HEALTH-RELATED QUALITY OF LIFE, AND
PSYCHOSOCIAL ASPECTS, OF ASTHMA.

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Chapter 1

Introduction

In recent times the rapid expansion in the knowledge of the pathology of asthma and the biology of the inflammatory effector cells has emphasised the pathophysiology and the pharmacological treatment of asthma (1,2). However, psychosocial factors have been a feature of the literature of asthma over many years. There have been episodic reports in the early literature suggesting a psychological causation in asthma (3,4), and some reported psychological factors as the most important stimuli in asthma attacks (5).

The view of psychosocial factors in the asthma literature has changed over the past decade. Earlier articles (6,7) comprising reviews of fatal asthma and asthma made sparse mention of psychosocial factors. Inadequate education of the patient, poor compliance and a lack of access to adequate health care services have been cited as relevant to asthma mortality and morbidity. (6,7) Recent reviews have considered psychosocial factors relevant in defining severity and as possible precipitating factors in attacks. (8) Similarly, asthma management guidelines have recently included some discussion on psychosocial factors. (9,10). This has usually been in the nature of a paragraph on emotions such as anxiety and stress under factors that induce or aggravate asthma (11). It could be argued that there are already many studies of the way that patients see their illnesses. However, for a very common condition, relatively few have been concerned with asthma, and fewer have provided an account of how medical and non-medical inputs combine to influence attitudes towards disease. (12) Few studies have examined the relationship between clinical activity, temperamental, psychological and socio-demographic factors, and asthma health outcomes, particularly quality of life. The relationship between factors such as coping styles, self-efficacy, attitudes towards medications, adherence, socio-economic disadvantage, autonomy preferences, physician behaviour, organisation of care, patient satisfaction, quality of life and morbidity and
health service use, remains undefined. The use of quality of life measures in asthma in settings other than clinical drug trials has received insufficient attention.

Overview
One approach to examining the influence of psycho-social factors on asthma is to intensively study patients recruited from hospital clinics, and follow them prospectively to see what happens in terms of health service use, and quality of life change but also determine what is of importance to them. This is the approach that has been used in the work that forms the basis of this thesis. It has also been possible to compare outcomes between two different hospital settings with differing levels of specialist expertise available for care provision, in a non-randomised observational study.

This thesis presents original work conducted by the author during the Western Region Asthma Pilot Project (WRAPP). The WRAPP project was originally designed as a controlled intervention study of the effect of protocol-driven consultations based on current international asthma clinical guidelines for use in all hospital encounters for asthma patients. Purpose-designed software (MCARE Asthma, Medical Communications Associates, Belair, South Australia) was developed for entry and retrieval of clinical data at point of care, and to provide access to test results, graphical display of data and clinical decision support according to current management guidelines. Frequent and prolonged delays at implementing the system, due largely to networking and system compatibility issues, has meant that at the time of writing the system was not yet fully operational.

Consequently, a longitudinal, observational study of hospital asthma patients, recruited from two different settings, has been conducted. The Queen Elizabeth Hospital (TQEH) is a 400-bed teaching hospital of the University of Adelaide, located at Woodville, a suburb in north-western Adelaide. It has a fully operational and specialist staffed Respiratory Medicine Unit. The Lyell McEwin Health Service is a 200-bed hospital located in Elizabeth, 25
kilometres north of central Adelaide, with recent linkages to TQEH across the Divisions of Medicine, Surgery and Critical Care. Care is provided via General Medical Units with one session per week from a visiting Respiratory Specialist.

The data collected covers the four broad areas of asthma outcomes recently identified by the UK Clearing House on Health Outcomes (clinical events; psychosocial impact; self-management; patient feedback).(32) The longitudinal design with at least 12 months follow-up allows insight into the socio-demographic, socio-economic and psycho-social characteristics that influence asthma health outcomes.

Chapter 2 is a critical review of the literature on psychosocial factors in asthma, and of measurements of health-related quality of life (HRQL) in people with asthma. In the light of this review, the intent of this thesis is given in further detail.

Chapter 3 presents the methods, including the survey instruments used in the study to measure clinical morbidity and health service use, quality of life, and a number of psychosocial factors of interest in asthma research. The socio-demographic characteristics and clinical and asthma management features of the study population are described here. The surveys contained previously reported items concerning morbidity, including symptoms and activity impairment, (13) medication usage, (14) socio-demographics and socio-economic status, health-related quality of life,(15,16) coping styles of avoidance/withdrawal, active, (17) and denial, (18) self-reported general treatment adherence, (17) medication dislikes, (19) attitudes and knowledge of medication, management decision autonomy preferences, (20) satisfaction with illness, (21) health as a value, (22) socially desirable response set, (23) self-efficacy, (24) social support, (25) Physician Participatory Decision Making, (26) and patient satisfaction with care (27).
Chapter 4 establishes and compares the cross-sectional, discriminative, and longitudinal responsiveness validity of the Short-Form 36 Health Survey (SF-36) and a modified version of the University of Sydney or Marks Asthma Quality of Life Questionnaire (MAQLQ-M). The modification made to the Marks instrument was to alter the response options from a 5-point Likert to a 7-point Likert scale. This was done in an attempt to increase the reliability and responsiveness to change, making this scale potentially more useful as a clinical measure. Comparison between these two instruments was made to assess which demonstrated greater construct validity in asthma. Comparison of the performance of the SF-36 in a representative population sample with that in the WRAPP study sample was also made to assess whether it performed consistently across different administration settings. The MAQLQ-M and the SF-36 were both found to be highly valid and responsive instruments in assessment of asthma quality of life. The MAQLQ-M showed a stronger relation with clinical measures of severity than the SF-36. The MAQLQ-M was high levels of reliability and responsiveness, with minimal floor and ceiling effects, thereby demonstrating its usefulness as a clinical assessment tool.

Chapter 5 examines clinical and psychosocial factors associated with quality of life in asthma patients, and factors associated longitudinally with changes in quality of life over a 12 month period. Little work has examined the effect of temperament, coping, personality variables and socio-economic factors on the scores for validated quality of life instruments in asthma. If health-related quality of life is considered an outcome, then factors which may explain the variance in this outcome for people with asthma, such as self-management behaviour, self-efficacy and coping styles and socio-demographic factors, need to be elucidated in order for effective interventions to be designed. Avoidance and approach/active coping seems to affect behaviour and health outcomes for a number of chronic illnesses. Some work suggests coping may be of some relevance in asthma, but this pre-dates the current approach to management using regular preventive medication. If coping strategies influence self-management behaviours then we would expect an impact on
quality of life and health service use in a longitudinal study. The interaction between coping strategies and socio-economic factors, and their consequent impact on asthma behaviour and outcomes, has not yet been well defined. While provision of appropriate primary care may reduce the impact of low SES on asthma, other problems of severe economic disadvantage persist to impact on asthma outcomes. Whether these are primarily financial, such as costs of transport, home care, or medical costs, increased environmental exposures, psychological and behavioural factors, ethnicity, or other factors, is unknown.

The results showed a considerable effect of psychosocial factors on HRQL. Both baseline scores and changes over 3 months in HRQL were significantly related to coping styles, particularly avoidance coping, and to a lesser extent active coping. Economic disadvantage, as assessed by recent difficulties and concerns about costs delaying seeking needed care, rather than income levels were also significantly associated with HRQL.

Chapter 6 establishes and compares the minimally important clinical difference over time in scores on these two quality of life instruments. The issue of what change on a HRQL instrument is clinically meaningful to patients has not been well studied in people with asthma generally, and there are no published attempts for either the SF-36 or the AQLQ-M. Similarly, little information is available comparing the performance of disease-specific and generic HRQL tools in asthma in assessing a minimally important change, and whether one is superior in this regard.

The results demonstrated that the minimally important clinical difference for the MAQLQ-M was around 0.6, similar to that reported for other instruments using the 7-point Likert response scale. However this varied for different levels of baseline HRQL. The MAQLQ-M was more responsive than the SF-36 component summaries.
Chapter 7 examines the use of an alternative scoring methodology for HRQL tools, item-response theory methods, to score these two quality of life instruments and to compare this with traditional methods. The construction of HRQL instruments tends towards scales which focus on the mid-range of quality of life impairment, and are scored with traditional summative methods which may not produce interval levels of measurement. Using item-response theory to score the SF-36 and AQLQ-M it will be possible to examine if these scales are equally discriminating at all levels of quality of life, and whether similar changes in scores represent similar changes in actual quality of life at all levels of initial HRQL impairment. This would have important implications for interpretation of HRQL scores in research and clinical situations. This analysis showed the non-linearity of the Likert summative scoring model, particularly at the extremes of the HRQL range for both the MAQLQ-M and the SF-36.

Chapter 8 examines the factors associated with the self-management autonomy preferences of asthma patients. Few studies examining the effect of self-management in asthma have taken the “individual perspective as the point of departure for their analysis”. (28) The patient is not looked upon as an individual making decisions about his or her welfare, and patient behaviour is viewed as inexpedient or a problem to the formal health-care sector. It has been argued that insights may be gained by viewing ‘non-adherence’ as a form of rational individual behaviour, given the circumstances of technology, prices, administrative regulation, and the individual’s preference, knowledge and income (28). From this perspective, analysis of individual behaviour can help determine who would benefit from education programs and from targeted interventions to change the factors that determine behaviour. Determining what factors are associated with the preferences of individuals to participate in self-management decisions can assist with determining in which patients for whom guided self-management is appropriate, and those who are best suited to more directed approaches (29). The association between self-management autonomy and future health service use is also examined.
This analysis showed that individuals with asthma do not desire to be predominantly responsible for decisions regarding asthma management. What factors might be associated with the autonomy preferences. The factors associated with autonomy suggest a complex interplay between an individual's psychological make-up and personal experience both of life and of asthma, and the attitude and approach of the responsible clinicians. Higher autonomy was associated with less likelihood for future asthma hospital admissions.

Chapter 8 also examines the factors associated with the propensity of physician's to involve patients in management decisions, and the relationship of this to self-management autonomy preferences of asthma patients. Investigating what issues inhibit the development of stable therapeutic partnerships between patients and their professional carers warrants further research. Whether organisational factors, (eg the amount of time spent with the patient), can influence physician behaviour sufficiently that it affects how much patients are involved with their care is of some importance in an era of cost-minimisation. A greater propensity for physicians' to involve their patients in management decisions was associated with longer office visits and a longer tenure of the relationship between a specific physician and patient. A higher physician participatory decision-making style was associated with higher quality of life, and lower risk for hospitalisation.

Chapter 9 examines prospectively the factors associated with hospital admissions and repeat attendances at emergency departments for asthma. These are arguably the areas in which greatest gains could be made in terms of morbidity and health care costs. Evaluating the extent that psychosocial and socio-economic factors are risk factors for morbidity relative to clinical status will have implications for strategies to reduce morbidity. The results showed that predictably markers of asthma severity, along with socio-economic factors such as education and unemployment were associated with future health service events. In addition, avoidance coping and quality of care, as assessed by possession of a written asthma action plan were related
to future hospitalisations, and a dislike of using asthma medications was associated with re-hospitalisations.

Chapter 10 draws conclusions and implications from these results. Discussion of the possibilities for future research concludes this thesis.