiences related to problems with teens accessing rescue medications during an asthma attack at school (C) Conflicts arose between parents and school personnel concerning the management of children with asthma. (U) Lack of support was the most frequently mentioned problem by caregivers (U) Parents were often unaware of practical issues regarding medication at school (U) **Staff inability/unease of knowing how to respond to asthma** **Prefer to keep children home** Little confidence in the ability of the schools to manage their child's asthma, most participants chose to keep their child when their child's asthma was likely to flare up (U) Many parents, however, report they prefer to keep their children home when experiencing an asthma flare-up because of the limited availability of the school nurse, and the lack of knowledge and expertise other school personnel have in managing childhood asthma (U)		

Teacher lack of knowledge Parents felt they could sense the teachers’ uneasiness of not quite knowing what to do or how to respond. (C) Lack of knowledge among staff on the variations in presenting symptoms that a teen might experience during an asthma exacerbation (U) School officials, administrators, teachers and coaches were perceived as having a lack of knowledge about the seriousness of these acute symptoms for the adolescent (U) Parents wished that school teachers had more knowledge about asthma care and were able to give asthma medication if needed (U) **Do not realise seriousness of asthma** One mother said that she did not believe that the school personnel realize the seriousness of asthma (U) One mother said that she did not believe that the school personnel realize the seriousness of the asthma (U) **School support** Family caregivers were also concerned about management of their child’s asthma at school (U) Parents perceived staff as unsympathetic to the needs of their sons/daughters, unaware of the serious nature of the condition and lacking in sufficient knowledge to know if the young person was having difficulties. (C) The level of asthma support and knowledge at schools		

experienced by caregivers varied greatly, as did their experiences with institutional willingness to support children with asthma (U) Lack of understanding of the school coaches concerning asthma (U) Despite almost all of the participants noting a need for school-based asthma support, only one participant commented on parent-school communication (U) The issue of a school nurse not being present was a problem for the families, but one they could not remedy (U) **Lack of credibility given to children when reporting asthma** Lack of credibility given to their teens when reporting acute asthma symptoms (U) **Ineffectiveness of communication within school itself** Caregivers were concerned about the schools' ineffectiveness in readily communicating important information on medical forms to permanent staff and substitute teachers (U) **Good school relations** In contrast, many suburban schools have full-time nurses, and a few of the parents in this study discussed the value of interacting with these nurses (U) Positive actions had been taken to care for their child		

when the child suffered an attack at school (U) **Communication with school personnel** Each year, parents, usually mothers, established links with significant persons in the school, such as the children's teachers, counsellors, or school nurses with whom they would entrust their children's safe keeping (C) Being able to regularly attend school and participate in sports was a goal the mothers had for their children. To ensure attendance at school or day care like other children, the mothers worked closely with the schools (U) Negotiations also had to take place with authority figures, in places where their child would be spending a larger part of his/her day. (U) Families also engaged in teaching with the child’s school by letter writing, meeting with teachers, and talking with the school nurse (U) Relationships that the parent was able to develop with other parents of asthmatic children, teachers, friends and family influenced the type of experience that they had. (U) Asthma effects on daily living in the family and community (U) **Affect on peer relationships/chlld embarrassment** Mothers would worry that the allergy symptoms might have an effect on children's peer relationships and		

learning (U) Social impact of asthma on their child, in terms of peer relations (U) Parents reported that their child experienced embarrassment when using inhalers in front of their peers or in public initially. However, this embarrassment seemed to fade with the passage of time. (U) It can be embarrassing as a subtheme for children who had asthma was reported by their caregivers (U) Parents brought up that their children felt embarrassed by these limitations or by having to use medication like their inhalers at school (U) Children felt embarrassed taking their medication in front of their peers (U) **Encouraging children to self-manage** Mothers talked with the teachers in advance about their child's condition and encouraged the children to take care of themselves (U) Directing their teens to do whatever was necessary to gain access to their asthma medications, even if it meant getting into trouble at school (U) **Advocacy for themselves and their children** Advocate for themselves when faced with accusations of child abuse and neglect (U) All of the mothers felt compelled to speak on behalf of their children, and this need extended beyond just being		

a voice for the children with the healthcare provider. The mothers advocated at the schools, so the best interests of their children would be taken into consideration (U) Caregivers advocated on behalf of their adolescent children through actions directed at the school's administrative level to develop and implement policies aimed at improving asthma management during school hours (U) **Triggers in the school environment** The need to anticipate the triggers was learned by parents during the "Learning to Manage" phase. (C) Strong concerns about their child's school environment (U) Changes in the environments to reduce the children's contacts with potential triggers (U) Changes in the environments to reduce the children's contacts with potential triggers (U) **School based asthma education** School based asthma education programs were helpful and informative for both children and parents (U) An unanticipated issue that surfaced from parents was the need for support and age-appropriate asthma education for teenaged children (C) Schools needed to adopt a stronger advocacy role in relation to issues such as asthma (U) Need for caregivers who are knowledgeable about how		

to care for their children's asthma (U) Educating babysitters, teachers, coaches, and others who were responsible for the care of the child with asthma was a major undertaking (social difficulty) (U) **Transition from home to school and from primary to secondary school** A final school battle reported by the caregivers was the transition from home to school. They had mastered the home care of their children's asthma, and when they then relinquished that care into the hands of the school, it was difficult (U) Parents expressed concern for their child when they moved to secondary school. In primary schools, particularly village schools, parents described talking to the young persons' class teacher about their condition, but at secondary schools such contact was not possible (U) Parents identified a variety of conflicts within the context of school and the transition of the child from the home environment, where many of the parents had learned to control the environmental triggers of asthma, to the school environment where the parent or vigilant caregiver was not present (U) **Transportation on school bus** Another incident that came up during the children's lives was the issue of transportation on the bus (U)		

U: unequivocal; C: credible

Appendix VII: Summary of findings table

Systematic review title: Experiences of parents and carers in managing asthma in children: a qualitative systematic review.

Participants: Parents and carers of children aged 0-18 years with asthma, wheeze or bronchiolitis.

Phenomena of interest: The experiences of parents and carers in caring for a child with asthma, wheeze or bronchiolitis. Barriers and enablers to providing asthma management to their child were examined.

Context: All settings, including (but not limited to) the home or community setting, primary health care setting and also the acute setting.

Synthesized finding	Type of research	Dependability	Credibility	ConQual score	Comments
Negotiating the meaning of having a child with asthma	**Qualitative**	**High**	**Downgrade one level***	**Moderate**	*Downgraded one level due to a mix of unequivocal (U) and credible (C) findings 128U + 26C
Impact on family life	**Qualitative**	**High**	**Downgrade one level***	**Moderate**	*Downgraded one level due to a mix of unequivocal (U) and credible (C) findings 110U + 15C
The process of getting a diagnosis and learning about asthma	**Qualitative**	**High**	**Downgrade one level***	**Moderate**	*Downgraded one level due to a mix of unequivocal (U) and credible (C) findings 203U + 40C
Relationships with	**Qualitative**	**High**	**Downgrade**	**Moderate**	*Downgraded

health care professionals and the emergency department experience			**one level***		one level due to a mix of unequivocal (U) and credible (C) findings 167U + 39C
Medication beliefs, concerns and management strategies	**Qualitative**	**High**	**Downgrade one level***	**Moderate**	*Downgraded one level due to a mix of unequivocal (U) and credible (C) findings 145U + 33C
With time, parents became more comfortable managing their child's asthma	**Qualitative**	**High**	**Downgrade one level***	**Moderate**	*Downgraded one level due to a mix of unequivocal (U) and credible (C) findings 99U + 21C
The need for support	**Qualitative**	**High**	**Downgrade one level***	**Moderate**	*Downgraded one level due to a mix of unequivocal (U) and credible (C) findings 114U + 21C