To Entrap and Empower:
Maternal Responsibility in an Age of Neo-liberal Health

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THESIS SUMMARY

This thesis explores the ways in which maternal responsibility for child health is constructed and perpetuated through medical and public health discourses in Australia. The main aim of the research is to examine the micro-dynamics through which pervasive social understandings about the responsibilities of women for their children’s health are created. An extensive literature exists which investigates ‘mother blame’, however this thesis extends existing literature by exploring how women come to be held responsible for their children’s health, particularly within the current context of neo-liberalism. The findings also contribute knowledge about the potential for public health and medical discourses to reproduce gender inequality, including maternal responsibility.

In order to explore how maternal responsibility is constructed through public health and medical discourses I apply the research lens of congenital health problems. Using this lens allows me to illuminate discourses of maternal responsibility through a study of the ways that responsibility becomes attributed and negotiated in the event of a ‘less than desirable’ child health outcome. Given the contextual location of the research, the micro-dynamics under analysis pertain specifically to the current neo-liberal social context, where individuals are continuously educated about the power of personal choice in determining life events and about the positive role of health advice in helping people to make health enhancing choices. My use of this particular research lens, therefore, offers insight into what happens when, for the most part, women have complied with what they understand to be the regimen of advice surrounding pregnancy and yet still experience a ‘less than desirable’ outcome. This highlights a perceived failure of technologies of the self, which has remained previously unexamined in the literature on pregnancy and maternal responsibility.

The data that inform the research include narratives from open-ended interviews with women who have a young child with a congenital health problem and with medical professionals. In conjunction with the interview data I analyse health education resources for pregnant couples and medical literature about the cause and prevention of congenital health problems.

The research methodology is underpinned by an understanding of discourse as the means through which social processes and social identities are constituted, performed and transformed. Therefore, my focus throughout the analysis is on eliciting the underlying meanings and social implications that arise from information and experiences related to child health. I utilise a critical post-structuralist feminist epistemological paradigm which allows for an analysis of the operations of power and marginalisation in influencing the construction of maternal responsibility. The theoretical underpinnings of this thesis are informed by
Foucault’s theories of governmentality and bio-power, Beck’s concepts of individualisation and risk and Butler’s work on performativity.

The findings reveal that, consistent with neo-liberal ideology, women are represented as having the ability, and responsibility, to control child health outcomes, regardless of social, biological or environmental constraints. Within this individualising discourse, reproduction is constructed as a process that primarily (or solely) involves the bodies and behaviours of women. This ignores the relational nature of reproduction and obscures the complex intersections of social and biological factors that influence child health. The absence of relational and environmental considerations lays a foundation for women to be held ‘legitimately’ responsible for the (eventual) health status of their children. Contributing to the power of the constructions that emerge from public health and medical discourses is the underlying representation of reproduction as a ‘natural’ process which is, therefore, unaffected by social context and best understood through ‘objective’ science.

The findings suggest that women give resonance to the discourse of maternal responsibility by regulating their bodies and behaviours before, during and after pregnancy. The findings also demonstrate, however, that women express agency and actively negotiate the dominant discourses to establish their own understandings of maternal responsibility.

Overall, the research reveals that public health and medical discourses provide a powerful framework for shaping women’s responsibility for child health within the current neo-liberal social context. Through their engagement with this framework, women replicate, oscillate between and, in some cases, resist dominant discourses as they rationalise and embody personal responsibility for their children’s health.
DECLARATION

This work contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution. To the best of my knowledge and belief this thesis contains no material previously published or written by another person, except where due reference has been made in the text.

I give consent for this copy of my thesis, when deposited in the University of Adelaide Library, to be made available for loan and photocopying, subject to the provisions of the Copyright Act 1968.

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________________________________________  _______________________
Toni Delany                                      Date
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Part 1

Establishing the Social and Theoretical Context of the Research
INTRODUCTION

Maternal responsibility is a pervasive discourse in Australian society and it has a particularly strong influence on understandings about the causes of child health problems. The social underpinnings of this discourse are less obvious than its existence, however, since it is widely assumed that women ‘naturally’ bear responsibility for their children’s health because they carry a pregnancy and give birth. Such a biologically reductive focus leaves the complexities that underlie the construction and attribution of responsibility for child health largely unquestioned.

In this thesis I apply a critical approach to examine the construction and implications of maternal responsibility for child health from a sociological perspective. Instead of assuming that women bear an inherent responsibility for their children’s health, I view maternal responsibility as a phenomenon that is made possible through social processes and relations of power. I explore maternal responsibility as a construct that emerges from deeply embedded assumptions and norms which permeate other, often unquestioned and unchallenged, domains of society. In particular, I focus on examining the influence of public health and medical discourses in constructing and perpetuating maternal responsibility for child health. As part of this focus I explore the micro-dynamics which operate within public health and medical discourses to support the attribution of responsibility to women. I also explore the broader social context that shapes these dynamics and which further legitimates the attribution of maternal responsibility for child health. In order to contextualise this focus and highlight the social significance of the research I draw upon the narrative of one of my interview participants, Louise.

I interviewed Louise in late 2008 after she responded eagerly to my request for an interview about her experiences of mothering a child with a congenital health problem. At the time of her interview Louise was 38 years old and was living on the eastern coast of Australia. Louise began explaining her experiences by recalling the excitement and anticipation that she and her husband, Patrick, shared during 2005 when they found out that Louise was pregnant. Already parents to three children, Louise and Patrick believed that they knew what to expect from the pregnancy and they felt no need for concern about the health of the

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1 I use the first person ‘I’ to refer to my position as the author of this thesis and to highlight my experiences during the research process. The researcher’s role is an integral part of a qualitative study and as such I use ‘I’ to acknowledge my presence as part of the research process (Liamputtong & Ezzy, 2006).

2 Pseudonyms are used throughout the thesis.

3 Any medical condition that develops before or at birth which produces some degree of disability or illness. A more detailed explanation is provided later in this Chapter.
Introduction

foetus. Given this, along with her Christian beliefs which discourage termination of pregnancy, Louise decided not to undergo prenatal testing in the early stages of the pregnancy and opted to have only the routine prenatal ultrasound at 18 weeks gestation.

During the ultrasound Louise and Patrick sensed that there was a complication with the pregnancy because the radiographer spent a longer period than usual studying the foetal images. After measuring the foetus the radiographer left the room and returned with a radiologist. Louise describes what happened next:

He came in the room and ... he sort of just said “She's got spina bifida and her ventricles aren't draining.” And he sat us down and said “You know, there's no right or wrong answer but you've got to consider termination” and ra ra ra. So it was just a big shock! I've got three other healthy kids and I took my folate and I like to believe I've got a healthy diet. I was extremely sick in my pregnancy and so I don't know if that ... people say that's not related because a lot of people get sick, but I'd throw up my folate tablet. I couldn't keep anything down.

After receiving the diagnosis Louise’s thoughts became concentrated on questioning whether her own behaviours and aspects of her own biology were linked to the cause of her unborn child’s health problems. This is even despite Louise believing that she had done everything she could to comply with the advice that she received during pregnancy to ensure her child’s health:

After finding out I kind of felt like I was always conscious of the way I was living ... was it going to affect the baby? Like you go through horrendous guilt because you think well ... I've caused this. And people make comments, whether they mean to or not. It's just really hard to let go because you’re just feeling so much guilt. You just feel like you caused it. That's the hardest thing. You think “What if I could have done better?”

Apart from stimulating self-reflection and feelings of self-doubt in Louise, the diagnosis also caused difficulties in her relationship with Patrick. Following the initial diagnosis Patrick

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4 Throughout the thesis this term is spelt using the Australian English spelling of foetus or foetal rather than the American English spelling of fetus or fetal.

5 Spina bifida is a neural tube defect which develops during the first trimester of pregnancy. It results from impaired development of the spinal cord (Saladin, 2001:495,501). The symptoms of spina bifida vary depending on the location and severity of the spinal cord damage. However, most infants born with spina bifida have a pigmented lesion or protrusion on their back at the location of the spinal damage (Saladin, 2001:495). Some affected individuals also suffer paralysis and other problems (Lewis, 2003:15).

6 Another complication that can be associated with spina bifida is a condition called hydrocephalus. Hydrocephalus involves the accumulation of excess fluid within the brain, which may cause brain damage (Lewis, 2003:15).

7 Folate is a B group vitamin that facilitates cellular growth and replication. Folate is the term used to refer to the naturally occurring forms of this vitamin, which can be derived from leafy green vegetables, fruit, peas and beans. Folic acid is the term used to refer to the synthetic form of the vitamin which can be sourced in tablet form or through fortified foods. It is currently recommended that women consume folate acid supplements prior to conception and during the first trimester of pregnancy to reduce the risk of neural tube defects by up to 70% (Bower et al., 2006a; Bower et al., 2006b). Like Louise, several of the other participants who are quoted throughout the thesis refer to this B group vitamin using the terms folate and folic acid interchangeably. However, the context in which they use these terms usually indicates whether they are referring to folate sourced from the diet or folic acid sourced via dietary supplementation.
chose to collect as much information as possible about spina bifida. However, Louise’s main priorities were maintaining her physical health and waiting until after the birth to find out what the health problems would mean for the child.

Louise’s reluctance to engage with information about the health problems resulted in her feeling pressured by her husband and by medical professionals to acknowledge the health problems. In some instances, Louise’s reluctance resulted in information about her child’s health being forced upon her:

> When the doctor pulled her out of my tummy he turned her around towards me and said “There's the defect there.” Even though he was positive and everything, that’s the first thing he showed me. I couldn’t even see it, it was so low down [on her back] and it was so hidden she just looked like a normal baby and she was kicking her legs around. I don’t know why he did that but, I mean, it was horrible and I try not to think about it because it’s upsetting that that’s what he showed me first ... but I think a lot of people thought I was in denial because I didn’t have any contact with the Spina Bifida Association and I wasn’t reading about it, that’s the only reason I can say he did that.

Following the birth of their child, whom they named Emily, Louise began to engage more actively with information about the particular form of spina bifida that Emily has and about the complications that are associated with it. Several times throughout the interview Louise reflected on Emily’s health status and expressed the relative positivity that is associated with it compared with the poor prognosis that Louise and Patrick received at the time of the initial prenatal diagnosis:

> She's just going from strength to strength, she walks or she runs, she’s busy, she’s cheeky. I’m very proud. Just recently we've had to start catheterising her every three hours because the nerves have grown such that she can’t open and shut the bladder properly ... but apart from that you wouldn’t know that there's anything wrong with her.

Despite the positivity that was associated with Emily’s health at the time of the interview, which was when Emily was three years of age, Louise frequently expressed strong feelings of guilt about her perceived personal contribution to Emily’s health problems. It was clear that Louise suffers considerably as a result of her guilt and that she finds these feelings difficult to relieve or escape:

> You’re told that folate is important and you think that that’s a cure and if it doesn’t work you must be deficient. You must have been doing it wrongly. And also because you were the one who carried the baby and did all the developing, that’s the biggest thing I think. Like the first thing I do say when I tell people about her ... when I open up and say “Oh ok she’s got this” is that I took my folate. That’s the first thing I say and maybe I’m my own worst enemy in talking about the link between folate and spina bifida, but I still do it every time.
Louise’s strong and enduring feelings of guilt also appeared to be influenced by her interactions with other people. In particular, Louise’s contact with medical professionals often led her to feel guilty even though she tried to believe that she did all she could during pregnancy to ensure the health of her child:

The medical staff didn’t look for specific causes with Emily so we don’t know if we have a gene for it, which is possible, but we’re not sure. Quite often though I come home upset when they assume it’s related to folate and they say the reason why she is doing so well is because she … she wasn’t completely deprived. So often I come home from medical appointments upset because they always tend to say it’s … it’s me. Not directly, but in a roundabout way. That is hurtful and I get annoyed with it. But my husband’s been fairly supportive. Apart from the fact that I do the fair share of the medical things … well more than my fair share but … he has been pretty understanding and he kept on saying it wasn’t anything I did. So that helps, but I still worry about the folate thing, especially when the doctors keep linking it to that.

At various stages throughout the interview Louise reflected more deeply on the parenting relationship that she shares with Patrick to explain how they negotiate Emily’s care, particularly during visits to hospital:

It was all me in the hospital with Emily, and Patrick sort of did what he could in between working. I mean I’m always the one that goes in the hospital with her just because … I guess because I’m her mother and Patrick would know that if I wasn’t with her, I’d be always wanting to know what was going on. And I guess he’s able to be more detached because he’s working. Men can handle that sort of thing better. But I take her to every single appointment; we have lots of them, like every three months. And like I said, I do most of her catheterisations and if he does it I do it with him. But yeah, all of the health care is done by me … for the majority of it all.

I asked Louise why she thinks such arrangements exist within her parenting relationship with Patrick:

I don’t necessarily prefer it … but I think it’s just the way it is. I don’t know. I think it’s the mother that mainly … takes on everything.

The sense of pressure that Louise expressed both in terms of needing to engage with information about the health problems and to “take on everything” related to Emily’s care was also evident within a different context during the interview. In this instance Louise explained that she felt a need to ensure that she and her children were dressed immaculately when attending medical appointments. Louise elaborates on why she felt this was necessary:

When you have a child with a condition you’re more conscious of what people think of you as a parent. I feel a need to show I can take care of her, that I am taking care of her and that I’m doing everything I need to do, so I need to show that I’m a capable mother and that’s one way I do it.
This final quote encapsulates several of the themes that are interwoven throughout Louise’s narrative. Louise’s statement reflects a strong sense of individual responsibility for issues related to child rearing and pregnancy. Louise’s sense of responsibility and her associated “need” to demonstrate her competency as a mother arise from her interactions with medical professionals and from the blame that she spoke of throughout the interview. In particular, self-blame appeared to dominate Louise’s thoughts about Emily’s health problems despite believing that she did all she could to ensure her child’s health during pregnancy. It is in the context of Louise’s attempts to try and understand and escape this blame, both that imposed by herself and the blame imposed by others, that the prominence of a sense of individual responsibility for Emily’s health problems becomes most apparent within her narrative. This highlights a complex and paradoxical tension in the effects of individual responsibility, which appear to construct Louise as both powerless and powerful (Ruddick, 1980) or, in other words, to simultaneously entrap and empower her.

Louise’s narrative also highlights her gendered responsibility for Emily’s health problems. Such responsibility is expressed through the division of care that she shares with Patrick and also through assumptions about the cause of the health problems originating from within Louise’s own body. Louise remains committed to assuming responsibility for Emily’s health problems despite her exposure to ideas that may challenge her sole personal responsibility, such as the suggested link between spina bifida and the genetics of both Louise and Patrick. This reflects further complexities within Louise’s experiences, complexities which allude to the strong influence of the construction of gender in determining her responsibility.

Another theme arising from Louise’s narrative relates to the power of professionals in encouraging particular interpretations of responsibility. Despite ongoing uncertainty about the cause of Emily’s health problems, the strong commitment of medical professionals to a causal link between folate levels and neural tube development encourages Louise, and other people in her life, to assume that Louise is folate deficient and that this caused Emily’s health problems. This interpretation continues to frame the contact between Louise and the professionals she consults with, despite a lack of definitive evidence and a lack of investigation of either Louise’s folate level or of other possible contributing factors. This highlights the strong influence of professionals and the implicit messages that emerge from their practice in attributing individualised and gendered responsibility for child health problems.

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8 As I show in Chapter 4 understanding about the cause of congenital health problems in conventional scientific research remains incomplete and inconclusive.
The final central theme of Louise’s narrative relates to her own influence in constructing her responsibility for Emily’s health problems. Louise’s self-blame and guilt are the aspects of her experiences that she regrets the most and wishes she could eliminate, particularly because of the negative effects these feelings have on her sense of self and the quality of her relationships with others. Despite her stated desire to “move on” from guilt, however, Louise maintains an underlying commitment to her acceptance of responsibility for the health problems by linking her behaviours to the potential causes while concurrently neglecting consideration of the potential influence of any factors that existed outside of her body or outside of her personal control. This both reinforces her sense of responsibility and reveals Louise’s role in negotiating, and potentially reinforcing, the attributions of maternal responsibility that emanate from her exposure to public health and medical discourses.

**Themes that shape the thesis**

In order to explore the main themes that arise from Louise’s narrative, and from my broader analysis, I structure the presentation of findings in this thesis according to four main themes. I examine each of these themes to explain the various micro-dynamics that operate within public health and medical discourses to construct and perpetuate maternal responsibility for child health. These themes are:

- the individualisation of responsibility for child health outcomes;
- the gendering of responsibility for child health outcomes;
- the transference and reinforcement of authority to medical and public health discourses; and
- women’s engagement with, and negotiation of, public health and medical discourses.

I consider each of these themes throughout Parts 3 and 4 of this thesis where I critically examine the findings of my research. I also link my findings with relevant social theory to address the three research questions that guide my analysis, which are:

- *How* is maternal responsibility constructed within public health and medical discourses?
- What *broader implications* do the constructions of maternal responsibility have for women’s roles and responsibilities in relation to their children?
• Do the practices and bodies of knowledge that are intended to improve maternal and child health also have the potential to compromise the wellbeing of women, men and children?

**A multifaceted study of discourses**

In order to examine the micro-dynamics that inform the construction and perpetuation of maternal responsibility I have undertaken interdisciplinary research which draws upon theories and methods from both the social sciences and health sciences. The research is situated predominately within the fields of public health and sociology. The interdisciplinary nature of the research facilitates a holistic approach to understanding how maternal responsibility for child health is constructed and, as part of this, to understanding the ways that social factors, power relations and the related operation of discourses influence understandings about the origins of child health.

Consistent with a focus on power, I situate the research within a framework of critical inquiry, drawing primarily upon a post-structuralist feminist research approach. I explain more about how critical theory and feminism contribute to the research in Chapter 2. However, both approaches position personal experience at the centre of analyses of social realities, which concords with the importance and utility of Louise’s narrative in beginning to understand the focus and social relevance of this research.

The multifaceted approach that I apply is strengthened by the use of multiple methods of data collection. I have collected various forms of data during the course of the research in order to achieve as deep immersion as possible in the discourses that operate within the fields of medicine and public health. My exploration of the findings that I have drawn from analysis of these various data sources forms a central part of the thesis. The findings also serve as the basis from which I contribute knowledge about how maternal responsibility for child health is constructed and perpetuated through the micro-dynamics that operate within public health and medical discourses. In an analysis of these findings I draw upon Foucault’s theories of discourse, governmentality and bio-power and I build upon these by applying Beck’s understandings of risk and individualisation as well as Butler’s notion of performativity. I take up these theories progressively throughout the thesis at the points where they become most relevant to the findings of my research. I also apply the ideas of several other authors from the fields of sociology, particularly feminism, and public health, to interrogate and explain the findings that have emerged from my analysis.
The research ‘lens’: Congenital health problems

... illness heightens awareness of many paradoxes, or problematic aspects of existence: the relationship between mind and body, between individual and society, as well as that between nature and culture. (Edwards, 1994:2)

In order to address the broad topic of maternal responsibility for child health, and to examine the ways that mainstream public health and medical discourses construct responsibility, I use the metaphor of a lens to explain my way of focusing the discussion.

A lens is a tool that I use to create a specific focus and, through that specificity, I develop an analysis that can be extended to illuminate the construction of broader dynamics of maternal responsibility. The particular lens that I have selected for this research is congenital health problems. I define a congenital health problem as any medical condition that develops at or before birth, which produces some degree of disability or illness. Importantly, I am restricting my focus to include conditions that are diagnosed within the first six years of life. This restriction is necessary given that it is the maternal-foetal relationship that is of greatest relevance to the study.

I chose to investigate maternal responsibility through the lens of congenital health problems for several reasons, which I introduce here but also elaborate in Chapters 1 and 2. By focusing on the experiences of women whose children are born with a congenital health problem I situate the research in a context where responsibility for child health is a central concern and, therefore, frequently discussed, debated and attributed. In other words, a focus on child health problems rather than positive child health outcomes is likely to provide greater insight about how particular attributions of responsibility are produced. By focusing on ‘less than desirable’ child health outcomes I concentrate the research in an area where perceptions of failed responsibility become particularly apparent and pervasive. This accentuates the responsibilities and mothering practices of women, therefore, making the micro-dynamics of how maternal responsibility is constructed and attributed more clearly visible. Enhancing this visibility even further, a focus on congenital health problems rather than health problems that are acquired by children after birth, positions the research in a context where a child health ‘problem’, and responsibility for it, is likely to be linked most strongly to the bodies of women if such linkages are to exist. This lens, therefore, provides

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9 I refer to the medical and public health discourses that I examine in this research as mainstream because they consist of dominant and widespread ideas about the causes and prevention of congenital health problems as well as antenatal care in general. These discourses are freely available, and, in some cases, actively directed at, people of reproductive age in contemporary Australian society, which makes them important examples of current understandings and knowledges in the fields of public health and medicine. Importantly, as I show throughout the thesis the ideas that permeate mainstream public health and medical discourses extend beyond these fields and have become embedded in the more subtle dissemination of particular values through a range of different communicative processes in society.
considerable scope for examining how and to what extent links established between women’s bodies and child health problems within medical and public health discourses influence the construction of maternal responsibility for child health.

Applying the lens of congenital health problems also provides a manageable focus for data collection. A considerable amount and variety of information exists within the fields of public health and medicine about the causes and prevention of congenital health problems. This information exists in written form and is also conveyed through practice, which are two contexts that are important foci for a multifaceted study of discourses. The information is also targeted at people of reproductive age at different times—before they conceive, during a pregnancy and also following the birth of an affected child. This variety in information provides considerable scope for understanding and cross checking (triangulating) how the relevant discourses operate across various contexts to convey risk, to identify strategies for risk management and, in doing so, to attribute responsibility for the prevention and cause of congenital health problems.

The materials under analysis in this thesis relate specifically to the lens of congenital health problems. They consist of chapters from medical textbooks, medical journal articles, health education resources and interview data. I undertook interviews with medical professionals and women who have given birth to children with the congenital health problems spina bifida, congenital naevus and congenital heart disease. In order to explore this diversity of data sources I apply a similarly diverse methodological framework which values both written and experientially derived forms of knowledge.

In addition to the interviews with mothers of children with health problems, I initially considered interviewing men who father children with congenital health problems. However, I decided not to pursue these interviews. The main reason for this was related to the time constraints imposed on my fieldwork. Given the specific focus of the research I needed to give priority to exploring the contrasts and similarities between women’s views, the views of medical professionals (five males, two females) and the content of the medical literature and health education resources. However, I acknowledge that by not capturing the experiences of men who father children with health problems I have some role in reinforcing the dominant focus on women in understandings about child health. Given this, and the potential gains

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10 Throughout the thesis this term is spelt using the Australian English spelling of naevus or naevi rather than the American English spelling of nevus or nevi. The American and the Australian spellings are increasingly being used interchangeably in Australia, however. This is reflected in the name of the relevant Australian support group which is called Nevus Support Australia. The American spelling was adopted during the naming of this Group in order to ensure that their website could gain maximum exposure on the Internet and be readily accessed by those in Australia and overseas.

11 I explain my rationale for selecting these particular health problems in Chapter 3.
from exploring the insights of men, I suggest that further research be undertaken (refer to Chapter 9) to build upon the findings of this study and to explore further the micro-dynamics that contribute to the normative absence of men from the context of reproductive health (I explore this absence in Chapter 6).

In summary, on the basis of the reasoning that I detail here and elaborate in Chapters 1 and 2, I have chosen to apply the lens of congenital health problems because it allows me considerable scope to explore and critically examine the concept of maternal responsibility as it exists and operates within the current neo-liberal context of child health in Australia. By using this lens I extend existing understandings about how maternal responsibility for child health is constructed through medical and public health discourses and negotiated by women themselves (even in cases where they believe they did all they could during pregnancy to ensure their child’s health). It is important to reiterate that the application of the research lens means that my attention throughout the majority of the thesis is on exploring the specific discourses that permeate thinking about the causes and preventability of congenital health problems. In the final section of the thesis (Part 4) I widen my focus by linking the findings back to a broader analysis of the construction and implications of dominant understandings about maternal responsibility for child health. Therefore, the overarching focus of the thesis is not on the congenital health problems themselves but on the impacts these have as examples of supposed ‘failed’ responsibility for child health outcomes.

**Terminology**

Before providing further information about the structure of the thesis, it is important that I clarify some of the terms that I use throughout. In particular I use the words *women who mother children with congenital health problems* in preference to the label ‘mothers’. I do so in order to avoid totalising or homogenising the identity of these women as related to only their mothering role. This is consistent with the post-structuralist feminist methodology that guides my research (refer to Chapter 2) and it is also important to highlight that having a child with health problems is just one aspect of these women’s identities, with other aspects, such as their gender, age, class and education, also being important factors in shaping their life experiences. Therefore, avoiding the term ‘mothers’ assists me to highlight that the women’s identities are multiple, complex and interwoven (Roe & Morris, 2004:2).

In addition I use the label *congenital health problems* in preference to other possible labels such as ‘birth defect’, ‘birth disorder’ or ‘birth abnormality’. My use of this term was opposed by a medical professional who provided advice to the Human Research Ethics Committee.
(HREC) of the University of Adelaide about whether my research should be approved. Their opposition was based on the following reasoning:

I found it too "politically correct" that a congenital abnormality was called a "congenital health problem" in this application. Frequently, I find that a parent of a child with a problem will be irritated by such correctness, preferring to acknowledge that it is indeed a disorder!

I defend my use of the term *congenital health problem* on the basis that I believe that it avoids stigmatising and applying strong value judgements to affected children in the way that occurs if referring to their health as defective, disordered or abnormal. Considerable power is conveyed by the language that people use when they are in positions of authority and I do not want to replicate destructive systems of power by labelling a child ‘defective’ or ‘abnormal’. Furthermore, I believe that the term *congenital health problem* is most appropriate for use throughout this thesis particularly because it was accepted, and used, by many of the women I interviewed, several of whom expressed criticism of other terms, such as ‘defect’, on the basis that these terms perpetuated negative assumptions about their child.

Throughout the thesis I also use the terms *relational, social, environmental and biological*. I use the term *relational* to refer to the relationships that women have with other people, which have the potential to influence their health and the health and outcomes of their pregnancies. In particular, I use the term to highlight the potential influence of the relationship between the two members in a heterosexual relationship on the health of the child they conceive and, in many cases, also continue to raise. However, in some contexts the meaning of the term *relational* also extends to highlight women’s broader relationships, such as those with their immediate family and the members of the community in which they live. I use the term *social* throughout the thesis to refer to the broader collective of Australian society as distinct from a focus on the individual. In addition, I use this term to point to the potential influence of social structures, such as class, ethnicity and status, in shaping individual’s realities and child health outcomes. Taking a different approach, I use the word *environmental* to refer to the potential influence of aspects of the physical environment, such as pollution, chemicals and food additives, on child health outcomes. Finally, I use the term *biological* to refer to the cellular, genetic and physiological processes which make reproduction possible and which contribute to the development and progression of health problems within the bodies of individuals.
Structure of the thesis

In order to explain the theoretical underpinning and findings of my research I have organised the thesis into four sections. Parts 1 and 2 of the thesis consist of two chapters each, Part 3 contains five chapters and Part 4 includes one chapter.

The aim of Part 1, which consists of this Introduction and Chapter 1, is to introduce the focus of the thesis and to establish both the social and academic needs for the research. In Chapter 1 I introduce some relevant observations that I made during the course of the research and I also review relevant academic literature to establish the academic significance of this research.

In Part 2 I explain how I undertook the research. In Chapter 2 I explain the multiple theoretical approaches that I apply as part of my interdisciplinary approach. In Chapter 3 I focus on the practical aspects of the research, explaining the methods that I used to collect, analyse and ensure the rigour of the research data.

Throughout the chapters in Part 3 I explain, explore and interrogate the findings of my research. In Chapter 4 I consider how the causes and preventability of congenital health problems are constructed in the research data. This Chapter serves as a basis from which I develop a more focused approach in the subsequent chapters of the thesis to explore the four main themes that I identified earlier. In Chapter 5 I explore the way that responsibility for congenital health problems is individualised. In Chapter 6 I consider how responsibility for congenital health problems becomes gendered through the positioning of women as centrally related to cause and prevention while men are excused and excluded from understandings about congenital health problems. Chapter 7 explains how medical and public health discourses become such powerful definers of gendered and individualised responsibility for congenital health problems, particularly through the discursive erasure of the uncertainty that permeates current understandings about the causes of congenital health problems. In Chapter 8 I consider the role of women in negotiating and perpetuating mainstream discourses and I explain the implications of this. Throughout all the chapters in Part 3 I explain the meaning of the findings that I have identified and provide evidence of that meaning through the presentation of quotes and other data from the research.

In Part 4 I conclude the thesis by shifting the focus of my analysis from the lens of congenital health problems to consider the broader concept of maternal responsibility. My aim throughout Chapter 9 is to draw together the findings that have emerged from the research and apply them to explain how maternal responsibility for child health is constructed and
perpetuated through discourses of medicine and public health. As part of the Chapter I also suggest possibilities for future research and practice in areas related to gender and health.
CHAPTER 1

Establishing the theoretical context

The motivation for this research emerged from several experiences which led me to question the construction of maternal responsibility; and the role of public health and medical discourses in relation to it. In this Chapter I document these experiences and explore various fields of academic literature to highlight the theoretical context and macro-social dynamics within which my research is located. In doing so I define further some of the gaps in knowledge that my research revealed and addresses. I also introduce some of the theories that I apply, interrogate and extend throughout the thesis.

Personal beginnings

While not yet a mother, I believe that my experiences of being mothered and of watching women close to me become mothers have had an important influence on my life. Furthermore, mothering is a role that is imagined for me within society (Kirkman, Maher & Souter, 2002) and it is a role that shapes my own imagination of my future—whether that be in the sense of becoming a mother or rejecting this role through ‘choice’ or circumstance. Mothering, for me, is complex, contradictory and inherently gendered. However, what is not inherent is the form that mothering takes and the responsibilities that are attached to it. Instead I understand these as culturally and contextually contingent. The contingency of maternal responsibility was reinforced during my experiences early in my candidature.

I began my candidature with the aim of researching a topic related to mothering, both because of its strong relevance to my academic training in the field of women’s health and because of its importance to me on a personal level. While initially vague about the aspect of mothering that I would focus upon, this soon became clear.

During the first week of my candidature I travelled interstate to support a family member, whom I will call Lily, whose infant child, Rose, had undergone cardiac surgery. The surgery restructured Rose’s heart because she was born with three heart chambers instead of four. Travelling to the interstate hospital to provide support and spending considerable time in the cardiac ward meant that I was thrust into an environment that was foreign to me. Because of this foreignness, and my strong bond with my relatives, I felt both intimately involved with the situation and yet also distanced from it. I understood that I was an ‘outsider’ (an etic observer) since the experiences of hospitalisation and mothering that I was witnessing were

12 An etic account comes from a person outside the culture or context they are writing about, that is, they are an observer rather than an active participant (Headland, 1990).
not my own. However, to a certain extent these experiences became my own (emic\textsuperscript{13}) in the sense that they had a profound impact on me and my thoughts about the construction of maternal responsibility.

Over the course of my stay in the hospital I sat surrounded by women in the cardiac ward who were mothering in a very specific and visible, although contradictory, context. These mothers were positioned as centrally involved in their children’s health and health care. This was partly because of their overrepresentation in the hospital ward, which was made even more apparent by the general absence of other relatives, including the fathers of the hospitalised children, many of whom did not have a constant or consistent presence. The presence of the mothers meant that they became centrally implicated in their child’s health care by having to consult with the medical staff on a daily basis and cope with any situation that arose. The central positioning of these women also occurred implicitly because all of the children in the ward were there for the treatment of heart problems that had developed before their birth, that is, while still in their mother’s womb. The relatively young age of many of the children in the hospital also meant that posters and signs encouraging ‘appropriate’ postnatal care existed on the hospital walls. The messages expressed in these signs encouraged mothers to breastfeed their infants. Such encouragement (as discourse) permeated the environment on the cardiac ward despite many of the mothers there being unable to fulfil this role easily or successfully because their children’s heart problems compromised their breathing and sucking abilities.

The responsibility of the mothers was amplified because of the open layout of the ward which meant that the cot or crib in which each infant lay was visible to all others in the ward. This meant that the behaviours engaged in by all mothers were visible to the medical staff, other mothers and visitors in the ward. I observed that this layout operated as a particularly effective mechanism in attributing responsibility because the potential for ongoing surveillance meant that women who were not ‘attentive enough’ to their child—either through their frequent absence from the ward or from their lack of concentration on the child—were cast with disapproval from others. Such disapproval manifest in speculation that I overheard between medical staff, other mothers and visitors about the reasons for particular women’s lack of attentiveness and discussion about the potentially negative implications of this for the health of these women’s children.

\textsuperscript{13} An emic account comes from a person located within the culture or context that they are writing about (Headland, 1990).
The implicit attribution of responsibility to mothers also arose from the dominant focus on them as sources of causation and risk. Such a focus was expressed during attempts by the medical professionals to locate the cause of Rose’s heart malformation. All of the investigations that were undertaken were focused at the level of the individual. Numerous genetic tests were performed on Rose and Lily, as well as on Rose’s father, Steven. When these tests showed no genetic cause, Lily was questioned about activities that she had engaged in during pregnancy. Very little, if any, attention was focused on exploring the possible influence of factors that are located outside the bodies of Lily and Steven, and in particular, outside of Lily’s behaviours. Compounding the assumption that Lily was a source of risk to her daughters’ health were comments made to her by a nurse. Following a brief break away from the ward, Lily and I returned to Rose’s cot. Upon touching Rose, Lily was accosted by the nurse on duty and instructed to wash her hands to prevent the possibility of spreading infection. As part of her instructions the nurse stated in an encouraging, although firm, tone that “No one touches my babies without washing their hands first.” This infers that Lily, and also other women on the ward, are ‘unclean’, certainly in a physical sense, but, as my later research indicates, within such a context this inference may also extend further to highlight the women’s overall positioning as sources of potential harm to their children’s health.

I found the dominant attribution of responsibility to women theoretically interesting given my broader experience of the hospital environment. The hospital environment itself was not conducive to healthy choices yet women had the responsibility for making healthy choices thrust upon them. In particular, the strong emphasis on women’s need to ensure proper nutrition for their child (expressed through messages about breastfeeding) was contradicted by the lack of healthy food that was available for purchase at the hospital. This is emphasised since the main food store located in the hospital was a McDonald’s fast food outlet. Furthermore, there was little privacy on the ward to support breastfeeding with privacy only provided through a curtain that could be drawn around the space in which each child’s cot was located. Therefore, in the context of an environment which did not support healthy choices, and which also undermined women’s confidence by constructing them as sources of risk to their children’s health, mothers were nevertheless represented as having considerable power over their child’s health and considerable responsibility to ensure healthy outcomes for their children.

The pervasiveness of attributions of maternal responsibility within such a contradictory context is both disturbing and theoretically stimulating. My observations motivated me to explore issues relating to maternal responsibility, the construction of risk and the ‘productive’
role of medical and public health discourses in relation to both responsibility and risk. Therefore, my observations in the context of a medicalised environment assisted me in identifying the importance of the topics that I focus on in this research. Upon returning to Adelaide, in my role as an academic researcher, I also observed that dominant themes surrounding maternal responsibility are perpetuated rather than questioned, which highlights further the academic importance of this research. I began making this observation at an academic conference.

While attending the *Fourth Australian International Academic Conference on Motherhood* in 2007 I gained exposure to some of the academic research that is being undertaken to examine issues associated with mothering. During the Conference, I noted that one of the most frequently discussed topics was maternal responsibility. Maternal responsibility was discussed and explained in different ways, with some presenters challenging traditional understandings of the required roles of women and mothers (Parker, 2007; Redina, 2007). However, others reinforced dominant understandings of maternal responsibility, either overtly or implicitly by, for example, advocating greater legislative control over the behaviours that pregnant women and mothers engage in (Werren, 2007). Despite the considerable discussion that surrounded the concept, little attention was devoted to an analysis of how understandings, and their effects, about the responsibilities and obligations of mothers are created and perpetuated in society. Instead, the existence of maternal responsibility was assumed and, based on this assumption, the presenters and audience members debated its relevance and appropriateness within the context of contemporary mothering concluding that “women can be blamed for everything.” Rather than replicating this assumption, my research extends analyses of maternal responsibility by questioning how understandings about the obligations of women in regard to child health are created and perpetuated through medical and public health discourses.

The dominant themes that I have identified so far were further reinforced at the mid-point of my research in 2009 during a public lecture presented by Australian obstetric researcher Dr Claire Roberts. The lecture, entitled *It takes two: How analysis of mum’s and dad’s DNA can predict and enhance pregnancy success* (Roberts, 2009), addressed the potential contribution of men and women to placental development and pregnancy outcome. Surprisingly, given the title, men’s potential contribution was not mentioned until more than half way through this lecture despite women’s potential contribution being addressed from the outset. When men’s contribution was finally mentioned, the findings presented by Roberts (2009) suggested that pregnancy success is determined by a complex interaction of maternal and paternal characteristics that, together, dictate how well the placenta develops.
and functions and how a woman adapts to pregnancy. More specifically, Roberts (2009) explained that some genes that men contribute to a pregnancy can make it more likely that a woman will experience particular health problems during the pregnancy, problems which present considerable risk to both the wellbeing of the woman and the foetus, and also make it more likely that the growth of a foetus will be restricted during pregnancy. Furthermore, Roberts reported that men or women with certain physical characteristics, such as obesity, are more likely to contribute genes to a pregnancy that will result in complications:

Men who were considered obese, that is their BMI or Body Mass Index was greater than 30 or their waist circumference was greater than 102 centimetres, they are more likely to father a growth restricted baby. How is that? We think that’s likely to be because factors that contribute to elevated BMI are similar to those that contribute to pregnancy complications ... and it’s likely these are genetic. You can also see for these three outcomes, gestational diabetes, gestational hypertension and preeclampsia, all the women in these groups, their BMI put them into the obese category and we feel sure that this has had a role to play in their pregnancy outcome. And these three here, pre-term birth, growth restriction and preeclampsia with growth restriction, all these women are overweight. So this is a serious health concern. We do need to encourage women to reduce their weight, hopefully prior to pregnancy. (Roberts, 2009)

This quote reveals an important contradiction. When speaking about obese men, Roberts (2009) suggests that their own genetic predisposition to obesity may translate into a genetic predisposition to pregnancy complications. However, when speaking about obese women, genetic predisposition is not mentioned—instead it is their obese bodily state that is implicated in pregnancy complications and this is presented as being reversible. The construction of women’s bodily presentation, and not their genes, as the predisposing factor is then used as a basis for the suggestion that women should lose weight before pregnancy, presumably by changing their behaviours. However, men are not encouraged to lose weight before conceiving. Instead responsibility for their obesity, and for the predispositions that this may create, is eliminated through a discourse based on genetic, rather than individualised, fault. This means that control over, and individual responsibility for, improving the outcomes of a pregnancy is attributed to women only. Potentially, this may translate into assumptions about women also carrying greater social responsibility for their child’s health outcomes, which is part of what I explore throughout the thesis.

Continuing with the relative absence of focus on men was Roberts’ (2009) discussion of practical strategies that could be implemented to achieve reductions in pregnancy complications. Despite the research findings which link the characteristics of some men to pregnancy outcomes, irrespective of the bodily characteristics of their female partners, all of the preventative strategies that Roberts (2009) suggested were targeted at achieving
behaviour change in women. This was demonstrated by the disparity that existed between the text that Roberts (2009) presented on her final PowerPoint slide and her verbal commentary while presenting this slide. The slide read:

<table>
<thead>
<tr>
<th>Knowledge to help ourselves</th>
</tr>
</thead>
<tbody>
<tr>
<td>• For all couples some simple modifiable factors can improve outcome</td>
</tr>
<tr>
<td>o Folate to reduce neural tube defects and DNA damage</td>
</tr>
<tr>
<td>o Reduce weight to normal BMI with diet and exercise</td>
</tr>
<tr>
<td>o Quit smoking</td>
</tr>
<tr>
<td>o Quit alcohol and other drugs</td>
</tr>
<tr>
<td>o Eat a good quality diet with sufficient protein and plenty of green leafy vegetables and fruit</td>
</tr>
<tr>
<td>• COUPLES SHOULD DO IT TOGETHER FOR OUR CHILDREN’S SAKE!</td>
</tr>
</tbody>
</table>

Source: Roberts (2009)

This is what Roberts (2009) said while presenting the slide:

*Couples* now have some more knowledge to help themselves. For all *couples* there are some simple modifiable factors that can improve outcomes. We know that if *women* take folate for at least the 3 months prior to pregnancy and in early pregnancy we can reduce the incidence of neural tube defects but also research in our group by Denise Furness is showing that we can reduce DNA damage. Also if *women* are encouraged to reduce their weight to normal BMI with diet and exercise, to quit smoking, to quit alcohol and other drugs and even caffeine, it’s been shown that *women* who take, who drink I should say, 3 or more cups of coffee each day have a higher risk for miscarriage. But also *women* should be encouraged to eat a good quality diet with sufficient protein and plenty of green leafy vegetables and fruit. I haven’t had time to show you our data today on the diet of *women*, but we’ve found that *women* who eat abundant fruit and vegetables and who aren’t vegetarian actually have better outcomes than those who don’t eat these foods. So I think we should urge *couples* to do it together for our children’s sake. [Emphasis added]

Women are implicated in every point that Roberts (2009) makes in her speech while men are rendered almost completely absent, except for their inclusion alongside women in the term *couples*. Therefore, there is a disparity between the research evidence which highlights men’s influence and Roberts’ (2009) representation of women as the *only* people who have control over the health of a pregnancy and as the *only* people responsible for ensuring this. Overall, the focus of Roberts’ (2009) research reveals her awareness that men are left out of dominant discourses surrounding reproductive health when they actually have an influence that is worthy of further attention. Yet Roberts (2009) added no depth to the exploration of this and within her lecture the relative absence of men was reinforced rather than questioned or explored. Rather than perpetuating this, my research examines how the normative
absence of men from discussions about pregnancy and child health is constructed as I consider the implications of it in legitimating and perpetuating maternal responsibility.

During the course of my research I observed that many of the themes that I identified in the hospital, at the Conference and during the public lecture are replicated across other sites of discourse and this contributes to the pervasiveness of these dominant representations. For example in 2008 the Government of South Australia released an initiative to encourage women to ring a telephone information line if they find out that they are pregnant so they can be pre-booked into the public hospital nearest to them for antenatal care and birthing. The framing of this campaign makes clear that it is directed solely at women, at the exclusion of male partners, and it locates pregnancy and the ability to become pregnant in a context of *testing* for women. This is evident because the framing of the campaign includes a focus on a representation of a ‘pregnancy test’. Through this representation the first stage of women’s assessment as successful or unsuccessful reproducers is established.

Figure 1.1

‘You’ve passed the test’ media campaign

NOTE:
This figure is included on page 20 of the print copy of the thesis held in the University of Adelaide Library.

Source: Government of South Australia (2008)

Upon passing the *test* of conception, through this campaign women are directed to engage with medicalised services, where, presumably, they will undergo surveillance with the aim of passing the *next* tests of successfully sustaining their pregnancy and giving birth to a healthy infant. Such surveillance is similar to that imposed on women in the cardiac ward, which appeared intensified because of the risky potentials associated with the ‘unclean’ women there. This campaign is still in operation in South Australia in 2010 and the slogan is widespread with related advertisements displayed on television and in shopping centres as well as in public hospitals and medical clinics.

Similar themes are also replicated, and emphasised, in prominent self-help literature on parenting. One important source of self-help literature is the book *Towards Parenthood: Preparing for the changes and challenges of a new baby* (Milgrom et al., 2009). This book is

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14 This is the only example of self-help texts that I discuss in the thesis. While self-help texts, and more broadly popular culture, provide other sources of discourse through which women may gain access to constructions of maternal responsibility, many of the ideas upon which these discourses are based stem from public health and medical understandings. Given this as well as the specific focus of the thesis and the time constraints imposed on the research, I decided not to undertake a detailed analysis of self-help texts.
marketed on the Internet and in promotional flyers as a progressive new text that is unique in combining the expertise of clinicians and academic researchers to create a practical guide to pregnancy and parenting. The aim of the guide is to facilitate “the positive adjustment of pregnant women and their partners” and to “assist soon-to-be parents to manage the demands of pregnancy and parenting” (Milgrom et al., 2009:back cover). The marketing of this book suggests a dual focus on women and men and on helping both people in the relationship develop strategies for coping with pregnancy and parenting. However, like Roberts’ (2009) seminar, despite the stated dual focus, the content of the book focuses on women as the main people responsible for not only pregnancy but also for shaping the dynamics of their parenting relationship with their partner. Men are largely excluded from a role in relation to pregnancy since the authors consistently refer to pregnant women as “mothers” while consistently referring to men as “partners”. This distances and denies men by not affording them the same status of parenthood as women during pregnancy. Other parts of the book also reinforce the idea that men do not have a relationship to the foetus during pregnancy. Instead, the role of men is only introduced and discussed in the book from the time of birth (refer to Chapter 2 of Milgrom et al., 2009 in particular). This suggests that women become mothers from the time of conception while men do not become fathers until the time of birth, and even then their parenting role is represented as more distanced, sporadic and more optional than that of women. Further reinforcing this is the complete absence of information in the book about how men can and should be allowed to contribute to the health of a foetus before or during pregnancy, while such information is discussed frequently in the context of women’s involvement.

The greater attention that is devoted to encouraging women to act in ways that will facilitate healthy reproduction compared to that focused on men, highlights the dominant and stereotypical assumption that women, and not men, are responsible for managing reproduction and for ensuring desirable reproductive outcomes (Jackson & Mannix, 2004:150). The widespread circulation of such ideas increases the probability that women will be held responsible for ‘less than ideal’ pregnancy outcomes. I explore these ideas throughout my research and, in doing so; contribute to knowledge about the micro-dynamics by which women are held primarily or solely responsible for the health of their children. While examining these issues I draw upon many social theories; I now introduce some of these to clarify the theoretical context in which my research is located.

The emphases on risk and individual responsibility that underpin the discourses that I have explored so far in this thesis are located in the social changes that are the result of a system
of social organisation characterised by neo-liberalism and individualism. Therefore, I now explain these concepts.

**Neo-liberalism**

Within the social sciences there is a debate about how social life is constituted in terms of the power of individuals versus the influence of the societies in which they live, or in other words, the power of agency versus structure. These debates have increased in the context of social changes that have arisen from the rise in neo-liberalism (Ferguson, 2001). Neo-liberalism operates as a pervasive ideology in the sense that it shapes our ways of thinking about and acting towards each other and ourselves (Barry, Osborne & Rose, 1996; Rose, 1996). Neo-liberalism is based on the belief that the current economic market creates the possibility for (all) individuals to be successful, healthy and happy. To create this potential, neo-liberal governments focus on facilitating economic growth in the belief that the effects of this will offer the conditions necessary for people to prosper and succeed. Given this focus, there is a shift away from governments taking responsibility for individuals and a movement towards a model where individuals are regarded as having an obligation to take responsibility for themselves in order to become self-reliant (Barry, Osborne & Rose, 1996; Rose, 1996). This shift informs the discourse of mutual obligation which requires individuals to make an active and ‘valuable’ contribution in order to ‘repay’ the support that they receive from society.

Under this rhetoric, discourses of ‘limitless choice’ provide a way for people to understand their circumstances, opportunities and responsibilities (Harris, 2004:40; Walkerdine, 2004). As explained by Nikolas Rose (2007b:4) this complex combination of ‘autonomisation’ and ‘responsibilisation’ gives a particular character to the contemporary politics of life in advanced liberal democracies, which impact considerably on understandings of health.

**Responsibility in the context of neo-liberal health**

Since responsibility has become a defining feature of the current neo-liberal era, it has important implications in terms of how health and the prevention of health problems are understood. These shifts in understandings are elements of the complex system of social governance that Rose (2000b) calls *advanced liberalism*. Central to the rationalities and systems of power that underlie advanced liberalism are the:

- revised ambitions of political government, the aspiration to govern ‘at a distance’, the fragmentation of sociality and subjectivity into communities and identities, the emphasis upon creating active individuals who will take responsibility for their own fates through the exercise of choice, and the organization of socio-political concerns around the management and minimization of risks to lifestyles of contentment and consumption. (Rose, 2000b:337)
Therefore, within the context of neo-liberalism individuals are not forced (overtly) to comply with rules or regulations or to obey particular authorities. Instead individuals are encouraged to adopt a model of moral agency which allows them to accept the consequences of their actions in a self-reflexive manner. This shift from the coercive imposition of power to the exercise of power through moral obligation can be understood as a move towards a governance of the self (Rose, 1999) which characterises and predominates advanced liberal societies.

Alan Petersen (1997) has also commented on the neo-liberal trend in terms of health care arguing that since the 1970s there has been an ideological shift away from state protection of health to the idea that individuals have the responsibility to protect themselves from risk. Therefore neo-liberalism creates a culture in which the autonomous self is expected to take responsibility for ensuring physical and psychological wellbeing. This influences understandings and experiences of both the origins of health and disease and who or what should be held responsible for poor health (Nettleton & Gustafsson, 2002).

In particular, conceiving of neo-liberal citizens as responsible has impacted on the moral ordering of health and illness. According to Rose Galvin (2002:117) the healthy person has become symbolic of the ideal responsible, active and autonomous neo-liberal citizen. Conversely, people who deviate from this ideal are rendered lacking and considered morally deficient and morally culpable, particularly because of the social ‘burden’ they are considered to create (Galvin, 2002). This alignment of health and morality assumes that all citizens have a duty to maintain and ensure their health status thereby creating links between health status and the right to participate as an active, empowered citizen. This has particularly important implications for women who are pregnant in neo-liberal society because the pervasive understanding is, for the most part, that they ‘choose’ their health, and subsequently the health of their child. This operates to construct women who do not achieve the idealised norm of health or healthy children as immoral individuals who have failed to uphold the responsibilities that entitle them to empowerment as self-defining, autonomous citizens. In this sense, health has become an organising principle of contemporary neo-liberal citizenship, which is made particularly evident through the political rhetoric of individual responsibility and exercised through the responsibilising strategies of public health and medicine.

**Individualism**

Arising from neo-liberal society are the conditions of individualisation. In a revised version of a classic text in this field titled *Individualism*, Steven Lukes (2006, first edition published in
1973) explains the multiple meanings of this concept and highlights its different applications. For Lukes (2006), the meaning of individualism is contextual and it differs according to the cultural location and time period in which it is applied. The contextual basis of the concept means that factors such as traditions and the forms of thought that are dominant in particular locations influence how it is applied. The meaning and applications of the concept also differ across academic fields. For example, historians and literary scholars use the concept as a basis for exploring how and when understandings of the individual emerged in contrast to understandings based on social collectives. Anthropologists use the concept to explore the different, culturally shaped conceptions of the individual or person. However, political theorists use individualism to explain the influence of liberal principles in shaping modern political thought. Lukes (2006) argues that despite the contextual bases and multiple meanings of the concept, it is now applied mainly as an ideological device. In this sense, the concept of individualism provides a means of exploring the socially constructed body of ideas about the role of individual agency in shaping social realities combined with the broader relationship of individuals to institutions, redistributive policies and to conceptions of neo-liberalism (Lukes, 2006). Within my thesis I use the term *individualism* in such an ideological way to refer specifically to the central ideas that underpin the individualisation thesis (which I explain next). This is the dominant way that individualism is applied within public health research and its use is relevant throughout my thesis as I both apply and critique the ideas upon which the individualisation thesis is based.

In the book *Individualization* (2002) two of the most prominent theorists in this field, Ulrich Beck and Elisabeth Beck-Gernsheim, explain the individualisation thesis and discuss how it relates to social context. They argue that Western industrialised societies are in the midst of a fundamental change in the nature of society and politics. They suggest that social changes, such as those resulting from post-industrialisation and globalisation, have liberated individuals from macro-structural determinants. Beck and Beck-Gernsheim (2002:202-204) argue further that social change has caused a destabilisation of the traditional parameters of industrial society by weakening the structures that previously constrained and guided individuals, such as gender, class consciousness and family roles. In combination with this, both authors (2002:202) argue that social change has led to an erosion of traditional support networks, such as the nuclear family, the church and communities based on human mutuality. The loss of these social supports and the liberation of individuals from social constraints is believed to have provided greater choice and fewer constraints on the construction of self-identity (Beck & Beck-Gernsheim, 2002:202,210). The individualisation thesis proposes, therefore, that individuals now have the opportunity, and obligation, to take personal responsibility for choosing their priorities and planning their own lives. This means that
individuals must now construct their own personal biographies in relative isolation from collective identities and take responsibility for their lives rather than relying on a socially prescribed biography (Beck & Beck-Gernsheim, 2002). This echoes the arguments of Michel Foucault as I will explain later.

Although the individualisation thesis proposes that individuals now have greater freedom in choosing self-identity, theorists who subscribe to this still recognise that inequality has some effect on this process. For these theorists, however, it is inadequate to explain the effects of inequality through the use of macro-social structures, which they consider to be sociological “zombie categories” (Beck & Beck-Gernsheim, 2002:203-204), such as class, gender or the family. Beck and Beck-Gernsheim (2002:204), in line with Anthony Giddens (1990, 1991), argue that because individualisation has destabilised social categories this means that no (one) common experience of class, gender or family relations is identifiable. Therefore, Beck and Beck-Gernsheim (2002:xxiv) propose that instead of basing theorisation of inequality on uncertain collectives it is necessary to reconstruct what social inequality means to the actors involved. That is, to analyse the behaviours and experiences of individuals within their own individual experience of reality and to connect these with empirical evidence instead of assuming a collective experience of inequality that structures individual experience (Beck & Beck-Gernsheim, 2002:xxiv). Despite some recognition of the potential constraints imposed by inequalities, individualised (neo-liberal) cultures foster and promote a belief in control by individuals through their expression of personal agency (Beck & Beck-Gernsheim, 2002:204). For this reason a focus on the desire to choose, direct and control one’s own life is central to the cultural ideology of individualised societies rather than a focus on what cannot be achieved as a result of inequalities (Beck & Beck-Gernsheim, 2002:203).

It is important to highlight that the individualisation thesis does not propose a completely unlimited freedom through agency however. Restrictions remain to some extent because although individuals are liberated from traditional ties they are re-embedded into new, less obvious, but still partly deterministic, systems of regulation (Beck & Beck-Gernsheim, 2002). Within these systems the ‘free’ individual becomes enmeshed in a network of patterns of expected behaviour (Beck & Beck-Gernsheim, 2002). These patternings operate to define what are acceptable ‘choices’ for individuals and, in doing so, they also construct norms of social behaviour. I draw on the example of physical exercise to illustrate this.

Individualism notionally posits that every individual has choice in preserving themselves from disease, and within the context of choice based discourse, this encourages individuals’ ongoing self-surveillance to offset risk and maintain health (Petersen, 1997:187). Individuals
engage with these ideas on the basis that they desire the proposed outcome of good health and, to achieve it, they engage willingly in ceaseless self-surveillance to discipline themselves in ways that are deemed consistent with the pursuit of good health, such as engaging in regular exercise (Petersen, 1997:187). By actively performing such self-discipline individuals express agency and constitute themselves in a position of conformity with the expectations, demands and regulatory effects that emanate from neo-liberal ideals. Therefore as John Coveney (2008) argues, individualisation leads to increasing moral pressure for self-discipline as a way of managing the self and the imagined outcomes that exist for individuals within society. However, as I explain later through an analysis of theory by Foucault and an exploration of my own findings, self-discipline does not always have the desired effect of conformity.

Turning to women’s roles as mothers, the individualisation thesis constructs this issue in a way that is quite different from the approach usually and previously applied by sociological theorists (gender theorists in particular). According to the individualisation thesis, there is no one, singular way for women to organise their lives in relation to a mothering identity (Beck & Beck-Gernsheim, 2002:202-203). Instead it is the responsibility of each individual woman to construct her own identity and to organise this in relation to the other individuals who make up her family (Beck & Beck-Gernsheim, 2002:203). In other words, for Beck and Beck-Gernsheim (2002) the life chances, opportunities and experiences of women who are mothers are not pre-determined by structures such as gender or class but they instead result from the unique biography that each individual woman constructs and expresses for herself through discourses of choice and individual responsibility. This, therefore, also renders ‘less than desirable’ mothering outcomes to be based on the decisions made by individual women. I explore the implications of this idea in greater detail throughout Parts 3 and 4.

According to Beck and Beck-Gernsheim (2002), the liberating effects of individualisation have made it possible for mothers to negotiate and construct their own biographies in the way that I have outlined. These authors illustrate this possibility through their supposition that individualisation has made “ideal intimacy situations” achievable (Beck & Beck-Gernsheim, 2002:xxii). The concept of ideal intimacy refers to a situation in which the parties involved in social relationships, such as parenthood and marriage, have equal opportunity to participate and engage in intimate interactions (Stickle, 1999:2). Beck and Beck-Gernsheim (2002:xxii-xxiii) argue that the process of reciprocal individuation, which is thought to shape our social interactions in a developed post-modern world, has not only made the achievement of equality in intimate relations possible but it has also provided individuals with the right to assert, defend or question any factual or normative claim that previously shaped intimate
relationships. The result of this is that previously naturalised and socially accepted living conditions become contestable (Beck & Beck-Gernsheim, 2002:xxii; Westerling, 2004:2). In the context of the discussion about mothers, this implies that the division of domestic labour can no longer be accepted on the basis of sex roles or tradition. Instead, according to the individualisation thesis, all women now have the opportunity to renegotiate and reinvent the division of domestic tasks within their familial relationships so that they are not burdened with total responsibility as they probably would have been before they were liberated from gender normative roles (Beck & Beck-Gernsheim, 2002:xxii-xxiii; Westerling, 2004:2). This proposition also feeds into the ideals of mutuality which characterise intimate relationships in neo-liberal society. Such ideals provide the basis for expectations surrounding, and beliefs about the possibility of, men’s greater involvement in pregnancy and reproduction.

The recency of men’s inclusion in these social domains is based on the belief that changes in the social model of gender have freed men from the constraints of dominant masculinity which discouraged them from nurturing. Therefore in contemporary society there is often an expectation that egalitarianism will be present during a pregnancy\(^{15}\), and, as such, post-modern couples tend to have strong desires to create egalitarian relationships (Swanson, 2004:2). However, according to Margaret Swanson (2004) couples are met with difficulty in achieving such equality. Such difficulty emerges because, as my research reflects, the structure of society and of gender roles has, in practice, not yet changed enough to accommodate egalitarian roles for men and women (Swanson, 2004:2). The inability to move away from gender differentiated roles even though egalitarian relationships are desired is called pseudomutuality (Swanson, 2004:3).

Pseudomutuality exists when a couple believes (or pretends) that they are sharing domestic duties equally but in practice they are conforming with traditional, unequal gender roles (Swanson, 2004:3). Pseudomutuality accompanies the belief that gender roles have shifted considerably to become equal or that gender equality is possible within neo-liberal society. In this sense pseudomutuality can provide individuals with a means of denying the unequal conditions which they still experience (Swanson, 2004:3). Such denial results in disjuncture between belief and action however (Bittman & Lovejoy, 1993:302). This occurs because there is a phenomena of simultaneous conformity to the discourses of egalitarian values and gender equality yet there is continuing commitment to the traditional sexual division of labour in the allocation of time and tasks (Bittman & Lovejoy, 1993:302). This makes pseudomutuality a kind of false-complementarity where the emphasis is on individuals

\(^{15}\) I acknowledge that the ideal of egalitarianism and including men as equal partners during pregnancy and in parenting is contextually specific. Egalitarianism is not uniformly desired across Australian society nor is it the envisaged arrangement in many cultures.
maintaining a sense of reciprocal fulfilment by denying or concealing evidence of their non-mutuality (Bittman & Lovejoy, 1993:302). It also implies that there is a strong discrepancy between the egalitarian ideals that are perceived and desired and the reality of the division of domestic and emotional labour within heterosexual relationships (Swanson, 2004:3). It is only through analysis of particular tasks or aspects of the relationship that underlying, and often hidden, gendered power relations and aspects of gendered inequality become visible (Swanson, 2004:3). Therefore, in a critique of the individualisation thesis throughout my research I show that there are still many structural constraints that prevent egalitarian relationships during pregnancy and in parenting, some of which I argue are strengthened by the ideas that permeate medical and public health discourses.

**Individualism and its tension with mothering**

Within the ideology of individualism it is also clear that people are understood as autonomous individuals, yet, in an important contradiction, it is recognised that a mothers’ primary role is to care for others (Roe & Morris, 2004:1). Therefore, for mothers, or women who have the potential to be mothers, although they are embedded in broader social discourses of autonomy, their experience of individualism is not the same as it is for people who cannot be a mother (i.e. men). In particular, dominant social discourse positions women as having the obligation to express their autonomy in ways that satisfy the needs of others rather than their own. This discourse becomes relevant to women before they become pregnant (as a basis for their obligation to plan pregnancy) as well as during and after pregnancy. Yet as I will show throughout this thesis, discourses about child health are most often articulated in a way that de-emphasises the particular experiences of women, instead, perpetuating consistent ideologies of individualism and strong personal responsibility for personal outcomes (Bulbeck, 1998:239, 504). This is even though the outcomes that are interpreted as women’s personal responsibility may be expressed in the bodies of others (i.e. their children) and that women may lack complete control over the contexts in which their caring relationships are expressed (Roe & Morris, 2004:1). So in one sense women are regarded as autonomous individuals yet in another sense their personal outcomes are interpreted as being connected to the outcomes of others rather than only those of the self—this adds a unique dimension to women’s experience of individualism (Roe & Morris, 2004:1) which is an important area for further consideration.

Kathy Weingarten (1994) suggests that an alternative version of individuality applies to mothers, and, I argue, also to women who are pregnant or planning for pregnancy. Up until the time of motherhood, or preparation for it, women, like men, are encouraged to embrace individualism and the associated notion of the autonomous, masterful self that accompanies
it. However, at the time of motherhood women’s positioning in regard to individualism shifts, that is, rather than acting as autonomous people women are expected to nurture individualism in others—namely their children and their male partners (through assisting them to achieve success and leadership) (Weingarten, 1994:64). Once a woman becomes pregnant or a mother they are required to seek the selfless gratification of caring for others, rather than acting primarily for personal gain. Traditionally, mothers practiced this ideal within the home by caring for their children, husbands and the house (Weingarten, 1994:64). In contemporary times this ideal still applies yet it is now loaded with additional difficulties, contradictions and guilt for women given that, with the rise of mutual obligation theories, mothers are also expected to engage in paid work in order to extend their caring role to financial provision for the family, especially in the context of current financial demands and expectations on families. This means that for women the individualised self is temporary, being possible only up until the time of pregnancy and motherhood (Weingarten, 1994:65).

Upon pregnancy (and even in the time leading up to it), women are expected to shift their sense of individuality, and corresponding sense of individual responsibility, to include care for their (unborn) child to uphold the enduring principles of morality and ‘proper’ citizenship.

**Pregnant embodiment**

Such understandings of the moral obligations of women upon pregnancy and motherhood come, in part, from the understanding of pregnancy being inside a woman’s body but as something that should take precedence over her own physical wellbeing. A body of literature has been developed across several disciplines, including philosophy and feminism, which considers the female embodiment of pregnancy and explores the ways in which dominant understandings of pregnancy may influence women’s experiences. Philosopher Iris Marion Young is one of the most influential and frequently cited theorists in this body of work. Young (1984) proposes that pregnancy represents a unique stage of life in which the usual dichotomy between the self and the other dissolves. A pregnant woman feels inner movements that originate from another being and she can experience those movements as her own because they are contained within her body (Young, 1984:46,49). Young (1984:46,49) also proposes that pregnancy creates experiences of flux and transition for a woman because it is a time in which her body is shared between herself and the other who is located inside her. This is a sharing, I argue, that also involves the need to meet social expectations and imperatives. Given the ambiguity that is associated with the bodily boundaries of a pregnant woman, pregnancy is often regarded as a condition that does not belong entirely to the pregnant woman herself (Young, 1984:45). Instead it is the state of her developing foetus and the imagined future of the society in which she lives.
While pregnancy is not regarded as a condition that belongs to the pregnant woman, the outcome of a woman’s pregnancy is usually conceptualised as the product of her body. One reason for this is that a pregnant woman provides the environment in which the foetus grows and in which the biological processes of foetal development occur (Maher, 2002:5; Young, 1984:45). Therefore, the processes that are associated with foetal development are thought to be highly dependent upon the conditions that are present within the body of the pregnant woman even though those processes are not considered to be her own. Pregnancy is also understood as belonging within the domain of science (particularly medicine) because it is based upon observable and measurable scientific processes that result in the creation of a being that is eventually separable (often through medical intervention) from the woman’s body (Young, 1984:45). Understandings such as these influence Western thinking about pregnancy and have particular implications for the conceptualisation of pregnancy, maternal responsibility and the appropriate role of medical professionals in regard to reproduction (Maher, 2002; Young, 1984). Consideration of such understandings, along with acknowledgment of the dominant focus on ‘choice’ (Maher, 2010), provides a foundation for exploring the strong influence of medicalisation on the discourses that I examined throughout the research.

**Medicalisation of reproduction and mothering**

Medicalisation is a sociological concept that has been applied to understand the processes through which a variety of experiences, such as pregnancy and child birth, have been defined as medical ‘issues’ or ‘problems’ and repositioned within the realm of science. Therefore, understanding medicalisation is central to understanding the power of medicine and public health in constructing and reinforcing maternal responsibility for pregnancy and child health.

For decades, women, and especially pregnant women and mothers, were expected to know ‘naturally’ how to foster healthy foetal growth and how to adequately care for their children. This belief began to change in the mid-nineteenth century, however, and with the numerous advances that occurred during the twentieth century, assumptions of the natural mother have been replaced by a reliance on medical and scientific advice (Apple, 2006:2). In Western capitalist countries science now defines what it means to be a ‘good’ mother and prescribes the practices necessary to achieve it (Apple, 2006). Therefore, the foundation of appropriate motherhood has shifted from the display of an ability to care for and love a child to a foundation that is based on extensive training and an acceptance of the need for, and the benefit of, scientific expert intervention in all facets of reproduction and child rearing (Apple, 2006:2).
This shift has arisen, in part, from the redefinition of pregnancy, birth and child rearing in ways that render them as legitimate areas of study and intervention for health professionals. This is an integral part of the medicalisation process and it occurs through the application of medical definitions to behaviours, phenomena and experiences not previously classified under the conceptual or therapeutic scope of medicine (Conrad & Schneider, 1980:75; Davis, 2009:211). The process of medicalisation also involves the rendering of particular behaviours or experiences as deviant, problematic and as based on a particular illness or deficiency (Davis, 2009:215). This shifts a behaviour or experience from the social realm into the realm of medicine making it a legitimate focus for authoritative regulation through medical processes. The medicalisation of particular experiences and behaviours usually results in, or coincides with, changes in social attitudes and the related terminology (Gabe, Bury & Elston, 2006:59-60). Medicalised terms such as syndrome, health problem and condition then become attached to particular experiences and behaviours. The medicalisation process is also often accompanied, and driven, by the availability of relevant medical interventions to address the ‘problem’. Therefore, medicalisation emerges from increasingly complex systems of technology, bureaucratisation and surveillance that encourage, and necessitate, a reliance on expert authority in order to understand and negotiate the world in which we live (Zola, 1972).

Understandings based on medicalisation began to appear in academic and medical literature during the late 1960s and 1970s, most notably in the work of Irving Zola (1972), Peter Conrad (1975) and Ivan Illich (1976). At this time, the movement of medical authority into the domains of everyday life was being promoted by health professionals, particularly doctors, yet it was opposed by other sectors of the community. The main reason for this was that medicalisation was viewed as a process of social control, through which people and populations would become further regulated by structures of authority (Goffman, 1961). This critique of medicalisation was documented in Conrad’s classic work *The Discovery of Hyperkinesis: Notes on the Medicalization of Deviant Behavior* which was published in 1975. Illich (1976) furthered Conrad’s critique by arguing that the expansion of modern medicine had created a social dependence on the authority of medical experts and, as such, had reduced the ability and opportunity for people to understand how to engage in self-care. Therefore, in the work of these authors, medicalisation was constructed as a largely top down, hegemonic process.

Within early feminist sociological theory medicalisation was also viewed as a predominantly hegemonic process. According to this view, medicalisation renders women’s bodies as manipulated and controlled by the patriarchal systems of the medical establishment.
However, authors writing in the 1980s and 1990s began to challenge the hegemonic view of medicalisation. In particular, Catherine Riessman (1992) explains the process through which women have actively participated in and, to some extent, gained from, their medicalisation. For women, medicalisation has provided an acknowledgement of their particular bodily needs and has addressed some biological issues experienced specifically by women through the invention of medicalised treatments, such as pharmaceuticals and contraceptives, and procedures such as caesarean section (Riessman, 1992).

The latter works of Michel Foucault also challenge a hegemonic view of medicalisation. Foucault’s (1980) theories on modern power, such as that manifest within the medicalisation process, suggest that it does not operate as a one directional hierarchy that works only to oppress people. Nor can power be understood as emanating from only one source, such as the medical establishment. Instead, for Foucault, as I will elaborate in Chapter 2, power constitutes “a productive network which runs through the whole social body” (Foucault, 1980:119).

Based on understandings of medicalisation as a *productive* force Carlos Novas and Nikolas Rose (2000) argue that medicalisation informs a cultural condition of society where biology has been incorporated within the fabric of contemporary subjectivity and socialisation. This inspires new modes of relations with the self and others, which these authors refer to as *somatic individuality*. Novas and Rose (2000) argue that a somatic individuality is created by the identification of risk in otherwise healthy people and the subsequent positioning of them as pathological agents. Rose has undertaken considerable research to explore the links between biology and social identity. From this, he proposes that individuals’ sense of self has become somatic in the sense that it is based largely on their relations with, and understandings of, the *potentialities* of their biologies (Rose, 2007b).

Medicalisation has had a significant role in this by rendering visible aspects of human biology that were not visible before, such as genetics and the foetuses carried within women’s wombs. Such visibility can amplify perceptions of bodily risk and, in doing so, reshape our social experiences and reorganise our relations with our bodies (Rose, 2007b). Rose (2007b) links this with the politics of advanced liberalism in which biological identity comes to generate biological responsibility, particularly for those people, identified through medicalisation, as posing a risk of transmitting disorders to others—such as pregnant women and those with an infectious disease. This understanding, combined with neo-liberal ideologies, encourages individuals to be self-regulating in the context of new medicalised forms of identity and sociality, in which moral responsibility for health is central. I apply this
understanding of medicalisation as I explore the dual operations of both authoritative discourses and women’s agency in constructing, perpetuating and negotiating particular understandings of maternal responsibility for child health.

Despite medicalisation involving greater agency than once thought, this does not mean that it is not unproblematic. In fact, one of the main foci of current debates around medicalisation theory relates to the possibility that medicalisation has now become so widespread that it has invaded virtually all areas of social life resulting in the redefinition of numerous experiences and behaviours as ‘medical problems’. This creates the framework necessary for the medical pathologisation of behaviours and experiences that have a predominantly social basis (Davis, 2009). The imposition of medicalised explanations and ‘solutions’ onto social problems or experiences operates to deflect attention from the social context to the individual (Davis, 2009:224). This means that it obscures the role of social structures and inequalities in producing the conditions necessary for particular social experiences and for particular social problems to emerge. Ignoring the social also obscures the need for social change in order to improve circumstances for individuals and social groups (Davis, 2009:224). Therefore, the process of medicalisation over-simplifies and individualises understandings about complex social realities in a way that denies the legitimacy of alternative interpretations. I also explore this further as I examine medical and public health discourses to highlight the effects that they produce for women in relation to understandings of the origins of child (ill-) health.

Within this discussion it is also important to recognise that individuals may actively engage with and embrace their own medicalisation (Rose, 2007a). This is particularly evident in the case of reproductive health since it is an area where individuals strongly desire and actively seek the best outcomes possible. Therefore, as new technologies and new interventions are developed and made routine in the area of reproductive health, pregnant and pre-pregnant couples actively consume and demand these in an attempt to optimise the outcomes of their pregnancy (Ettorre, 2002:67). This process has involved technologies such as testing and screening becoming an accepted part of antenatal care (Ettorre, 2002:67), thereby increasing medical power over pregnancy and increasing the credibility of medicine and public health as sources through which optimal reproductive outcomes can be achieved. Through such power, discourses of medicalisation also create an obligation to act in the present in relation to the potential futures that are now rendered visible for women (Novas & Rose, 2000:486). This idea, and the implications of it in terms of maternal responsibility, is centrally related to the notion of a risk society, which I now explain.
**Risk society**

A consequence of medicalisation is the formation of the contingent concept of risk (Nettleton & Gustafsson, 2002:109). The incorporation of the social into the gaze of medicine has meant that risk factors are not restricted to physical symptoms but also extend to include people’s behaviours and social circumstances. The result of this is that discourses of risk have become a pervasive component of modern life (Beck, 1992; Gifford, 1986). Indeed under the context of promoting good health a plethora of risk factors have emerged which are subject to medical scrutiny and control (Nettleton & Gustafsson, 2002:110). Therefore, in the context of medicalisation and pervasive discourses of risk “everyone has their own susceptibilities, everyone becomes, in potential at least, asymptotically ill and a suitable case for medical tutelage” (Rose, 2001:25).

Health has not always been understood in terms of risk however. In the pre-Renaissance era understandings of ‘fate’ and ‘destiny’ had a strong influence on health related discourses. Within these discourses health problems were explained as emerging from personal misfortune, or from the actions of spiritual beings (Gabe, Bury & Elston, 2006:87). Therefore, explanations about the role of human fault or personal responsibility in relation to health problems were largely irrelevant. Since the seventeenth century, with the emergence of modernity and the corresponding rise of determinist ideologies, ideas about health began to change (Gabe, Bury & Elston, 2006:87). This change resulted in health problems being understood as the product of causal laws of nature whereby risks to health could be identified and measured scientifically to establish cause and effect relationships (Gabe, Bury & Elston, 2006:87). Consistent with such an understanding, the study of threats to health became a scientific endeavour based upon mathematical calculations of probability. By the nineteenth century understandings of risk had developed further and health risks were thought then to emerge from both causal laws of nature as well as human action. As such, particular people and social groups became more closely associated than others with risk factors for certain health problems (Gabe, Bury & Elston, 2006:87; Lupton, 1999:15). During this period, risks were associated with both positive and negative outcomes since they were understood as producing both losses and gains (Lupton, 1999:8,15). However, in contemporary society, understandings of risk have again shifted to a position where risks are understood as involving only negative outcomes. Therefore, in terms of health, risks are now predominantly interpreted as representing danger (Gabe, Bury & Elston, 2006:87).

Stemming from contemporary understandings, broad categories of theory about the socio-cultural dimensions of risk have emerged. One of these is a cultural symbolic perspective which has developed from the work of anthropological and cultural theorists such as Mary
Douglas. Douglas (1966) focuses on examining the cultural beliefs and practices that operate to maintain social norms. Within this perspective the designation of risks is thought to maintain cultural boundaries of acceptable and unacceptable behaviour by labelling those who transgress such boundaries as deviant and, therefore, dangerous (Douglas, 1966). Through this process 'risky' people and groups become defined and positioned as blameworthy for posing a threat to those who conform to accepted cultural standards (Douglas, 1966; Lupton, 1999).

A second broad category of theory is related to the concept of a risk society. This theory is dominated by the writings of sociologists Ulrich Beck and Anthony Giddens. The risk society approach is based on a weak social constructionist perspective which posits that objective hazards exist within society which pose risks to health, yet the meanings that we apply to those risks are mediated through social and cultural processes (Beck, 1992; Giddens, 1991). A main focus for these theorists is to understand the ways in which macro-social processes, such as globalisation and individualisation, increase social perceptions of risk by creating greater global interdependencies and by encouraging individuals to be reflexive about their social positioning and the threats that exist in relation to it (Beck, 1992, 2000; Beck & Beck-Gernsheim, 2002). Theorists who focus on the risk society posit that predictions about the future are based on imagined risks and threats. Expert predictions of future risk, for example of environmental catastrophe, combine with neo-liberal individualism to heighten individuals’ awareness of their role in constructing the imagined future and also about their responsibility to modify their behaviour to protect against, and control for, perceived threats, for example by reducing reliance on fossil fuel (Lupton, 1999). The result of contemporary social conditions being characterised by individualisation, risk and the requirement of self-reflexivity is that parents have to deal with new and contested forms of knowledge, and from this, new forms of responsibilities and anxieties. This leads me to a discussion of dominant ideologies of mothering in Australian society.

**Ideologies of mothering**

According to Sharon Hays (1996) the most pervasive ideology of motherhood in contemporary Western societies is intensive mothering. Hays (1996) describes intensive mothering as the expectation that mothers should give of themselves and their resources unconditionally to ensure their child’s nurturance. An intensive mother is held, and holds herself, responsible for satisfying the needs and desires of her children and for shaping the kind of adult they will become. As such, ‘good’ mothering is measured by the outcomes of the child—which has important implications for mothers of children with health problems.
The social dominance and pervasiveness of intensive mothering is important because, as Foucault (1988) suggests, discourses which are normalised and widely accepted become normalising in that they establish a basis from which individuals and their behaviours become regulated, by both themselves and others. Therefore, women undergo (and undertake) a series of ‘tests’ that are consistent with dominant ideologies of mothering which determine whether they meet or fail the standards of acceptable motherhood. As the range of expertise over motherhood increases, the number of tests increase and there becomes more and more ways that women undertake self-surveillance (Smart, 1996:47). If women fail to reach the normalised standards of ‘good’ mothering through appropriate self-regulation, other ‘experts’ may hold them accountable (Hays, 1996:71). The imposition of such blame on mothers may lead to their discrimination, and possibly even, social isolation (or worse effects). The result of this is that, based on the ideology of good mothering, it is expected that women devote their energy to child rearing, yet in an important contrast, their expertise and knowledge about how to do this is not valued but is instead relegated below that of scientific ‘experts’.

According to Martha McMahon (1995) and Miranda Roe and Anne Morris (2004) the ideology of intensive mothering is linked to constructions of children as being ‘precious’ and ‘sacred’. This linkage has been strengthened over the twentieth century and it, combined with an increased awareness of risk, has created new areas of perceived ‘need’ in relation to child rearing and mothering. The construction of increased need has contributed to the burden of intensive mothering for women by furthering unrealistic and unreachable expectations of ‘good’ mothering (Roe & Morris, 2004:8). It also strengthens the moral aspect of mothering by creating the impression that a failure to achieve ‘good’ mothering results in a threat to what is held sacred within society. As the burdens and expectations on mothers have increased, there has been a corresponding breakdown in community collectivities and extended families which has shrunk the sphere of responsibility for the care of children (Roe & Morris, 2004). This breakdown of social ties legitimates focus on women as the primary influence in the lives of their children and combines with the sacredness of children to render women who do not care for children in ways that are socially validated as morally deficient.

**Maternal responsibility**

Each of the ideologies that I have covered in this Chapter so far influence how women’s responsibilities are viewed by society, by ‘experts’ and women themselves, and, as such, have strong links with the central topic of my research, which is maternal responsibility. Within existing literature the term *maternal responsibility* is generally used in a way that refers to a perceived failure on behalf of women to meet their expected obligations to their children, families and communities. Therefore, maternal responsibility is not usually
discussed in positive terms to highlight a mother’s contribution or to recognise the power and agency of women as individuals within their relationship of care to their children (Roe & Morris, 2004:1). The negativity surrounding the attribution and discussion of maternal responsibility is felt particularly strongly by women who mother in less than empowering circumstances (Roe & Morris, 2004:1) and, as my research shows, by those whose children display ‘less than ideal’ characteristics, such as a congenital health problem.

Much of the literature on maternal responsibility in the context of child health problems reflects this negative focus on maternal culpability. Focus in many sources is on the role of courts and legislation in defining maternal responsibility by prosecuting women for particular behaviours that they engaged in during pregnancy which are believed to have caused problems with the health and development of the foetus. These behaviours may include things such as the consumption of alcohol, or even engaging in sexual intercourse during pregnancy if advised not to by a medical professional (Blank, 1992). The prosecution of women for foetal neglect and abuse began in the 1980s and still continues in countries such as the United States (US). Up until 1993, according to conservative estimates, at least 200 women had been charged with offences relating to foetal harm in the US (Daniels, 2001:316). Most of these charges were dismissed, however, they were serious in nature including charges of manslaughter for stillborn infants born to women who were suspected of using drugs or alcohol during pregnancy (Daniels, 2001:316).

In keeping with the focus on ‘failed’ responsibility authors who study maternal responsibility in the context of child health also suggest that the cultural dominance of assumptions about women’s ability and responsibility to care for their children is potentially damaging. Such assumptions interact with ideals surrounding motherhood to create particular understandings about what constitutes ‘good’ and ‘bad’ mothering, and from this, ‘good’ and ‘bad’ ways of being a woman (Lifton, 1998). These assumptions impose restrictions on the actions of women and render them vulnerable to social disapproval if they act in ways that are not consistent with what is considered to be ‘good’ mothering behaviour (Hays, 1996). Some authors have labelled the social disapproval that is inflicted on women within this context as maternal blame.

‘Mother blame’
A considerable amount of literature on maternal blame exists across various fields of inquiry. However, little attention has been focused on exploring whether women who give birth to children with congenital conditions may experience maternal blame and whether they blame
themselves. Importantly, there is also a distinct lack of consideration about the phenomena of maternal blame within the existing bodies of public health and medical research even though, or perhaps because, women are commonly represented as solely responsible for their children’s health.

This framework makes it plausible for women to be held responsible for anything that occurs in their children’s lives (Weingarten, 1994:43). For example, explanations for autism provide clear examples of the operation of such absolute ideas about maternal responsibility manifesting in maternal blame. Autism is now generally understood to result from the neurophysiology of the brain, which influences the development of physical, social emotional and linguistic skills (Weingarten, 1994:43). However, throughout history mothers were held responsible for the emotional and physical effects that autism produces in children. This attribution of responsibility involved women being blamed for being emotionally distant and ‘cold’ towards their children and, in doing so, depriving them of the love and care they needed. The symptoms of autism were therefore believed to represent a child’s defence against their hostile and emotionally unavailable mothers (Weingarten, 1994:43). Such a construction of causation perpetuates a focus on failed maternal responsibility and legitimises the blaming of women for their children’s health problems.

**Men, reproduction and responsibility**

Perpetuating the dominant focus on women and maternal responsibility, I have identified an enduring discourse in the literature that is relevant to this research which represents men and fathers as occupying a peripheral role in regard to reproduction. An example of this is provided by philosophical analyses of men’s encounters with the pregnant body which indicate that men can feel uninvolved in pregnancy because they experience a sense of biological distance from it and it, therefore, becomes a disembodied experience for them (Dempsey, 2004; McCreight, 2004). A similar discourse is also evident in some public health related literature, especially in the work of David Gordon (1995), who asserts that men’s sense of masculine identity may suffer more from a loss of sexual function than from becoming infertile (refer to Chapter 6).

The lack of focus on men in terms of literature that examines the links between responsibility and child health is likely to have played some part in perpetuating the negative focus on women. The lack of focus on men in this literature has links to dominant understandings of

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16 Within the body of literature on child disability there is also a distinct lack of focus on how blame operates within a neo-liberal context or on how parents rationalise the cause of their child’s health problems in social contexts that are underpinned by neo-liberal ideals of self-determination and free choice. My research explores both of these issues as part of a broader focus on the construction and implications of maternal responsibility in neo-liberal society.
hegemonic masculinity which distance men from the nurturance of their children (Gordon, 1995:250). The current lack of focus may also be related, in part, to gendered differences in political movements.

The health needs of women were a focus in the women’s movements that emerged in the 1960s and 1970s. The current focus on women’s health (although this is still often threatened by political and financial factors) in Australian society is testament to the success of these movements in bringing the health needs of women into popular consciousness (Manderson, 1998). But much of the research in the field of women’s health is still premised on the belief that men occupy a more privileged position in society, making a specific focus on men’s health unnecessary and potentially threatening to the focus and resources directed to women’s health. However, in this thesis I argue that a more relational focus is required in order to adequately understand the factors that contribute to the contexts in which pregnancies are undertaken and in which the origins of child health outcomes are interpreted. This is necessary because as Rob White claims “men’s health is a social issue, with implications for all sections of society” (White, 2002:268), including implications for women, children and reproductive health.

The work of Cynthia Daniels (2001) makes an important and rare contribution to this field by examining how masculine ideals have influenced societal and scientific understandings about men’s relationship to reproductive health, or lack thereof. I draw upon Daniel’s work throughout this thesis and extend the focus on men’s absence by positioning it alongside an analysis of women’s centrality to explore the micro-dynamics through which maternal responsibility for child health is created and perpetuated.

**Gendering public health research and highlighting the gaps**

Contributing to the existence of other important absences in the relevant literature, much of the public health and epidemiological writing that includes a focus on gender still reflects a biomedical approach (Australian Women’s Health Network, 2008; Kavanagh & Bentley, 2008). The widespread use of the term gender in these writings does not necessarily mean that the principles of the women’s health movement or of feminist theory have been incorporated into mainstream studies of health (Rogers, 2004, 2006). Instead in much of these writings the presence of the word gender indicates a ‘sex-difference’ analysis, by which I mean a descriptive focus on the way that sex, like height or weight, acts as a measurable

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17 I argue that hegemonic masculinity still operates in this way despite the rise of individualism and the related assertion that masculinity no longer has constraining effects for men. I elaborate on this throughout the thesis.
variable within studies of particular aspects of health and illness (Fee & Krieger, 1994; Krieger, 2003; Lippman, 1999:286).

The comparatively limited focus on an analysis of gender as a social construct and product of power relations within the field of public health is problematic for two main reasons. First it does not provide adequate acknowledgement of the complex and multidimensional basis of gender as it operates in the social and political systems within which individuals live (Rogers, 2006). Therefore, rather than examining how gender operates as part of the social structures which influence health, a ‘gendered’ approach is used to seek sex differences and to provide biologically reductionist explanations of health and of responsibility for health (Lippman, 1999:286).

Second, the research findings of studies which apply gender in a sex difference approach are taken up mainly by industries as a way to increase the profitability of a focus on women’s health. This actually increases the surveillance and medicalisation of women’s bodies. The detection of sex differences, through a supposed focus on gender, justifies new medications and other health products specifically targeted at the ‘needs’ of women which construct women’s health, not as influenced by the social context in which it is embedded, but as arising from problematic female bodies which provide opportunities for profit (Lippman, 1999:286).

I address these two issues by contributing to a growing body of critical public health literature. In doing so, I focus on the role of gendered power in mediating women’s experiences of maternal responsibility for child health.

Continuing my analysis of the gaps that are present within public health literature, a wide body of work has been developed in Australia and overseas which examines and critiques the approaches that are used by public health and medical professionals to promote reproductive health. Within this body of literature, however, many authors have focused only on assessing the effectiveness of particular approaches rather than on exploring the broader, social implications of the advice itself. For example, a small number of research projects have been published which examine the health promotion messages that are targeted at women of reproductive age (refer to Kowalyk, 2006 for an example). Most of these assess the effectiveness of health promotion messages in achieving behaviour change among

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18 Several authors have made an important contribution to critical studies of public health by focusing on the role of gender, as a social construct, in contributing to health inequalities. Some of these authors include Hilary Graham, Dorothy Broom, Sally Gifford and Helen Keane. Authors in fields other than public health have also forged ahead in this area, which highlights further the comparative lack of concentrated public health analyses of gender as a social determinant of health and wellbeing.
women rather than considering women’s experience of such messages. Similarly, numerous theses have been published both in Australia and overseas that address issues related to pregnancy. However, many of these consider the biological aspects of pregnancy rather than investigating the social factors that influence maternal and child health (refer to Summers, 2009; Vanderlelie, 2006 for recent examples).

Assumptions about the universal benefit of medical and public health interventions also appear to dominate the existing literature. Implicit in such assumptions is a reluctance to consider the potential for certain practices to reinforce gender inequality. I have identified only one article in this field which provides a critique of the ways in which women have been targeted by health promotion messages in the United Kingdom (UK). The author of this article, Amanda Amos (1993), does consider the potential for public health practice to reinforce gendered stereotypes; however, the implications of this in terms of understandings about reproduction or maternal responsibility are not examined. Furthermore, few authors have previously considered whether there is any potential for health promotion messages, and the social context from which they are derived, in and of themselves, to have a negative impact on the wellbeing of women. Therefore, consideration of the gaps that are present within the existing bodies of research highlights and supports the importance of my research in contributing understanding about the dynamics through which particular gendered and individualised attributions of responsibility for child health become both possible and pervasive in Australian society. I explore these possibilities throughout my research via a critical analysis of discourse in conjunction with an analysis of the social implications that are produced through current, dominant understandings.

Conclusion
Throughout this Chapter I have situated my research within the relevant social and academic contexts to which it relates. I have made clear that the research extends literature on maternal blame by exploring how it is that women come to be held responsible. My research also locates a study of maternal responsibility in the neo-liberal context that pervades Australian society, which is characterised by understandings of the ability of individuals to define their life outcomes through making choices that are consistent with authoritative health advice. In doing so, my research extends existing understandings about maternal responsibility by exploring how women negotiate their maternal responsibility within a neo-liberal context when, for the most part, they believe they have acted in accordance with medical and public health advice but still do not achieve the child health outcome they desired.
The findings of my analysis also contribute knowledge about the potential for public health and medical discourses to perpetuate gendered stereotypes and to, therefore, reproduce gender inequality in ways that impact on individual and social wellbeing. This is an important contribution of the research since public health and medicine are usually viewed as fields which promote health. Therefore, their potential to contribute to a social context which constrains the health of some individuals through a reinforcement of social inequality is often overlooked. My contribution in terms of this, combined with my overarching focus on exploring the dynamics that make particular constructions of maternal responsibility possible and enduring, highlights the originality of, and need for, the research that I present. I now explain how I undertook the research that I report in this thesis while reviewing further academic literature to explore the methodological underpinnings of the study.
PART 2

Exploring the Construction of Maternal Responsibility
CHAPTER 2

Methodology

Throughout Part 1 I established the social and academic relevance of my research. This included an analysis of the current gaps in knowledge and an identification of what further research needs to be undertaken to address those gaps. My aim in Part 2 is to explain how I explore maternal responsibility. Therefore, throughout Part 2 I shift my focus from an analysis of what we need to know to a consideration of how we may come to know. Understanding the underpinnings of research requires an assessment of both the theories and the practices that inform the research design. Throughout this Chapter I present the theoretical framework in which my research is located. First, I consider the concept of **epistemology**.

**Constructionist epistemology**

Epistemology provides a means of explaining what kinds of knowledge have informed research and why some forms of knowledge are deemed more justifiable, valid or convincing than others (Turner, 2006:171). In the context of research, epistemology provides a conceptual means of explaining which theories of knowledge underpin the theoretical perspectives that are applied in research (Creswell, 2003).

The research reported in this thesis is framed within a constructionist epistemology which posits that knowledge is produced, reproduced and mediated through social processes. Constructionists reject determinist or positivist assertions of the ‘objectivity’ or neutrality of knowledge (Creswell, 2003:6-9). Instead they argue that knowledge is embedded within the socio-political context through which it emerges or is created and, therefore, can never be objective or value free (Creswell, 2003:6; Crotty, 1998:8-9). For constructionists, knowledge is subjective and negotiated. Knowledge is also considered to be multiple and varied rather than representing an absolute truth (Creswell, 2003:8). The fluidity and plurality of knowledge emerges from its basis within social context where it is produced through the multiple meanings that individuals apply to their experiences and interactions (Creswell, 2003:8; Crotty, 1998:8-9). The understanding of knowledge as multiple and varied encourages constructionist researchers to explore the complexity of social realities rather than striving for understanding within pre-determined categories or seeking a ‘normative’ synthesis (Creswell, 2003:9). Furthermore, for constructionists, it is only through an analysis of the contexts within which knowledge exists and operates that meaningful understanding about the nature of social realities can be achieved. A variety of different research perspectives are underpinned by constructionist epistemologies (Crotty, 1998) and I have drawn upon two of these to inform my research.
Applying a critical approach to gendered understandings
I apply the theoretical perspectives of critical inquiry and feminism throughout the research. I now explain each of these perspectives, beginning with the heritage of critical inquiry. Examining the heritage of the critical approach provides insight into its scope and potential utility in the context of my research.

Heritage of critical theory
The origins of critical social theory are most closely associated with the Frankfurt School of Social Research. The Frankfurt School was founded in 1923 as a centre to foster socialist research (Crotty, 1998:125; Stirk, 2000:14). From its beginnings, the theory that emerged from The Frankfurt School offered an alternative to traditional and, at the time, dominant, economic explanations of social realities. As the basis for this alternative the founders of the School aimed to develop an analysis of the ways in which ideology and politics shape social realities.

The Frankfurt School was involved in challenging the rise and widespread influence of a set of theories based on instrumental reasoning. Those who apply theories of instrumental reasoning see the world, including other people, as agents who can advance their own interests and they act on the basis of an imperative to exploit situations to achieve gain (Makaryk, 1993). This way of thinking is common within industrial societies and, according to critical theorists like Jurgen Habermas (1971), it is linked closely with, and reproduces, structures of domination. Instrumental reasoning is antipathetic to cooperative and communitarian values (except where these values are perceived to also offer strategic benefit) (Habermas, 1971; Tucker, 1998).

The theory that emerged from the Frankfurt School contributed to the development of a set of understandings that offered an alternative form of thinking, which, following Max Horkheimer's influential essay in 1937 (see Horkheimer, 2002 for a reprinted copy of the 1937 essay), was referred to as critical theory. Critical theory offers a way of understanding the world which asserts that the whole of society is greater and more powerful than the sum of individual parts. For critical theorists the virtue of being human means that we all possess the quality and potential for rational thought (Horkheimer, 2002). Therefore, critical theorists’ view of an ideal society is one in which all groups and members participate to create, transform and optimise the social environment that they are a part of (Wiggershaus, 1995).
In the spirit of transformation, one of the main aims of the critical perspectives that emerged from the Frankfurt School was an interest in the dynamics of social change. Therefore, while there was considerable diversity in the theories that were produced from the School, the overall intention was consistent. That intention was to provide a means of searching for social knowledge within a context of social action (Wiggershaus, 1995). Critical theorists view such action as, ultimately, increasing the potential for emancipation and freedom from the constraints of inequality and social marginalisation (Crotty, 1998:159; Stirk, 2000:135).

Working from the basis of this brief explanation about the heritage of critical theory, I now move on to identify some of the main principles that underpin my critical approach to this research.

**Distinctive features of a critical approach to research**

Drawing upon the main tenets of critical theory, a critical approach to research aims to understand and critique existing social and political systems while also assisting in the development of strategies for practical social change. The task of a critical researcher is to penetrate particular understandings of the world to show how they are produced and what the implications of their production are (Aronowitz, 2002:xiii). Therefore, undertaking critical inquiry involves exploring the ways in which social circumstances are mediated by dynamics of power as well as by various interrelated sources of inequality, such as those formed on the basis of gender and class (Lather, 2004:205). Within a critical approach a pre-given reality that exists outside of relations of power is not possible, instead ‘reality’ itself is a product of human practice and social process (Aronowitz, 2002:xvi). Given the emphasis on power, inequality and social change, a critical approach is often orientated towards research involving disenfranchised, marginalised groups\(^{19}\) (Lather, 2004:208).

Within a critical approach both the methodological underpinnings of a study and the associated methods of inquiry are recognised as being politically charged. This means that rather than being viewed as objective and distanced, the process of research is understood as a powerful force in defining, evaluating and reporting the social phenomena under investigation (Lather, 2004:208). Such an understanding makes it necessary for critical researchers to reflect upon and document their position in relation to their research (which I began in Chapter 1) and also to carefully examine the influence of the research process in shaping the findings that are produced. The aim of this reflection is not to objectify or reduce the influence of the research process on the production of knowledge but is instead intended

\(^{19}\) However, consistent with an analysis of the workings of power, critical theory has also been applied in studies which involve elite and advantaged groups in order to better understand how power and status are reproduced.
to achieve as open and honest value-based approach to research as is possible (Lather, 2004:208). Therefore, it is clear that for critical theorists research knowledge develops out of the social relations involved in the research process itself as much as it does from the findings and outcomes of that research (Aronowitz, 2002:xvi). Emanating from a critical approach are the principles that underlie feminist theoretical perspectives. I now explain the unifying features of these perspectives and identify the particular feminist perspective that I adopt in this research.

Feminisms and feminist research approaches

Use of the term *feminism* and claims of a distinct *feminist knowledge* have been widely criticised for their reification (Turner, 2006:503) of a singular and universal feminist perspective. Rather than representing an homogenous body of knowledge, feminist theory includes considerable diversity and plurality; both in terms of the understandings proposed and in terms of the standpoints taken by feminist researchers (Crotty, 1998:160-161). There are in fact many *feminisms* and while there are some unifying bases from which feminist thought has emerged there are also many distinctive differences between the multitude of feminist theories (Crotty, 1998:160-161). My aim in this section is not to provide a comprehensive explanation of the different kinds of feminist perspectives. Achieving that complex and large task is neither possible nor necessary within the context of this interdisciplinary thesis and it has been done elsewhere (see Connell, 2004 for an example). Instead my aim is to highlight some of the main tenets of feminist research that are shared by those who apply any one of the multiple feminist perspectives and to then identify the particular feminist perspective that I apply.

A feminist approach to research does not prescribe particular methods for undertaking or analysing research. Instead it offers a way of thinking about the research process and about the phenomena under investigation (Holloway & Wheeler, 2002:217). Therefore, what makes research feminist relates more to the motives, concerns and knowledges that underpin the research process than to particular modes of inquiry (Brayton, 1997).

Overall, a feminist approach to research involves a focus on gender and on the influence of gendered power relations on social experience. The intention is to make gender, and the power dynamics associated with it, visible. In doing so, the goals of a feminist approach to research also involve rendering women as visible and as legitimate social contributors (Holloway & Wheeler, 2002:217). Although contemporary feminists acknowledge that there is no singular category of women with a shared universal experience, it is generally understood...
that women, as a social group, may experience similar forms of social disempowerment through the operation of gendered politics (Weber, 1998:vii). Therefore, the application of a feminist perspective in this research assists me in moving beyond essentialist\textsuperscript{20} and homogenous explanations of women’s lives to seek meaning through the experiences of a particular group of women during interviews. In addition, the application of a constructionist feminist epistemology encourages me to value women’s own interpretation of the effects that particular medical and public health discourses may have on their experiences and guard against the tendency to universalise those experiences (Hargrove, 2004:5).

Research that involves a feminist approach typically shares the emancipatory aims of critical theory; however, its particular focus is on understanding gender based power. Therefore, the majority of feminist attention in research has been devoted to an examination and critique of women’s social positioning. Such critique involves analysing the origins and effects of gender based subordination and envisioning possibilities for both collective and individual resistance. The overall intention of feminist research is to further gender equality and women’s social inclusion. As such, an analysis of power, and its effects, is central to feminist approaches, making them compatible with, and strengthening of, the critical methodology that I apply in this thesis.

**A post-structuralist perspective**

The particular feminist approach that I apply in this research is based on post-structuralism. Post-structuralist feminism is a mode of knowledge production which applies theories of language, subjectivity and social process to explore the meaning and complexities of social experiences (Weedon, 1987:40). Post-structuralism seeks to deconstruct claims of knowledge to show that they are particular interpretations that have been selected from the many that are possible rather than representing definitive ‘truths’ (McLaughlin, 2003:91). My main aim in applying this approach is to explore the operations of power in constructing and perpetuating particular understandings of maternal responsibility.

Much of the work on power that has been undertaken using a post-structuralist feminist approach has been inspired by Foucault. I apply a number of Foucault’s theories throughout this thesis in order to understand more about the dynamics through which maternal responsibility becomes constructed and perpetuated in medical and public health discourses. I also extend Foucault’s theories in order to explore the multiple layers of complexity that underlie these dynamics. Therefore, I now introduce Foucault’s perspectives on power,

\textsuperscript{20} In this context *essentialism* refers to biologically determinist assumptions about the fixed, pre-determined nature of reality.
knowledge and subjectivity since they provide an important basis for the critical post-structuralist feminist analysis that I develop in this thesis.

**Foucauldian understandings**

Michel Foucault (1926-1984) was a French historian and philosopher. Foucault’s work continues to have an important influence, not only within the field of philosophy but also on sociological analyses (Gutting, 2008) and studies of health (Keane, 2009:450). Foucault’s main contribution to social constructionist analysis is to link knowledge and subjectivity to the production of social meaning and experience (McLaughlin, 2003:115). Foucault did this primarily through a focus on power.

**Power**

Foucault understood modern power to be a constantly shifting and dynamic set of relations that emerge from social interactions and, therefore, pervade the social body. As I mentioned in Chapter 1, Foucault offers an account of modern power (Foucault, 1979:26) which is based on an analysis of the way that power flows through the capillaries of society rather than being concentrated in a sovereign state. Foucault challenges understandings of power which assume that it is totally repressive (as do Marxist and Freudian conceptions of power). While Foucault does not deny that power can function repressively in some instances, he explains that, primarily, power is a productive force that “produces reality; it produces domains of objects and rituals of truth” (Foucault, 1979:194).

**Knowledge**

For Foucault, knowledge and power are inextricable. Power relations define which knowledges are most acceptable and from which sources these knowledges are most legitimate (Foucault, 1979). Therefore, it is not the inherent truth of knowledge that leads to its power within society but its relationship to ideals of legitimacy and authority. This understanding of power/knowledge led Foucault (1979) to reject the argument that there is a natural world over which science can produce ‘true’, objective and linear understandings. Instead, for Foucault, knowledge is always socially mediated and socially productive. Therefore, by producing particular kinds of knowledge about a particular kind of world, science produces that world. I explore this potentiality further throughout the thesis as I problematise the assumptions that underpin scientific knowledge about the biological bases of women’s influence over, and responsibility for, child health.
Subjectivity

Power, according to Foucault also produces subjects. Foucault (1982) theorises that the self exists through the power relations which form knowledge. Knowledge establishes the basis from which the self develops by producing ideas about what the self should become and what the self can become. Therefore, for Foucault (1982) knowledge provides the scope of possibility for the self and operates to govern its development. Foucault also proposes that modern power subjects individuals, that is, it simultaneously creates them as subjects by subjecting them to mechanisms of power. To explore these processes Foucault (1979) examined the disciplinary practices that were applied in schools, factories and prisons during the eighteenth century. Given the centrality of disciplinary power to my analysis in Chapters 4 to 7 of this thesis, and my critique of it in Chapter 8, it is important to differentiate how Foucault understands disciplinary power.

In his analysis Foucault (1979) draws upon Jeremy Bentham's design for the ideal prison, called the Panopticon (Figure 2.1), which, for Foucault, captures the essence of disciplinary power within society.

Figure 2.1

Bentham’s Panopticon

NOTE:
This figure is included on page 50 of the print copy of the thesis held in the University of Adelaide Library.

Source: Coveney (2009)

At the periphery of the Panopticon is a ring of cells and at the centre of that ring there is a tower that has wide windows which face the ring of cells. Each cell has a window that faces the tower. These windows allow the inside of each cell to be seen from the middle tower. The tower also produces light making any figure in the cell visible at any time. This light works to obscure each prisoner’s view of the central tower so they cannot be sure if a guard is present.
This spatial arrangement means that each prisoner is isolated from communication with their peers yet they remain in a context of continual, yet indeterminable, surveillance by the guard who may or may not be present.

The planned spatial arrangement of the Panopticon is intended to compel inmates to impose surveillance on themselves by creating the perception in their mind that they are permanently visible to an authoritative ‘gaze’. The authoritative gaze, whether the guard is present or not, provides a source of continual surveillance, and, therefore, operates as a mechanism of control by encouraging the inmates to act in accordance with the ‘rules’ of the system and, in doing so, avoid the threat of punishment (Foucault, 1979). The Panopticon has been taken up as an architectural design of hospitals, particularly emergency and high dependency units, as was evident to me in the cardiac ward that I referred to in Chapter 1. Through individuals’ enactment of self-surveillance in order to comply with the requirements of the regime of disciplinary power in which they are located, the inmate (and perhaps also those in the cardiac ward) then become “the principle of [their] own subjection” (Foucault, 1979:203).

Foucault (1982:208) questions why individuals would engage in the process of self-surveillance since it leads to their own containment. He (1982) suggests that the main reason is that by accepting and actively reproducing the subjectivity that is defined for them, individuals gain a sense of self that allows them to participate in the world as legitimate beings. Through this sense of self, individuals gain the power to express their individuality. Importantly, according to Foucault, such an expression of individuality is limited by the same regulatory forces that led to an individual’s subjection which means that individuality is never unbounded.

Many feminist authors draw on Foucault’s understandings of subjectivity and disciplinary power to critically analyse the operation and implications of normative standards of femininity. By expanding Foucault's examination of disciplinary power, Sandra Bartky (1997) considers the disciplinary practices that specifically shape feminine bodies. For Bartky (1997) these include dieting practices and other activities which limit the movement and expressions of female bodies. Bartky (1997) also builds upon Foucault's analysis of the Panopticon. In particular, she observes that through gendered disciplinary practices, for example dieting and keeping one's body presented ‘appropriately’ through particular dress and using cosmetics “it is women themselves who practice this discipline on and against their own bodies … just as surely as the inmate in the Panopticon, a self-policing subject, a self committed to relentless self-surveillance. This self-surveillance is a form of obedience to patriarchy” (Bartky, 1997:149).
Bartky’s use of Foucauldian theory indicates that some feminists have found Foucault’s analysis of power useful; however, Foucault’s work has also attracted criticism from feminist authors. In particular feminist authors have challenged the claim that individuals are produced through power. This claim is regarded as problematic because it posits individual agency as having only a conformative function and not one that can operate to modify and shape the knowledges that produce individual subjects (McNay, 1992). The result of this understanding is that individual bodies are rendered passive and the operation of power is reduced to an imposed effect rather than being understood as a dynamic process (Alcoff, 1990; McLaughlin, 2003; McNay, 1992:12). Throughout this thesis I apply Foucauldian understandings of power in the contexts where they help illuminate the influence of public health and medical discourses on understandings about maternal responsibility. However, particularly in Chapter 8, I also draw upon feminist critiques, and in doing so, extend Foucault’s theories in relation to agency.

**Gendering Foucault**

Another aspect of Foucault’s theories that is problematic within the context of my post-structuralist feminist approach is the almost complete absence of gender analysis within his original works. This is a major weakness in Foucault’s theories of power because it fails to capture the gender dynamics involved (McLaughlin, 2003:121). It also fails to recognise the centrality of gender in the operation and development of subjectivity (McNay, 1992). Even though Foucault does not produce gendered understandings of subjectivity or power, his central arguments are, to a large extent, applicable to feminist analyses. This is evident since feminists can draw upon Foucault’s main ideas and apply them to understand the way that dynamics of power inform gendered realities, and conversely, the way that gender informs dynamics of power (McLaughlin, 2003). Therefore, in applying Foucault’s theories within my analysis of gendered power, I interrogate and extend his ideas to explore the complex interaction of gender, power, knowledge and subjectivity in the construction and perpetuation of maternal responsibility for child health. I now return to an explanation about the theoretical perspectives that I apply in my research to highlight the power and value that a critical post-structuralist feminist approach can offer.

**The value of a critical post-structuralist feminist approach**

The approach that I apply in this thesis is particularly useful in allowing me to value subjective experience as a legitimate form of knowledge. This is desirable within the context of my research because it allows for understandings about maternal responsibility other than those based on biological determinism and it provides space for exploring the construction
and experience of knowledge about child health. Furthermore, the valuing of subjectivity repositions individuals, and in the case of my research, women in particular, as legitimate knowers rather than simply objects about whom knowledge may be produced. This again reinforces the value of Louise’s narrative (described in the Introduction to the thesis) in establishing the social relevance of this research. Valuing subjective knowledge is imperative in the context of my research given the tendency for authoritative discourses, particularly those that circulate within the fields of medicine and public health, to dominate and to define what is both knowable and who is most knowledgeable.

Exploring, interrogating and disrupting the authoritative transmission of knowledge are central processes for both feminist and critical researchers who are concerned with analysing the relationships between authority as a form of social power and the production of knowledge. Given this, the exploration of power relationships is a central focus of my research, particularly as a means of understanding how women may be positioned through their contact with medical professionals and during their exposure to particular discourses about maternal responsibility.

Consistent with the critical post-structuralist feminist view that knowledge is a manifestation of social power and that research is a process through which that power can be executed, applying this approach also encourages me to be attentive to the power dynamics inherent in research relationships and also to the potential impact of such power relations on the process and outcomes of research (Olesen, 2005:250-251). Therefore I reject traditional understandings of the distanced relationship between myself as the researcher and the research participants. This rejection increases the potential for a re-conceptualisation of research practice as involving collaborative knowledge formation (Olesen, 2005:250-251). Such a collaborative approach is intended to empower research participants by positioning them as contributors of knowledge rather than as passive objects who are subjected to an interrogation by an ‘expert’ during interviews. On the basis of this, I understand myself as being as much of an agent in the production of this research as the participants. Acknowledging my agency and social position as the researcher is important in both highlighting the nature of my potential influence as well as in reorientating the power relationship between myself and the participants (Brayton, 1997). In order to provide such acknowledgement in this thesis, and to avoid replicating the obscuring and potentially damaging effects of supposed researcher objectivity, I apply a reflexive approach (refer to Chapter 3) (Grbich, 2004).
Consistent with the focus on social change, one of the most obvious advantages of applying a critical post-structuralist feminist approach throughout this research on maternal responsibility is that it assists me to focus on developing strategies to improve the experiences of women who give birth to children with health problems. As inferred previously, both critical and feminist research perspectives encourage means of enacting change in order to destabilise structures or practices that reinforce social inequality (Creswell, 2003:9-11; Hargrove, 2004:5). Feminist researchers often view women as an oppressed group who are controlled to varying extents by the (often unacknowledged) influence of social institutions and political and economic systems (Holloway & Wheeler, 2002:217). Therefore, rendering visible the processes through which women may become oppressed through such structural influences is a vital first step in providing the potential for positive change. However, I also highlight the contradictory effects of power in the lives of the women I interviewed in order to make clear that power is not always oppressive. As my findings show, women’s engagement with dominant medical and public health discourses can allow an expression of agency which influences their understandings about maternal responsibility. Highlighting the contradictory effects of power is vital in understanding how women experience it, and from this, in being able to make contextually relevant suggestions for positive change.

Facilitating an opportunity for women to express their experiences through this research is also an important practical means of highlighting the contradictory effects of power and maternal responsibility in their lives. At one level, providing women with an opportunity to be ‘heard’ through research is important in overcoming the often obscuring effects that supposedly gender-neutral research can have in terms of women’s experiences. On another level providing a means for transmitting women’s voices also provides some potential for women’s empowerment through raising consciousness about their experiences (Holloway & Wheeler, 2002:217). This indicates that the applied basis of my critical post-structuralist feminist approach is important because it facilitates the development of theories that are both scholarly, practical and which provide the opportunity for women’s self-expression. This approach, therefore, allows greater potential for the research to inform social change and to question current practice and policy in order to, potentially, undermine particular power hierarchies and their resultant forms of social disempowerment (Letherby, 2003:85).

In summary, consideration of some of the tenets that underlie the critical post-structuralist feminist approach that I adopt have highlighted the value of this in extending knowledge about maternal responsibility as part of this research. The application of a critical post-structuralist feminist perspective allows me to explore the power relations that are embedded in, and reproduced through, women’s experiences of reproduction and mothering (Hargrove,
Furthermore, applying this perspective allows consideration of the possibility that the current practices and cultural beliefs that surround child health in Australia, and which inform the roles that women are expected to assume in relation to it, may contribute to broader systems of gender inequality. I now move on from exploring the value of the critical post-structuralist feminist approach to address the more specific concept of discourse which is a central component underlying my theoretical and analytical approach.

**Knowledge as productive: The concept of discourse**

Consistent with the theoretical approach and constructionist epistemology that I apply I understand knowledge as productive and constitutive within the social system rather than as merely descriptive of hierarchical differences (Carabine, 2001:268; Coveney, 2000:5). The application of such understandings is useful within the context of my research because it allows scope for exploring how power relations operate to define ‘legitimate’ knowledge about maternal responsibility, and from this, how women are situated on the basis of such knowledge constructions. In order to explore these issues I apply the concept of discourse as a central focus of my thesis.

Within the relevant bodies of academic literature, there is considerable debate concerning the meaning of the term discourse and, as a result, several different definitions of the concept have developed (Bacchi, 1999:39). The understandings of discourse that I apply in this thesis derive mainly from the work of Foucault. According to Foucault (1972), discourse represents a manifestation of social power. Foucault (1972) proposed that social phenomena and social meanings are constructed within social discourses and, therefore, no phenomenon or knowledge can exist outside the discourses through which it is created and through the language in which it is discussed. Foucault (1972:48) argues further that discourses are not “a mere intersection of things and words: an obscure web of things, and a manifest, visible, coloured chain of words.” Instead, for Foucault, discourses are “practices that systematically form the objects of which they speak” (1972:49). Consistent with these ideas the term discourse is used throughout the thesis to refer, in part, to the systems of language that operate within the texts that are under analysis (i.e. the words that are used, the ideas that are conveyed and the ideologies that permeate the explanations that are provided). The intended meaning goes further than this, however, to also convey the potential for language to create and reinforce systems of power and knowledge (Holstein & Gubrium, 2005:490). I understand these systems of knowledge to have the effect of (re)producing existing power relations and social hierarchies and, in doing so, (re)constituting the social positioning and identities of individuals and groups. However, it is also important to acknowledge that counter-discourses must also exist and have the potential to subvert
Chapter 2

dominant discourses. Otherwise change would be impossible, dissent would be unheard of and discourses would remain hegemonic and static. These ideas about the power of discourses in both (re)producing systems of power and in posing challenges to dominance stem from Foucault’s (1972) understanding of discourse as constitutive, dynamic and disruptive, which provides the basis for my analytical approach.

Critical discourse analysis

As explained by Sara Mills (2004:20), undertaking discourse analysis as part of research is most valuable because of the questions that it enables us to ask about the constructed nature of our experiences and of the texts that we are exposed to. Methods of analysis that are based on a Foucauldian approach to discourse provide opportunities to reject the “realist notion that language is simply a neutral means of reflecting or describing the world” (Gill, 2000:172). The central tasks of these analyses are to examine how language constructs social phenomena and to investigate the ways in which it produces certain social realities (Liamputtong & Ezzy, 2006:261). I apply critical discourse analysis as the main method of data analysis in this study. Its use assists me to investigate the ways in which the language that is applied within the fields of public health and medicine, as well as that used by women themselves, may operate to construct certain ideas about reproductive responsibility, the causes of congenital health problems and the role of gender in ascribing particular understandings about these issues. While I elaborate further on the practical aspects of undertaking critical discourse analysis in the next Chapter, I now consider some of the theories that underpin my approach to critical discourse analysis.

Foucauldian understandings of discourse have provided the basis for various models of discourse analysis and have been applied by many researchers in their use and development of these models. In particular, two such Australian researchers, Deborah Lupton and Carol Bacchi have undertaken extensive social research in Australia utilising discourse analysis across the academic fields of gender studies, public health and politics. Both have applied Foucauldian theories to develop analytical approaches that focus on eliciting and understanding the interrelationships that exist between discourse, social knowledge and existing systems of social power and organisation. The approaches that have been documented by Lupton (1994) and Bacchi (1999) form the basis of the model of critical discourse analysis that I apply in this thesis. I have chosen to base my model of discourse analysis on those used by these researchers because they both outline clear analytical approaches that are applicable to the interdisciplinary nature of my research and to the local Australian context in which I am undertaking this research (Connell, 2007).
Consistent with the approaches documented by Lupton (1994) and Bacchi (1999), critical discourse analysis provides a means of revealing the ways in which social realities are constructed and reproduced through circulating discourses which produce particular kinds of political effects. Such effects arise from the way that discourses operate to “define, describe and delimit what it is possible to say or not to say (and by extension—what is possible to do or not to do)” (Lupton, 1994:29). Discourses are also viewed by Lupton (1994) and Bacchi (1999) as structured in ways that benefit or support some groups and individuals while marginalising others. In this sense, discourses (re)produce power relations while operating at an ideological level to define shared beliefs “which give structure to everyday life and which assist individuals to make sense of their world” (Lupton, 1994:29).

For both Lupton (1994) and Bacchi (1999), critical discourse analysis, as a methodology, is novel in that it incorporates a post-structuralist perspective. This perspective privileges the role of language in shaping people’s understandings about the social world and in (re)producing behavioural norms (Bacchi, 1999:39-40; Lupton, 1994:30). The very nature of discourses means that they usually remain implicit and largely unquestioned (Lupton, 1994). Therefore, rendering particular discourses visible is one of the main aims of my approach to critical discourse analysis. Other aims of my approach include questioning both the construction and potential implications of the discourses that operate within society.

**Qualitative strategy of inquiry and mixed methods**

Consistent with my theoretical framework, I have chosen to adopt a predominantly qualitative methodological approach. This approach allows me to incorporate the central tenets of a constructionist epistemology and critical post-structuralist feminist perspective while allowing for the use of critical discourse analysis as my primary method of inquiry. The influence of the qualitative approach is demonstrated by the development of detailed, ‘thick’ (Geertz, 1973) and integrative analyses of the discourses and social processes under investigation (Carabine, 2001; Creswell, 2003:196). This kind of analysis is vital in order to understand the complexity of the issues that I am exploring.

Interpretive approaches, such as those allowed for with qualitative research studies, are favoured within the fields of constructionism and feminism. This is mainly because these approaches provide greater scope for deeper analysis of identified phenomena as well as the privileging of subjective meaning (Crotty, 1998:15-16). However, it is increasingly accepted that applying a combination of qualitative and quantitative approaches can be complementary and effective in opening up greater potential for learning through research.
(Bryman, 1988; Creswell, 2003:15-16). For this reason, the use of mixed methods is becoming recognised as a characteristic of quality research in the social sciences.

The qualitative approach that I utilise is complemented by limited use of the quantitative research technique of content analysis. Quantitative content analysis is applied in order to provide initial insight into the number of times certain issues appear within particular data sources. This provides an overview of the content of the texts under examination before I engage in qualitative discourse analysis. Further information about the technique of content analysis that I have used is provided in Chapter 3.

**Conclusion**

The methodological framework that I apply in this thesis addresses discourse, power and subjectivity. I adopt this methodology to explore the established meanings, values and gender relations that operate as mechanisms of social power to inform the construction of maternal responsibility through medical and public health discourses. Applying this approach assists me to examine how maternal responsibility is constructed and perpetuated and how particular understandings of maternal responsibility remain pervasive despite the existence of competing interpretations (Weedon, 1987:169). Throughout Chapter 3 I detail the specific techniques and processes that I used to undertake the research. This involves a practical explanation of the steps that I have followed to ensure that I uphold the principles of the critical post-structuralist feminist framework upon which I base this research.
CHAPTER 3

Methods

As I explained in the Introduction, my research consists of three principal components: an analysis of medical texts, an analysis of health education resources and an analysis of interview data. In order to provide a clear and detailed explanation of the processes that underlie each of these principal components I address them separately in this Chapter. I also describe the supplementary research activities that I undertook and the reasons for these. Consideration of ethical issues, research constraints and qualitative rigour is also presented in this Chapter to provide further insight into why I used certain research processes and how they can be judged appropriately for quality. To begin the Chapter I return to a discussion of the research lens to explain how and why specific congenital health problems were selected as case studies. Following this I examine the processes involved in each of the three principal research components.

Research lens: Congenital health problems

As I explained earlier, the research lens of congenital health problems was selected because it provides a definable focus for the study of discourses of maternal responsibility. The choice of specific congenital health problems as case studies for the research was made with consideration of four dimensions which conceivably influence the attribution of responsibility for causing congenital health problems. These dimensions are the level of existing understanding about cause, the severity and visibility of the health problem and the existence of relevant support groups.

Level of existing understanding

The first factor that I considered when selecting the health problems related to the existing level of understanding about the aetiology21 of the health problem. In particular, I considered the degree to which aetiology is attributed to lifestyle factors and behavioural choices, or in contrast, to factors that are deemed to be outside parental control. I chose one health problem where the common attribution of responsibility is linked to lifestyle factors and for which the cause is relatively well understood. This health problem is spina bifida. Spina bifida involves impaired development of the spinal cord in the early weeks of pregnancy (Saladin, 2001). I also chose two other health problems for which there is little knowledge about cause but where parental lifestyle is not usually seen or understood as being implicated. These health problems are congenital naevus, which involves the formation of pigmented lesions on the skin of an infant (Oakley, 2001), and a group of cardiac problems known as congenital

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21 This term refers to origins or causes.
heart disease. I have included further information about the known causes, symptoms and frequency of spina bifida, congenital naevus and congenital heart disease in Appendix 1.

Severity
A second consideration was the severity of the health problem and its prognosis. Congenital heart disease can be associated with shortened life expectancy and, in some cases, extremely compromised health (Gibbin, Touch, Broth & Berghella, 2003). In contrast, the course of congenital naevus is progressive but unpredictable and rarely life threatening despite its markedly disfiguring impact. Furthermore, spina bifida is a relatively stable health problem and it may or may not result in shortened life expectancy depending on the severity of the spinal lesion and the associated complications (Saladin, 2001).

Visibility
Third I considered the degree of visibility, disfigurement and disabling impact of the health problems. Congenital naevus was chosen in part because it is so marked on the body and in the absence of a clear cause it is possibly open to superstitious explanations. The effects of spina bifida can also be visible, particularly if the affected individual cannot walk or requires walking aids. However, the invisibility of congenital heart disease belies its seriousness.

Support
Finally I considered the practical aspects of recruitment by selecting health problems for which there exists some form of support group. Some rare disorders are well supported by interpersonal support groups whilst other more common health problems are not. Support groups exist in South Australia for all three of the health problems that I selected. This is an important consideration given that I am based in South Australia and I planned to undertake as many interviews face-to-face as possible.

Specificity of case studies
In terms of my methods it was important that I selected specific congenital health problems for two main reasons. First, as alluded to above, I decided to recruit women who mother children with congenital health problems who belong to support groups. Working with support groups is one of the few practical ways to access women who share this experience without violating their privacy. The recruitment of women from support groups was also expected to reduce the likelihood that the participants would experience any significant distress or harm.

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Historically, naevus has been linked with the action of the devil as punishment for the 'impure' thoughts or behaviours of women. Refer to Chapters 6 and 8 for further discussion and critique of relationships established between women’s ‘impurity’ and the staining of the foetus during development.
as a result of the interviewing experience. This is because it is likely that members of support
groups would already have reached a level of comfort about discussing the ways that they
feel about their children’s health problems given that they may have had prior experience in
expressing such feelings with members of their groups. In addition, the members of support
groups already have access to an established network of support people with whom they
could discuss any issues that arose during the interviews. Given that there are no support
groups that focus on congenital health problems in a general sense, it was necessary for me
to select specific health problems and then approach groups who shared a focus on those.

The second reason that I selected specific health problems was because it assisted with the
selection of data sources in some aspects of my research. In particular, there is a huge
amount of existing medical literature about the causes and preventability of congenital health
problems. Therefore, I made the decision to focus my search by selecting medical journal
articles on the basis that they related to the congenital health problems already applied as
case studies. However, in my selection of health education resources and medical textbooks
I chose sources which provided a more general overview of the current, authoritative medical
and public health discourses about the management of conception and pregnancy and the
cause and prevention of congenital health problems.

Foetal alcohol spectrum disorder

When I originally designed the research, I selected four, rather than three, congenital health
problems as case studies. The fourth health problem, foetal alcohol spectrum disorder
(FASD), was selected because the normative attribution of responsibility is almost entirely
related to the lifestyles of pregnant women. FASD is a term that is used to label the various
physical abnormalities and behavioural problems that are believed to be caused by women’s
consumption of alcohol during pregnancy (Manning & Hoyme, 2007) and, as such, it is
strongly linked with discourses of maternal responsibility. The strength of these linkages, and
the subsequent importance of considering FASD as part of this research, was reinforced in
the early stages of the project when I applied for approval from the Human Research Ethics
Committee (HREC) of the University of Adelaide. In response to my application the HREC
raised several concerns, one of which pertained specifically to my proposed interviews with
women who have a child with FASD:

Some HREC members have major concerns regarding the inclusion of
women who have had a child with foetal alcohol syndrome. This choice of
abnormality was considered odd given that one could say that the women
had caused the problem. They are concerned that the research could cause
harm and distress to the women. Can this group be excluded from the
research?
In response to this question I made clear that the direct relationships of blame established between women and FASD is one of the primary reasons that women who share this experience need to be included. The basis on which such blame becomes attributed requires exploration since, contrary to the assumptions reflected in the comment made by the HREC, there is no consensus within the relevant literature regarding women’s exclusive responsibility for FASD. Therefore, I maintained that FASD was an important inclusion in the research during my ensuing contacts with the HREC. I also argued further that its inclusion provided a means for learning about the ways that women construct their own understandings about the origins of their child’s FASD as well as examining the influence of medical and public health discourses in constructing dominant, and socially pervasive, understandings about the origins of FASD. My reasoning was accepted by the HREC and I was permitted to interview women who have a child diagnosed with FASD as part of my research (HREC Approval Number H-079-2007).

However, when I contacted the coordinator of the relevant support group in South Australia I found out that it would be extremely difficult for me to recruit women who had given birth to a child diagnosed with FASD, particularly if these women had to fit my selection criteria of having a child with this health problem who was aged six years or less. One reason for this is that a diagnosis of FASD usually requires the medical observation of developmental delays and/or learning difficulties in conjunction with other symptoms. Such delays and difficulties are not usually apparent until a child reaches the latter stages of their childhood, which means there are few cases diagnosed in children aged six years or younger. In addition, there are very few confirmed cases of FASD in Australia compared to some other parts of the world. This may be due to a lower incidence or the lack of a specialised team for FASD diagnosis and treatment in Australia. The lack of available services may result in some individuals who are suspected to have FASD being diagnosed with other health problems, such as attention deficit disorder and autism, for which services exist. In addition, given the social problems experienced by many parents who have a child affected with FASD, and the correspondingly high rates of adoption and fostering for FASD affected children, it would have been difficult for me to recruit women who had given birth to children with either diagnosed or undiagnosed FASD through the support groups. This difficulty reflects the methodological dilemma faced by Susan Astley and colleagues (Astley, Bailey, Talbot & Clarren, 2000) in their attempts to undertake research with women who had given birth to children with a diagnosis of FASD. Their attempts were rendered almost completely futile because a high proportion of children are separated from their mothers and are residing in

23 Uncertainty pervades current understandings about the mechanisms through which alcohol affects foetal growth. I identify some aspects of this uncertainty in Part 3.
adoptive care or foster care, with no or only limited contact with the women who gave birth to them (Astley et al., 2000). All of these factors meant that I had to change the research design to include three, rather than four health problems, and deal with FASD only from a theoretical perspective in the thesis (refer to Chapters 4, 6 and 7 for consideration of discourses specifically related to FASD). I decided to retain questions about FASD in my interviews with medical professionals so that I could gain further insight into the operation of medical practice in relation to this congenital health problem. I have included further information about the risk factors, symptoms and frequency of FASD in Appendix 1.

The previous account highlights the reasoning behind the selection of specific case studies for the research. It also makes clear that the focus on these particular health problems is complemented by a broader focus on the causes and preventability of congenital health problems within some components of my analysis, namely the analysis of the health education resources and the medical textbooks.

**Medical texts**

Medical discourses are integral to discussions about congenital health problems and they have a significant influence on women’s experiences of having a child with health problems. Women have considerable contact with the medical profession both during and after pregnancy, particularly at the sensitive times at which their children’s health problems are diagnosed, explained and treated. Therefore, an analysis of medical discourses is important in learning about the ways in which congenital health problems are interpreted and understood. To develop this knowledge I analysed medical literature to explore how the causes are constructed and explained and to examine how responsibility for preventing or causing congenital health problems is attributed and conveyed.

When designing the project I expected that articles drawn from authoritative medical journals would provide comprehensive and current sources of medical information about the causes and prevention of congenital health problems. In order to locate relevant medical articles I began by searching electronic databases of medical literature, including the Australian database *AustHealth* and the international database *PubMed*, using relevant search terms (as listed in Appendix 2).

However, following an extensive search, I located very few relevant articles. The strategies that I employed during this search involved entering the search terms as Medical Subject Headings (MeSH) where appropriate, entering various combinations of terms, limiting the search period to the two years prior to the search (i.e. 2006 and 2007) or, conversely,
broadening it to the period between 2000 and 2007 and searching for the terms in the full text of articles or the abstract only. Furthermore, I could not find a search term or strategy that consistently located the kind of literature that provided an overview of factors relating to cause and prevention. The majority of search results that I obtained during these initial searches were totally irrelevant, only semi-relevant or too clinical in that the articles mainly reported findings about the actions of specific micro-biological enzymes in foetal development or the importance of particular foetal characteristics in making medical diagnoses. Although the inclusion of the search term abnormality as a MeSH term did garner some useful materials and provided a manageable number of review articles (total=5), I was forced to conclude that medical journal articles were not the best source of medical literature to explore for general information about the causes and preventability of congenital health problems. This is probably because one of the main purposes of medical journals is to report new knowledge or refinements to knowledge. Therefore, because medical understanding about the causes of congenital health problems is believed to be relatively well established, medical journals may not routinely publish recent articles about these issues. This proposition is supported by literature which assesses the appropriateness and utility of particular kinds of medical literature for different research tasks (Carron, 1999; Fraser, 2003; Guyatt & Rennie, 2002).

I, therefore, broadened my search of medical literature to include medical textbooks that are routinely used by and recommended for medical students who study the fields of neonatology and obstetrics. Textbooks provide a good source of information about the causes and prevention of congenital health problems because they include base level information about biological processes, physiology and anatomy. An advantage of using textbooks is that it allows a more comprehensive content analysis of the context in which the causes and prevention of congenital problems are discussed because I could examine the information that surrounds discussion of these issues in the textbooks. Furthermore, textbooks provide a central basis for the learning of medical students and their learning will be pivotal in shaping future practice. This means that an analysis of textbooks is useful in theorising about the likely outcomes of future practice in relation to congenital health problems.

On the basis of these considerations I set myself the aim of selecting relevant textbooks that were used to teach undergraduate and postgraduate medical students in Australia during the period of data collection, which was 2008. In order to find out which books were recommended for use I contacted two medical schools. I selected medical schools that are located in Australian universities that belong to the Group of Eight, which is the national
group of leading universities. From the Group of Eight I selected the University of Adelaide because it is regarded as the most prestigious medical school in South Australia (University of Adelaide, 2010). I chose the University of Sydney because it is the largest medical faculty in Australia and, therefore, teaches the greatest number of medical students (University of Sydney, 2010).

Academic staff at both medical schools provided me with the lists of texts that were recommended for undergraduate students who study paediatrics (a stream of which is infant medicine, which is also known as neonatology) and obstetrics in 2008. Only one text book was recommended by the University of Sydney for students studying obstetrics and this book also appeared on the list provided by the University of Adelaide. Similarly the University of Sydney recommended only two books for paediatrics students, both of which also appeared on the University of Adelaide list. All three of these books were selected to form part of the material for my analysis.

In order to find out which textbooks were recommended for use by postgraduate paediatrics and obstetrics students I contacted the Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG), which trains and accredits obstetricians in Australia, and The Royal Australian College of Physicians (RACP), which trains neonatologists. One of the books that is recommended by RACP is also on the University of Adelaide list for undergraduates, therefore, I selected that book for analysis on the basis of a cross match. None of the RANZCOG texts appeared on any of the other three lists. However, one of the books that RANZCOG recommends was directly related to the topic of the research because it is specifically about birth ‘defects’, therefore, I selected that book on the basis of relevance. This indicates that the criteria that I used to select the textbooks were based on cross matchings and relevance. This process resulted in the selection of five textbooks in total, which are:

- *Practical Paediatrics* (Roberton & South, 2006)
- *Nelson Textbook of Pediatrics* (Kliegman, Behrman, Jenson & Stanton, 2007)
- *Before We Are Born: Essentials of Embryology and Birth Defects* (Moore & Persaud, 2003)

When two different editions of the same textbook were recommended on the lists, I selected the more recent edition. In order to make my selection of data manageable I also selected
specific chapters from each textbook. I chose the chapters that included the most relevant information about the causes and prevention of congenital health problems. This resulted in the selection of 10 chapters across the sample of textbooks. I did, however, skim read the other chapters of these textbooks to understand the context in which the relevant chapters appeared.

Following the selection of textbooks, I developed a more focused and contained approach to searching for relevant medical journal articles, as these articles would now supplement my analysis rather than form the main focus. In doing so I limited my searches to the four congenital health problems that I selected as case studies for the research. Limiting the articles to those written about the four health problems provided a more practical and specific focus which made it possible to develop a search strategy that was more effective in locating relevant literature.

In order to select the medical journal articles I used the international medical database PubMed to search for all journals that were attached to the subject headings obstetrics and perinatology (which is the field of study relating to the management of high risk pregnancies or pregnancies affected by complications). I then selected the journals from this list that had a relatively high impact factor of two or over that were published in the English language and that were in publication throughout 2000 to 2007. This was important so that I could access the most recent articles. After selecting the journals through this process I searched within the selected journals for articles that discussed the aetiology, causes or preventability of the four selected health problems. This process revealed 15 journal articles that explained the causes and preventability of the four health problems, even though much of the discussion in these articles remained highly clinical and less relevant than the information I sourced from textbooks. The articles in the sample mainly report on research that was undertaken in the US or Europe about the four health problems through methods such as systematic reviews, case-control studies and cohort studies (refer to Appendix 3 for a table of details). Before explaining the methods I used to analyse the medical articles and the medical texts I now explain how I collected the health education resources.

**Health education resources**

My goal in this aspect of the data collection process was to obtain the health education resources that are routinely provided to couples when they first visit an antenatal service. Health education resources are an important source for analysis given that it is partly through

\[24\] The impact factor is a measure of the average number of times articles published in a science or social science journal are cited. Therefore the impact factor also reflects the circulation of a journal and the level of prestige associated with it.
these resources that couples are educated about the factors that influence health during pregnancy and, as part of this, also educated about strategies that can be used to prevent congenital health problems.

Given the co-existence of public and private medical systems in Australia I obtained the resources that are routinely provided to women who visit either public or private care facilities. It should be noted that women who receive a diagnosis of a foetal complication during pregnancy are usually transferred to the public system for birthing. This is because public hospitals are equipped with specialist equipment and specialist teams that may be needed to manage the birth effectively. However, women may still choose to begin their pregnancy with a private service provider before the complication is diagnosed or they may even continue to consult with a private practitioner if complications are not detected before birthing begins.

In order to obtain the health education resources that are routinely provided I contacted staff at all six major public hospitals in metropolitan Adelaide. These are the Flinders Medical Centre, the Lyell McEwin Health Service, Modbury Public Hospital, the Queen Elizabeth Hospital, the Royal Adelaide Hospital and the Women’s & Children’s Hospital. I asked the parent educator, antenatal educator or a consulting midwife at each of these hospitals for copies of all of the health information and education materials that were routinely provided at the first antenatal visit. In order to obtain the health education resources from private obstetricians, I contacted the three specialists with the largest case loads in metropolitan Adelaide and spoke with the receptionists or nurses at these clinics. These people either posted the resources to me or I visited the relevant locations and personally collected the resources.

The final sample of health education resources consists of 6 different pamphlets from private practices and 15 pamphlets and booklets from the public hospitals. I also collected a ‘Mother to Be’ Bounty Bag which is distributed to all pregnant women during their first consultation at a maternity hospital or clinic in Australia (EMAP Australia, 2010) irrespective of whether they are public or private patients. The Bounty Bag contains commercially funded health information and product samples. One of the items included in the Bounty Bag is a guide to pregnancy which I included as part of the sample.

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25 The Queen Elizabeth Hospital and Modbury Public Hospital no longer offer birthing facilities; however, women can still attend antenatal appointments at these hospitals.

26 I obtained information about which specialists had the largest case loads from the antenatal coordinator at a large specialist hospital in Adelaide who had access to this information.
I analysed the content of all the health education resources using the same processes that I applied to the medical literature, which I now explain.

**Analysis of the medical literature and health education resources**

In order to analyse how the causes and prevention of congenital health problems were explained in the medical literature and health education resources, I undertook a two stage process. This involved an initial content analysis followed by a secondary, more in-depth, stage of critical discourse analysis.

**Content Analysis**

Content analysis (Krippendorff, 1980) is a technique that I used to describe the form and content of the written materials. To begin my content analysis I devised a list of categories which I framed in the form of questions that I used to interrogate the medical literature and health education resources. I applied the following broad questions to begin the analysis. These questions are based specifically on the work of Foucault (1976:11):

- What is the article/chapter/health education resource about?
- What issue(s) is/are identified?
- Who/what is spoken about?
- Who/what is not mentioned?

I then extended the content analysis by asking the following questions, which I developed specifically for this research:

- Who/what is specifically mentioned as being responsible for congenital health problems?
- Are women/mothers mentioned? If yes, how many times? If yes, how are women/mothers mentioned—in what context?
- Are men/fathers mentioned? If yes, how many times? If yes, how are men/fathers mentioned—in what context?
- Are couples mentioned? If yes, how many times? If yes, how are couples mentioned—in what context?
- Are families mentioned? If yes, how many times? If yes, how are families mentioned—in what context?
- What is the solution or recommended action to prevent/treat the health problems or to address the risk factors?
- Does the discussion include consideration of biological factors?
Does the discussion include consideration of factors that are not related to biology? If yes, what factors are considered?

I began the content analysis by reading each of the selected medical articles, textbook chapters and health education resources. I then re-read each of the sources and made notes in response to each of the questions. Throughout the analysis I also noted any issues, apparent assumptions or instances of language use that I considered interesting or unusual so that I could explore these further during the critical discourse analysis. In this way I was creating an 'audit trail'. Throughout the content analysis of all of the texts, I compiled tables that included the quantified results of the analysis.

The application of content analysis techniques during the first stage of the analysis process was useful for two main reasons. First, the content analysis facilitated my early immersion in the data because it encouraged me to read the literature closely. Second, the results of the content analysis informed the approach that I applied during the subsequent critical discourse analysis. If I had not undertaken the content analysis, I would have been less familiar with the content of the literature and, therefore, also less certain about the kinds of questions that were relevant to the discourse analysis. Furthermore, if I had not developed a high level of familiarity it would have been more difficult for me to identify relevant themes during the early stages of the discourse analysis.

Critical discourse analysis

Following the content analysis I began the process of critically analysing the discourses that permeated the sources. During the discourse analysis I devoted further attention to the presences and absences that I identified during the content analysis but I also examined the sources to consider the implied values and concepts that emerge from them rather than only those specifically mentioned (Fairclough, 1989, 1995; Wetherell, Taylor & Yates, 2001). The aim of this is to develop a more comprehensive understanding about the implicit meanings that arise from medical and public health discourses surrounding congenital health problems.

In devising my method of critical discourse analysis I drew upon the techniques that are documented by Lupton and Bacchi in two particular texts. These are Moral Threats and Dangerous Desires: AIDS in the News Media (Lupton, 1994) and Women, Policy and Politics: The Construction of Policy Problems (Bacchi, 1999). While examining the analytical
techniques that are used throughout these two texts, I developed a list of broad questions that I asked of the data. These are:

- What ideas, values, notions, concepts and beliefs are present in the texts?
- Which ideas, values, notions, concepts and beliefs are absent?
- Whose voices receive attention over others?
- Whose interests are served by the reproduction of these ideas, values, notions, concepts and beliefs in the texts?
- How might audiences’ views of the world be influenced by the texts?
- What kinds of stereotypes are perpetuated in the texts?
- What norms and values are privileged over others?
- What is the ‘problem’ represented to be? What assumptions or presuppositions underlie these representations? What effects are produced by these representations?
- How would the response differ if the ‘problem’ were thought about or represented differently?
- How are subjects constituted within the texts?
- Who is likely to benefit and suffer from the particular representations provided through the texts?
- What is left unproblematic in the representations that provide the basis of the discussion in these texts?

My analysis of the medical literature and health education resources proceeded simultaneously with my design of the questions for the interviews. This approach allowed for further exploration of the discourses that shape understandings about congenital health problems since the themes identified during the early stages of the project assisted in shaping my questioning during the interviews that I undertook (Liampittong & Ezzy, 2006).

**Interviews**

From the outset of the study I planned to undertake interviews with women who have given birth to and who mother\(^27\) children with the congenital health problems congenital heart disease, spina bifida and congenital naevus. Interviewing provided important opportunities for me to explore the understandings that the participants had come to about their experiences and the origins of their children’s health problems. This is because people’s articulations of their experiences are not simply expressions of their beliefs about a topic, instead they are better understood as accounts which are imbued with broader social and

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\(^27\) I am using the term *women who mother* from this point as a shortened way of indicating that the women have given birth to, and are mothering, a child with one of the congenital health problems.
ideological meanings and which reflect the operations of discourses in individuals’ lives (Nettleton & Gustafsson, 2002:110). Furthermore, I was conscious of the need to give a voice to those whose experiences I was writing about in order to avoid speaking ‘for’ them. Therefore, in keeping with the post-structuralist feminist position that underlies my methodology, the voices of women who mother children with congenital health problems feature prominently in Part 3 of this thesis throughout the findings chapters.

As my analysis of the medical literature and health education resources proceeded, and as I began interviewing, it became clear that the micro-dynamics of medical practice are important contributors to discourses surrounding maternal responsibility for child health. Therefore, I decided to also interview medical professionals in order to gain insight into practice based discourses and to extend further the broad and multifaceted study of discourse that I undertake in this project.

**Participants**
In total I interviewed 35 participants; 28 women who mother children with congenital heart disease, spina bifida or congenital naevus and seven medical professionals who work in the fields of obstetrics, paediatrics, neonatology and genetics.

**Women who mother children with congenital health problems**
I undertook these interviews during 2008 and 2009. There was some diversity in the characteristics of the women I interviewed. The participants were aged between 26 and 42, with their average age being 34 years. 24 of the women lived in a marital or long term de-facto relationship with the man who fathered their child with congenital health problems. Of the four women who were not in this situation, one was divorced, two were recently separated and one had never been in a committed relationship with the father of her child and instead lived with her elderly parents. Two of the women had only one child while the others had at least two, with one woman having six children. One of the women was pregnant with her third child at the time of the interview and six others expressed a desire for more children. However, the remaining 21 women stated either that they were unsure whether they would have more children or that they definitely did not intend to get pregnant again. The residential locations of the women varied, with 15 residing in South Australia, eight in Queensland, three in New South Wales and two in Victoria. The majority of the women lived in privately owned homes in urban suburbs; however, some lived in rented accommodation, government housing and remote rural locations. 10 of the women did not have private health insurance at the time of the interview and of those 18 who did; three had joined private health insurance specifically to cover the costs associated with their child’s
health problems. The primary source of income for the families in which the women lived was wages derived either from their paid work or that of their male partner. Several of the women also received government payments for being a carer or for sole parenting. The average gross fortnightly family income within the participant cohort was approximately $2,800, but some women were reliant on far less than this, with one woman who was a sole parent raising two children on a fortnightly income of $788. The majority of the women I interviewed were born in Australia, however, one was born in India, another was born in Papua New Guinea and two were born in England.

Medical professionals
I interviewed medical professionals during the early months of 2009. The group of medical professionals consists of two females and five males. Four of the participants were employed exclusively within the public hospital system while the remaining three worked in both public hospitals and private practices in Adelaide. The ages of these participants ranged from 51 to 62 years and their average age was 56 years. All but one of the participants were born and trained in Australia. The remaining participant was born and trained in the Netherlands. The professionals had worked in their fields between 11 and 40 years, with the average length of their experience being 25 years.

Sampling and recruitment processes
I selected all of the participants using purposeful sampling techniques (Liamputtong & Ezzy, 2006:46-48). Purposeful sampling is the most appropriate sampling method for this research because it allowed information rich and relevant cases to be selected for in-depth study. The potentially sensitive nature of the interviews also required that participants self-select to participate.

As I explained earlier, the women who mother children with congenital health problems were drawn from support groups related to their child’s health problem. To begin recruiting these women I sought the assistance of the support group coordinators. I sent the coordinators an introductory letter, which included a brief explanation about the focus of the research and outlined what I would ask each coordinator to do if they agreed to assist. Initially, I contacted four coordinators, three of whom agreed to assist. In the latter stages of the project I contacted another coordinator who also agreed to assist with recruitment.

After gaining the support of the support group coordinators I negotiated a mutually convenient date with each coordinator for recruitment to begin. On the nominated date, we
arranged for invitation letters (written by each of the coordinators) and information sheets (refer to Appendix 4) to be sent to all women on the membership lists of the group who had a child aged six years or less with spina bifida, congenital heart disease or congenital naevus. My contact details were printed on the information sheets and all potential participants were asked to contact me directly if they wished to participate. This method of recruitment ensured that the privacy of each individual was protected because I did not know the names of any of the women who did not contact me. It also meant that the coordinators did not know who volunteered since the participants contacted me directly.

Since I received few responses to the letters that I sent to women in one of the support groups, I followed up with a reminder card three weeks following initial contact. I sent the reminder because I understand that parenting is demanding and I thought that some women who may have been interested might not have had time to contact me. Therefore, the reminder gave the women another chance to make contact if they wanted to. The reminder card looked like that which is presented in Figure 3.1 and it generated several more responses from the women in that particular support group.

Figure 3.1

Reminder card

A friendly reminder about the letter I sent recently. If you’ve decided to participate but have not yet contacted me, I hope to hear from you soon. We can arrange your interview at any time that is convenient for you, such as during the week, on weekends or at night. Any queries—please give me a call or send me an email. Thank you, I appreciate your time.

(08) 8303 3723, 0402 917 549 or toni.delany@adelaide.edu.au

In total I sent 116 letters of invitation, 34 women responded and 28 agreed to participate in the interviews. Of the 28 participants, 12 had children with congenital heart disease, 11 had children with spina bifida and 5 had children with congenital naevus. The main reasons given by women who responded but simultaneously declined participation related to being already overburdened with commitments, especially paid work and meeting the needs of their children.
To recruit medical professionals for the interviews I liaised with University of Adelaide Emeritus Professor of Obstetrics and Gynaecology Jeffrey Robinson. Professor Robinson compiled a list of professionals working in fields related to the diagnosis, treatment and management of congenital health problems in public and private practice in Adelaide. I sent letters of invitation and information sheets (refer to Appendices 5 and 6) to all 12 professionals on this list. I also followed up the letters via email and telephone contact with the invited professionals. A total of seven professionals responded to the invitations to take part in the study, all of those did, initially, agreed to participate. However, one of the professionals withdrew after arranging an interview because of an unexpected increase in her workload. This left six professionals who I interviewed from the list provided by Professor Robinson and I recruited another medical professional on the basis of a referral from one of the existing participants. This resulted in an eventual sample of seven medical professionals.

The recruitment of interview participants was terminated when I became satisfied that the collected data was rich enough to cover the dimensions that are of interest in this study and when no new themes were being revealed. To determine when it was appropriate for data collection to cease, it was necessary for the processes of interviewing and analysis of the transcripts to proceed simultaneously (Creswell, 2003:190; Ezzy, 2002:75). I now describe the processes that I used to undertake the interviews and analyse the data that emerged.

**Data collection: In-depth interviews**

In order to learn about the experiences of the participants I used open ended questioning techniques during the interviews (Judd, Smith & Kidder, 1991:239-240). Open ended, semi-structured in-depth interviews are the most appropriate form of data collection for this study because the mothers of children with congenital health problems and medical professionals are not homogenous groups. It is, therefore, important that the participants are given the opportunity to express freely their own experiences and circumstances. The use of semi-structured interviews also allowed me to investigate the meanings that the participants attach to certain events (Liampittong & Ezzy, 2006; Popay, Rogers & Williams, 1998:344-345). I developed two semi-structured interviewing schedules, one for use with each group of participants, and these were used to guide questioning during the interviews (refer to Appendices 7 and 8). The participants were encouraged, however, to express their opinions and experiences in an unrestricted way. I interrupted their narratives only to facilitate a deeper response or to seek clarification.
I piloted the interview schedule that I designed for interviews with women who mother children with congenital health problems by interviewing four women who had been pregnant in the last five years. I undertook these interviews in the month prior to commencing the interviews with the participants. The aim of the pilot interviews was to assess whether the draft interview schedule that I had developed to guide my questioning was effective. I also aimed to identify any questions in the schedule in which my intended meaning was not clear. During these interviews I also assessed whether the order of questioning was appropriate and I sought to identify any particular sensitivities around the issues that we discussed. After each of the pilot interviews I modified the draft interview schedule accordingly, however, no further changes were necessary following the fourth interview.

During the interviews with women who mother children with congenital health problems I aimed to explore the participant’s experiences during pregnancy, at the time of their child’s birth and while seeking medical treatment for their child. In particular I probed to learn about the participant’s beliefs about the origins of their child’s health problems, the participants’ knowledge of related health promotion messages, their feelings about these messages and the impact that the health problems may have had on their family and on their relationships with others (such as friends and colleagues). I probed using non-directive requests for elaboration such as by asking: Why do you believe that? Where/How did you learn that? Who told you that? How did you come to that understanding?

While I undertook the majority of the interviews in person, I also interviewed some women by telephone because they lived outside metropolitan Adelaide (which is where I am located) in rural South Australia or interstate. I undertook these telephone interviews after I had already undertaken several face-to-face interviews. This meant that I was at ease with the interview process and was already beginning to notice emerging themes. Therefore, the less personal medium did not comprise my confidence with the interviewing process or compromise my ability to gain understanding about the experiences of the participants.

Interviewing by telephone provided several advantages. In particular it allowed me to broaden the recruitment criteria and the geographical reach of the research. I believe it also allowed some participants to express their beliefs and emotions more easily. However, the less personal medium created some difficulties in that I could not observe the non-verbal communication of the participants, such as interpreting pauses, and this detracted from the flow of the interview in some cases.
While interviewing the medical professionals I aimed to explore how the causes of congenital health problems are constructed through verbal, practice orientated discourse and to examine how or whether responsibility is located and conveyed through practice. I examined these issues by asking the medical professionals questions that encouraged them to speak about causes in a general sense. I also asked specific questions about the apparent dominance of explanations that are based on the apparent linkages between maternal characteristics, maternal behaviours and congenital health problems both in a general sense and in the specific example of FASD. During interviews with some of the medical professionals I posed specific scenarios and asked the participant how they would respond to the scenario (refer to Appendix 8). Use of the scenarios was particularly beneficial when the dynamic of the interviews were such that the participant was quite reserved, which forced me to probe the issues that I wanted them to reflect on.

Most of the interviews with the medical professionals proceeded according to the planned course of the interview schedule, especially since several of the participants provided very direct, concise answers. However, one of the interviews proceeded differently. I approached this interview in the same way as the others by providing an information sheet in advance and opening with the same broad question. However, for a reason unknown to me, this particular participant believed I was interested in hearing about the history of antenatal screening and he began providing a detailed account about how particular tests had been introduced progressively in Australia over a given time period. During the early stages of the interview I tried to redirect the participant back to the questions that I had prepared. While he did answer a question when I asked, he would then immediately return to explaining the history of screening tests. I felt anxious about this in the early stages of the interview because I was concerned that I would not gain relevant information. However, as the participant continued to explain the history of screening I noticed that he was also, indirectly, explaining his views and values about women’s behaviours and decisions during pregnancy as well as the dynamics that exist between couples and medical professionals. Therefore, I let the participant continue to explain the history of screening tests in Australia because I was gaining useful insights without shaping the content of the participant’s narrative. This approach proved useful since I gained information and examples that I probably would not have if I continued to redirect and interrupt the participant. Through my later reading about research methods I found that Elizabeth Ettorre (2005) encountered a similar experience while interviewing a medical professional. Her reflections support the value of allowing interviews to proceed in a way that is unanticipated if that is what the circumstances demand since this can provide rich and valuable data. Furthermore, the approach that I applied during this interview enhanced the rigour of my approach because it demonstrates that I remained
flexible in my application of research methods during the study so that the methods remained relevant to the particular experiences that I encountered.

The interviews with both the medical professionals and the women were conversational in nature, which encouraged the participants to feel at ease to articulate their experiences in their own way. In order to enhance the comfort of the participants all of the interviews were conducted at locations chosen by the participants and at a mutually convenient time. The majority of the interviews with the women who mother children with health problems were undertaken in their homes or at my office at the University of Adelaide. However, three of those interviews took place in a hospital cafe and one interview also took place in a public eatery at the choice of the participant. The women were all interviewed individually; however, other people were sometimes present in the homes of the women when the interview took place. Sometimes the children of the participants were also present at the interview. I tried, respectfully, to discourage this by offering to arrange someone to care for the child(ren) for the duration of the interview. The reason for this was that I had decided to try and avoid the presence of children during the interviews since I believed it may distract the participants and also influence the feelings and experiences that they were willing to discuss. However, the offer of child care was not taken up by any of the participants and even in interviews where children were present this did not appear to impact significantly on the dynamic of the interview or on what women said, which allayed my concerns. Overall, the interviews with the women lasted from 40 minutes to 150 minutes, with an average length of approximately 75 minutes.

All of the interviews with the medical professionals were undertaken at their place of work. These interviews were all undertaken with no other people in the room and there was minimal disturbance during the interviews. The interviews with medical professionals lasted from 35 minutes to 90 minutes with an average duration of 55 minutes.

I audio taped all interviews with the permission of the participants. This allows for an accurate reproduction and record of the expressed beliefs and experiences of the participants in the findings of this study (Judd, Smith & Kidder, 1991:258). The use of a tape recorder also allowed me to give the participants my full attention during the interviews. I annotated and selectively transcribed each interview. I also sent a CD containing the audio of the interview to each participant. With this CD I reiterated the option of the participant to withdraw any information that they had disclosed during the interview. Only one of the participants used this option and she asked me to remove sensitive information relating to financial matters.
Analysis of interviews
Following each interview, I began the process of analysis. My analysis of the interview data involved three processes beginning with taking notes and culminating in a critical discourse analysis.

Stage 1: Post-interview note taking
Immediately after each of the interviews I wrote one to two A4 pages of notes. The notes consisted of observations that I made during the interview of things such as the non-verbal communication that had occurred (such as body language and the emotions expressed by the participants) as well as potentially relevant observations about the environment in which we had undertaken the interview, particularly when that was the participant’s own home. I also wrote notes about the particular issues that appeared to be central to the participants’ experience and about any themes that emerged strongly from the interview. As part of this initial stage of the analysis I also reflected on the interview process and made notes about aspects of, or emphases within, the interview schedule that I wanted to change before the next interview. Making such changes to the interview schedule allowed me to include questions about themes that appeared to be emerging in the data and it also allowed me to make sure that the interview schedule, and my interviewing techniques, remained relevant and appropriate to the emerging themes.

Stage 2: Transcription
I performed the second stage of the analysis process during transcription. While I was selectively typing the transcript from each interview and re-reading it to check its accuracy I was able to develop a high level of familiarity with the interview data. This assisted me to identify emerging common themes between interviews and to understand the relationships between participant experiences and existing theoretical concepts. For example, it was during the transcription phase of the analysis that I first identified the strong relationships that exist between the experiences of the participants and existing social theory on individualism (refer to Chapters 1 and 5). When I recognised a common theme across interviews or a link between participant experience and theoretical concepts I recorded these relationships. This assisted in the identification of important and consistent discourses in the third stage of the analysis process.

Stage 3: Post-transcription discourse analysis
While undertaking the discourse analysis of the interview data I applied the same principles and process that I used in the critical discourse analysis of the medical literature and health
education resources. Applying such a focus assisted me to explore what factors influence women's beliefs about their responsibilities for their children's health and what influence, if any, medical and public health discourses have in informing these beliefs. Furthermore, through beginning to link the emerging interview findings with existing theory I began to consider what broader effects the ways that women construct their experiences may have in terms of their understandings about the origins of child health and subsequently their responsibilities as mothers.

I used the qualitative analysis program NVivo to organise my discourse analysis of the interview transcripts and to assist with coding the data. The coding process that I used enabled me to identify themes and concepts in the data (Ezzy, 2002:86). Through this process, emergent theory is developed and is further refined as the coding process proceeds (Ezzy, 2002:86-87). During the initial stages of the analysis, I used open coding to experiment with a variety of conceptual labels and ways of organising the data (Ezzy, 2002:89). After this initial exploration, I analysed the data further during a process of axial coding. This involved the data being re-read and organised under sub-headings within the major themes. Axial coding involves a more intense analysis, from which the relationships between the themes can be identified and compared (Strauss, 1993). I then used selective coding to identify the core codes and central stories in the analysis (Ezzy, 2002:93), which I report in Part 3 of the thesis.

**Distribution of findings**

Following completion of the analysis of the interview data I sent a *Summary of Interview Findings* to the coordinators of each of the support groups who assisted with recruitment and also directly to the participants who mother children with congenital health problems. The purpose of this was to provide all members of each of the support groups, including those who had not participated directly, with information about the findings that were emerging from my analysis. Before sending the Summary I liaised with each of the coordinators to negotiate the most useful format for me to use to disseminate the findings, which, for one group, involved writing an article for the group newsletter. For the other three groups I printed a brief summary which was then posted or emailed to members of each the groups.

Following dissemination of the findings, I received some feedback from women who had not participated in the interviews. This feedback suggested that the research had value in their lives. I received feedback from several women (but no men) in Australia and in the UK. The feedback from women in the UK was gained because a member of one of the support groups in Adelaide distributed the Findings Summary to members of the UK division of her support
group. I have included a selection of the comments that I received via email from women in the UK:

Thank you so much for this article. It touched on everything that I have felt. It makes me feel human again hearing and reading stories like this. I am not alone, and sometimes I need that reminder.

I couldn't have put it better myself, although my child's condition is one of the brain rather than the heart I can relate so much to this. This would be great for family & friends to read so they can understand some of the feelings and experiences Mum's with seriously ill kids go through.

I'm glad to see someone is doing some research into this. It does affect us mums (obviously) but it affects us in ways other people would just not understand. I'm not going to name names here, but I know of heart parents who have been treated for Post Traumatic Stress Disorder and even grief counselling for the healthy child they did not have. I have not had either of those, but sometimes I wonder if there is a small amount of those in all of us heart parents?? Thanks again.

**Emotion and participant benefit**

The emotion conveyed through these comments was also expressed by the participants during the interviews. A small minority of the participants who mother children with health problems became emotional and cried during their interview. They expressed emotions such as grief, sadness and regret when discussing experiences related to the treatment of their child and when recounting other painful experiences. In these instances, I offered the participants the option of taking a break but in most cases they declined this, preferring to continue with the interview. However, because of their outward displays of emotion and their difficulty in composing themselves it was sometimes necessary for me to introduce a more conversational tone to the interview for short periods which involved me talking more than I usually did about issues related to their experiences or by drawing, in a confidential way, on the experiences of other participants which may have been similar or slightly different to their own. This technique both gave the participant time to compose themselves and in some cases also encouraged them to continue sharing their experiences, sometimes in more detail, once they gained composure. Particularly after the interviews in which participants began crying or showed signs of becoming upset I spent a longer time thanking them for their participation and for sharing such sensitive thoughts with me. In response to this several of the participants told me that they had benefited from the opportunity to express their feelings and that rather than their expression of emotion having a negative impact on them they felt it had provided an outlet through which they could release their emotion.

Importantly, one common aspect of the experience of mothering a child with a congenital health problem appears to be representing yourself as able to cope and able to provide the
best, most emotionally stable and caring environment for your child as possible (refer to Chapter 8 for an analysis of this). I found that for many women this meant that they did not dwell on thinking about their own feelings and did not engage in discussions about the emotional impact of their experiences because they never felt they had the opportunity to do so or they did not feel comfortable doing so. One participant expressed concerns about not having ‘worked through’ her own emotions by saying:

I haven’t dealt with my feelings and I still don’t get much time for myself, so I do worry that, one day, I will breakdown and not be able to do anything.
(Simone, 29 years old, 1 year old daughter with spina bifida)

On the basis of such concerns, several of the other participants indicated that being interviewed had benefited them by giving them an opportunity to take the time to reflect upon and express their feelings openly:

You are the only person I have ever opened up to about some of this stuff. I don’t tell others how I feel because they’ll just say “Oh well you shouldn’t have done that” or “You shouldn’t have done this” and they wouldn’t think any further than that, but with you I feel like I can say this stuff and you won’t judge me like that.
(Cassandra, 33 years old, 2 year old daughter with congenital heart disease)

You are doing more for women than you realise I think.
(Win, 35 years old, 1 year old son with congenital heart disease)

In addition, I found that the content of several interviews provoked emotional responses from me, including sadness, anger and empathy. In order to work through my emotional responses and to use them in way that was theoretically productive, rather than destructive, I used a journal to write about my feelings and the reasons I believed I felt particular ways after the interviews. I also discussed my emotional response with my research supervisors, which I found useful in helping me understand how what I was feeling could inform my understanding of the nature of the discursive processes that operated in the women’s experiences. The expression of emotion by me represents the integrated, rather than distanced, role that I had in the interviews, which upholds the tenets of my critical post-structuralist feminist approach.

**Interviews as a process of jointly generating knowledge**

Just as the interviews sometimes provoked emotion from the participants and myself they also became a shared process of generating knowledge. Several of the participants told me that they had never thought about particular issues that I questioned them about and had never really thought about particular aspects of their experiences before the interviews. This response arose particularly from my questioning about whether men were included in the
information the women received about strategies for ensuring reproductive and child health before and during pregnancy. Also, as reflected in the previous quotes, the provision of time for women to reflect upon their experiences during the interviews provided several participants with the opportunity to talk about issues they had never spoken about before, thereby, enhancing their learning about their experiences as well as my own learning.

**Supplementary research activities**

Along with the main components of my analysis, which included the analysis of the medical literature, the health education resources and interview data, I also undertook some additional research activities. These activities allowed me to become as immersed as possible in the discourses surrounding child health, which enhanced my ability to identify dominant discourses and explore the content and implications of these through my analysis. Examples of the supplementary research activities that I engaged in are listed below.

**Antenatal appointments**

I attended antenatal appointments with a couple who I knew through my personal network. I attended five appointments beginning from 12 weeks gestation to the final appointment two weeks before the woman gave birth. This experience provided me with insight into the information that is conveyed during antenatal appointments, the contexts in which the appointments are undertaken and the dynamics that are part of a couple’s engagement with health professionals during these appointments. While attending the appointments I also gained the opportunity to speak with the pregnant woman and her partner about how they felt about the information provided to them at the appointments and how they were feeling about the pregnancy in general.

**Vitamin supplements**

I also explored the range of vitamins that are recommended for people before and after conception to promote their reproductive health and the health of their subsequent child. This involved identification of the vitamins that were sold in stores in Adelaide and the media campaigns that promoted such vitamins. This was an important activity since discussion about vitamins features prominently in public discourse about the prevention of congenital health problems.

**Informal conversations**

During the course of the research I spoke with several women among my personal contacts who were pregnant or new mothers. Such informal conversations allowed me to ask women
how they felt about the medical and public health information they were exposed to and about how they felt about maternal responsibility in a more general sense. Where possible, I also asked the male partners of these women similar questions about their expectations of fatherhood and how they felt about the pregnancy.

**Academic events**

I attended several academic discussions throughout my candidature which focused on the topics of reproductive health and child health. These discussions took the form of seminars, workshops and public lectures aimed at educating people about the factors that influence reproductive health outcomes and they involved a range of speakers, most of whom had training in medicine, particularly the fields of paediatrics and obstetrics. The example of Dr Claire Roberts’ lecture that I drew on in Chapter 1 is an example of one of these events.

The information and understandings that I derived from these supplementary activities complement those that I derived from the principal components of my research. I draw upon my observations from some of these activities throughout the thesis where they enhance or extend the range of data that I present. I now explain the considerations that I made throughout all stages of the research in relation to ethics and rigour before moving on to explore the findings.

**Ethical considerations**

According to the critical post-structuralist feminist approach that I adopt in this study, all theory that is derived from research has a moral basis, and as such, is inextricably associated with ethical considerations. This makes an awareness of the potential impacts of research activities an important component of the research design. Furthermore, given the sensitive nature of the issues surrounding this research, comprehensive consideration of ethical issues was imperative. For both these reasons I made it a priority to ensure that I undertook all stages of the research in an ethical and responsible manner. As part of this, I gained approval from the University of Adelaide Human Research Ethics Committee (HREC) before involving any human participants in the research (HREC Approval Number H-079-2007). I also adhered fully to the following principles of ethical conduct, which have been established by the National Health Medical Research Council (NHMRC) (2007) to guide research involving human participants.
Research merit and integrity
In order to ensure the merit and integrity of the work, I committed to collecting, interpreting and reporting all data in an honest manner. I have also disseminated the research to the participants and invited scrutiny and comments from members of the support groups. I plan to continue to disseminate the research both in the form of this thesis and also in research papers so that it can contribute to public knowledge.

Justice
I took all possible steps to ensure that the participants were not exploited or burdened unnecessarily during the research process. Participation in the interviews was voluntary and I endeavoured to make it as convenient as possible for the participants. In addition, the coordinators of the support groups were provided with all of the materials that they required to distribute the information sheets and findings summaries, including envelopes and stamps. This ensured that they did not incur any financial costs as a result of assisting with the study. In order to uphold the principle of justice I also ensured that the inclusion and exclusion criteria that I applied during the recruitment of participants were appropriate to satisfy the aims of the research and did not unnecessarily discriminate against any social group.

Beneficence
All potential participants were advised before they consented to an interview that they could not expect to benefit directly from their involvement in the study. However, it is clear that some participants did benefit from their participation as a result of being allowed an opportunity to discuss their experiences. All participants were also informed that they were free to withdraw from the study at any time without their decision resulting in any negative future repercussions for them or their families (for further details about this issue refer to the consent form which is included as Appendix 9).

Before commencing the interviews I recognised that some of the issues that would arise may be particularly emotional and potentially distressing for the participants. I also recognised that despite having an established network of support in the form of a support group, some of the women who participated in the interviews may, instead, prefer to speak with someone who would ensure their anonymity. To give the participants this option, and to ensure beneficence, I provided each woman with the details of confidential telephone counselling services that they could contact anonymously following their interview. I also met with my supervisors regularly during the course of interviewing to discuss the emotional responses of the participants and consider if any other steps should be taken. However, I did not perceive that
the women were experiencing severe emotional distress during the interviews; therefore, we foresaw no need to modify the approach that I was applying to protect future participants.

**Respect**

One of my main aims throughout the research has been to respect the participants and their information. One way that I ensured this was by gaining their written informed consent before interviewing the participants. Before each interview I provided detailed written and oral explanations about the purpose of the research, the expected applications of the findings and the nature of the participant’s involvement in the study. I also sought the permission of the participants to audio tape the interviews before each interview was commenced, informing the participant that the recorder would be turned off at any time they chose.

I sought to protect the confidentiality and privacy of the participants at all times. This has been achieved through the use of a numerical coding system on all research documents and through the inclusion of pseudonyms rather than participants’ actual names in all resulting papers and publications. For some participants I have used multiple pseudonyms in this thesis because, if read together, the quotes that I have included could possibly be identifying. Furthermore, copies of the audio files and written transcripts of the interviews are stored in a locked and secure cabinet and on a password protected computer as a further safeguard.

Consistent with an ethical approach, it is vital that researchers ensure the quality and credibility of data collection and analysis. However, the NHMRC guidelines (2007) do not provide criteria that are readily adaptable to assessing the extent to which qualitative research meets these standards (Daly, Bandyopadhyay, Riggs & Williamson, 2008:51-52). Therefore, I will now extend my discussion of the research design to explain how I ensured that the research was of a high quality and that the findings can be regarded as credible.

**Qualitative research rigour**

In assessing the quality of research the questions of validity and reliability remain contentious and ever present. Traditional, positivistic research presents the concept of validity as an assessment of whether research represents the ‘reality’ of the phenomena or issue being studied (Liamputtong & Ezzy, 2006:33). Similarly, within positivistic research reliability refers to the extent to which the findings of a study can be replicated by another researcher (Liamputtong & Ezzy, 2006:34). Although highlighting important issues, the concepts of validity and reliability have historically been derived from experimental and positivist research methodologies. Therefore, a number of problems are associated with applying them to the
assessment of qualitative research. For example, it may be difficult to assess the reliability of the present study using such positivistic criteria given that these fail to take into account the individualised and contextualised nature of interactive inquiry, the contextual contingencies associated with discourse and the interpretive basis of research findings. Effectively assessing the quality of research requires criteria that are more relevant to the particular features of the work under evaluation (Popay, Rogers & Williams, 1998:344). For these reasons an alternative concept has been developed to assess the quality and credibility of qualitative research. This concept is called rigour (Popay, Rogers & Williams, 1998).

Rigour provides a means of assessing the strengths of qualitative research in ways that are conceptually appropriate to qualitative approaches. In general, rigorous research involves sound reasoning and the choice of methods that are appropriate to the issues under investigation (Liamputtong & Ezzy, 2006:38; Popay, Rogers & Williams, 1998). Rigorous research is also trustworthy in the sense that it involves clear documentation of the research process as well as the findings, interpretations and decisions made during the research. Overall, ensuring rigour means establishing and maintaining integrity, authenticity, honesty and fairness throughout the research process (Liamputtong & Ezzy, 2006:44). There are various ways in which rigour can be incorporated into qualitative research processes. I will now identify some more of the strategies that I have used to develop a rigorous approach in this study.

Throughout the study I have focused on selecting methods that would enable a full and proper exploration of the issues that are relevant to the focus of the research but which, at the same time, have allowed for flexibility and adaptability. One way I have maintained such flexibility is by asking open ended questions in the interviews and by encouraging the participants to raise any issues they believed were relevant to their experiences. This style of interviewing allows greater potential for developing rich and deep understanding about the multifaceted and variable nature of participant experience. Allowing participants’ scope to discuss issues openly, in a environment in which they feel safe, also provides opportunity for the research to illuminate the subjective meanings that they apply to their actions and to the contexts in which they live (Creswell, 2003:8). Developing such an approach is important in maintaining qualitative rigour because it increases the extent to which the research can be regarded as relevant and applicable to the realities of the participants’ lives (Liamputtong & Ezzy, 2006:344-345).

While analysing the data I have also actively pursued themes that have emerged unexpectedly. This has increased the depth and theoretical rigour of the research by
providing insight into unanticipated, yet potentially important, themes that may allow for
greater understanding. For example, the issue of maternal intuition emerged unexpectedly
during the interviews and, after further consideration, it has proven to be quite a useful and
powerful concept in understanding the ways that women may become both empowered and
disempowered through current discourses of maternal responsibility (refer to Chapter 8).

Another way that I have ensured rigour is by using triangulation, or in other words,
incorporating multiple methods, data sources and theories within the research. Triangulation
is useful because it assists in overcoming the bias that may emerge from the use of single
methods or single theories (Liamputtong & Ezzy, 2006:40). Triangulation has also allowed
me to build a more comprehensive understanding of the issues that are related to this
research. Such understanding is not likely to have emerged had I used only one method,
such as just interviewing, or only one data source, such as written medical texts.

Triangulation has also proven to be useful in allowing me to identify similar themes across
different data sources. Identifying the consistency of some themes and discourses has
helped me to establish and provide evidence of the validity of the findings that have emerged
and, therefore, contribute further to the rigour of the research.

In addition, the rigour of the data analysis process has been enhanced by the development
of collaborative analyses of a selection of interview transcripts and some sources of medical
literature. I have analysed some of the participant quotes in conjunction with my research
supervisors. This has allowed for a comparison of and discussion about the main themes,
which has also contributed to the trustworthiness of the analysis process (Rossman & Rallis,
2003:63-64,122). I have also maintained a journal throughout the stages of data collection
and analysis to assist in my reflection upon my interview experiences and to record
observations that I made during the analysis process. This practice has facilitated the
documentation of emerging analytic insights, which, subsequently, has contributed to the
richness of the data that I have collected (Liamputtong & Ezzy, 2006:273-274).

The ‘thick’, rich descriptions that are provided throughout the thesis also provide additional
evidence of rigour by demonstrating attention to understanding the complexity of participant
experience and medical and public health discourses. Such rich descriptions enhance rigour
by highlighting the effort that has been expended in exploring and interrogating the social
realities that are under investigation (Ezzy, 2002:54). Strategies that I have used to achieve
such a thickness, or depth, in my data include seeking additional clarification from

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28 This was done in a way that did not compromise participant anonymity since a coding system was used in place of the participants’ name and other personal details.
participants after their interviews when necessary to expand on particular ideas. My use of a tape recorder throughout all stages of the research to document particular experiences that arose during field work, such as unexpected but relevant conversations with midwives about health education resources, also contributed to the depth of my understanding and the subsequent rigour of the analyses that I present.

**Reflexivity**

In order to further ensure the rigour of qualitative research it is important to reflect upon and acknowledge the possible influence of the researcher’s own position within the research. Reflexivity is the process of reflecting critically upon the self as a researcher and as an instrument within the research (Guba & Lincoln, 2005:210). Reflexivity encourages researchers to examine the ways that their research is *shaped*, particularly through their social location, choice of research topic, selection of methodological approaches and through their interactions during the research process (Guba & Lincoln, 2005:210). For these reasons, reflexivity is consistent with, and an important means of acknowledging, the subjective nature of constructionist feminist inquiry (Liamputtong & Ezzy, 2006; Olesen, 2005:250-251).

Acknowledging, rather than denying, the relation between the researcher and the research also assists in making visible the processes involved in the formation of research knowledge (Liamputtong & Ezzy, 2006:38). This practice, therefore, contributes to the depth of understanding that can be generated and provides greater potential for thick description of my findings and analysis (Patton, 2002:437). A reflexive consideration of why a researcher may select a particular research topic over others can also provide deeper insight into how and why particular issues become situated as research ‘problems’ within certain contexts and, from this, how and why particular patternings or phenomena may occur. For these reasons it is important that I reflect upon my own position in relation to the research and consider how my personal biography may be relevant.

I am a woman aged in my mid-twenties. I was born in Australia, with predominantly Anglo-Celtic heritage. Throughout my life I have lived in a socially disadvantaged suburb of Adelaide, South Australia. Living in such a location has provided the basis for my interest in factors that produce, maintain and perpetuate forms of social disadvantage, particularly those based on gender and class.

My particular interest in discourses that surround mothering, reproduction and social inequalities stems in part from my educational training and also from personal experience (as documented in Chapter 1). I hold two undergraduate degrees, a Bachelor of Health Sciences, with a major in Public Health, and a Bachelor of Social Sciences, with a major in Gender
Studies. This training prepared me to critically examine the way that issues related to women's health may be influenced by gender, discursive practice and structural constraints.

Apart from influencing my choice of research topic, I believe my personal biography also influenced the data that I collected during the interviews. Throughout my educational training and employment history I have gained considerable experience in undertaking in-depth interviews and in liaising with research participants. I believe that this prior experience, in conjunction with the pilot interviews, increased my confidence during the interviewing component of the study. My confidence, experience and formal training in interviewing techniques allowed me to assist most of the participants to feel relatively comfortable during the interviews and, in turn, also increased the effectiveness of the interviews in eliciting relevant and deep information. My age and sex also worked to my advantage during the interviews with the women who mother children with health problems. Given that I am a relatively young female researcher I found it easy to develop rapport with most of these participants, particularly those aged in their twenties or early thirties. I also believe that being a woman allowed me to recruit more mothers than would have been possible if I had been a man, particularly given the sensitive, gendered and personal nature of the research topics. In addition, it was evident that my admitted lack of first-hand experience of pregnancy and mothering encouraged some participants to provide considerable detail about their experiences of pregnancy, birthing and caring for their children. This enhanced the depth of the interview data and may have also allowed me access to details and feelings that the women may have felt were unnecessary to disclose if I had personal experience of pregnancy or raising children.

However, I believe that my biography may have detracted from the effectiveness of the interviews with some of the medical professionals. Almost all of the medical professionals inquired about my professional background before we commenced the interview. Some professionals appeared to be perturbed by my social and health science, rather than medical, background. This was despite my affiliations having been clearly stated on the information sheet that I sent to each prospective participant before the interview. I cannot be certain about the reason for this but I suspect that some of the professionals were sceptical about how worthwhile the interview was going to be if my intention was not, or at least not directly, to inform medical practice or theory. Some of the medical professionals also appeared guarded in their responses to my questions and this dynamic persisted despite my attempts to facilitate deeper discussion. It is difficult to determine the exact reason for this as it may have resulted from factors unrelated to me, such as the heavy workloads of the professionals and the resultant constraints on their time and mental energy. However, I sensed that the
guarded approach of some professionals may have resulted from their uncertainty about how I was going to utilise the research findings. In cases where I detected such uncertainty I made an effort to again clarify the purpose of my study and reiterate the right of the participant to edit the transcript of their interview. Such assurances were not always effective in improving the interview dynamic however.

Despite the reflexive and rigorous nature of the research, some constraints are also associated with the design. I now acknowledge these constraints as a final way of highlighting how the research knowledge that is reported in this thesis has been shaped.

**Potential constraints**

If positivistic criteria are applied to the analysis of this research it may be argued that the findings of the interviews cannot be generalised to broader populations of mothers or medical professionals because the participant cohorts are not representative. However, in terms of the qualitative methodology that I have employed in this study this is not a significant problem. The aim of the interviews was *not* to provide population-based data but was instead to explore the depth and complexity of the issues under investigation. The interview data were also intended to *supplement* the other sources of data, which, together, form a broader, more holistic approach to analysing the construction of maternal responsibility, and in particular the influence of medical and public health discourses on that construction. In addition, the quotes that I presented earlier in this Chapter show that there is an element of generalisability in the findings since they relate to the experiences of some women who mother children with health problems in the UK as well as Australia.

It may also be argued that potential for bias exists in relation to the processes that were used to recruit the interview participants. Comments on my study design by members of the University of Adelaide Human Research Ethics Committee (HREC) raised the possibility that women who belong to support groups would be more “self-assured” than other women and, therefore, more willing to challenge health professionals about their treatment or manner. Members of the HREC also suggested that those most likely to participate in an interview were women who had a “negative comment to make.” These are reasonable matters to raise; however, neither of these factors appear to have had an obvious influence on the data that I gained from the interviews. It is conceivable that women who belong to support groups may have different understandings about their experiences compared to other women, particularly if the groups provide them with counselling or similar opportunities to express and work through their feelings. That said, few of the women who participated in the interviews had accessed any formal counselling services through their support groups. Instead most of the
participants were loosely connected to the support groups and they used the groups primarily to gain information about services that are available to assist their child or to socialise informally with other parents. While informal socialisation may have provided opportunities for the women to discuss their feelings, most participants indicated that they did not do so, preferring only to discuss more practical parenting matters with others in the group rather than share personal feelings. In addition, several of the women who participated reported no negative feelings about their contact with medical staff. Therefore, while it is not possible to determine definitively whether the selection processes and the issues identified by the HREC produced bias, it does not appear to me that these issues had a considerable influence on the data. However, I acknowledge that by only sampling participants from support groups I could not access the experiences of women who felt reluctant to identify with a support group based on their child’s health problem and who may, therefore, have been denied access to information and support.

A final issue relates more to a specificity of the research than a constraint. Most of the data that I have analysed is drawn from Australia (excluding some of the international medical texts). Given the already broad focus of the analysis and the use of multiple data sources, it would have been difficult for me to broaden the project further to also include consideration of multiple cultural and geographic settings. The specificity of the analysis may limit the extent to which the findings are applicable to understanding discourses and experiences overseas and within cultures other than those of Caucasian Australians (only one of the participants I interviewed was not Caucasian). Acknowledging this specificity is particularly important because experiences of health and illness are shaped by the health systems, cultures and dominant discourses that an individual is exposed to. While the Australian specificity of the research may limit the generalisability of the findings, it also provides some benefit in terms of allowing for a more nuanced and thorough examination of reproductive experience within the particular health, cultural and political systems that currently operate within the Australian context. Furthermore Australia has traditionally been regarded as ‘second rate’ to Europe (Dixson, 1986:40) but influential theorists, such as R.W. Connell (2007) are now highlighting the acceptability and value of a specific focus on Australian cultures and Australian societies.

**Conclusion**

Throughout this Chapter I have explained the methods that I applied to design and undertake the research that is reported in this thesis. The focus on the practical aspects of the research has been combined with consideration of the methodological basis of the research throughout Part 2. I have explained that the research involves multiple components and
multiple layers of analysis. The analysis of several sources of medical and public health discourses, in conjunction with participant narratives, assists me in developing comprehensive and rigorous findings. The remaining chapters of this thesis are focused on an exploration of these findings.
PART 3

Exploring the Findings
As a preface to my analysis of the research findings, I identify two contexts that are relevant to this study of maternal responsibility. First, I highlight the plethora of health promotion messages that currently govern ‘responsible’ pregnancy in Australia. These messages define what women must do before, during and after pregnancy in order to optimise their child’s health. The messages form a central part of the web of public health and medical surveillance in which pregnancies are embedded and they also have a role in establishing knowledge about the cause and prevention of congenital health problems. After identifying these messages, I explain some of the practicalities associated with parenting children who have congenital heart disease, congenital naevus and spina bifida to supplement the description of each health problem that I present in Appendix 1. I explain these practicalities in conjunction with identifying the relevant health promotion messages to bring to the fore two aspects of the context through which my interview participants mother their children and negotiate their maternal responsibility.

Health promotion messages governing ‘responsible’ pregnancy

The following lists of health promotion messages demonstrate that there are many behaviours that women are expected to select, reject and change in order to optimise the health outcomes of their child. To create the following lists I collated relevant health promotion messages from the health education resources, medical textbooks and medical journal articles that I analysed for this research. Therefore, while I do not present these as exhaustive lists, they contain health promotion messages that women are commonly exposed to, especially during their early antenatal appointments. It is clear from these lists that the current messages target women’s behaviours before, during and after pregnancy and instruct women about appropriate ways to behave in many different aspects of their lives. Presenting these recommendations in three separate lists highlights the fact that there are very few areas of the lives of women who are pregnant or planning pregnancy which are free from medical and public health surveillance or self-scrutiny in the quest to minimise risk to child health.

Health promotion messages targeted at women before pregnancy

- Stop drinking alcohol, smoking cigarettes and using illicit drugs before conceiving.
- Attain and maintain a healthy body weight (as determined by the standardised Body Mass Index) and do not become obese. If already obese try to reduce body weight through dietary change and increased exercise.
• Eat foods that are rich in vitamins and minerals, particularly green leafy vegetables, oranges, rice, lentils, beans, pasta and wholegrain breads, since these are rich in folate.
• Supplement the diet with folic acid tablets.
• Have medical tests to assess immunity against diphtheria, tetanus, whooping cough and rubella before conceiving. If immunity is not present, get immunised for these diseases before conceiving.
• Review prescribed medications to ascertain whether they are safe for use in pregnancy.
• Cease using the contraceptive pill before trying to conceive (recommendations vary and advise cessation either one month prior or three months prior to attempting conception).
• Visit a general practitioner to have a general health check in order to detect any issues that may compromise the success of a pregnancy.

Health promotion messages targeted at women during pregnancy
• Do not consume any alcohol.
• Do not smoke cigarettes. If smoking cannot be eliminated, reduce the number of cigarettes smoked per day.
• Avoid exposure to passive smoke.
• Do not take illicit drugs.
• Do not take over-the-counter drugs, especially aspirin, without advice from an appropriately qualified health professional.
• Ensure all prescribed drugs are safe for use in pregnancy.
• Take folic acid supplements during the first trimester of pregnancy.
• Eat a diet rich in nutrients, especially folate and protein.
• Limit intake of fish, particularly species known to carry high levels of mercury.
• Limit caffeine intake.
• Do not consume processed meats, pre-prepared foods (such as sandwiches and salads), unwashed fruit and vegetables and unpasteurised food products (especially soft cheeses) as these may contain the bacteria listeria.
• Maintain a healthy body weight (as determined by the standardised Body Mass Index) and do not eat excessively during pregnancy.
• If overweight, do not attempt to lose weight during pregnancy. Instead focus on consuming a healthy, balanced diet that is rich in nutrients.
• Get plenty of exercise but do not over-exert during exercise. Modify exercise regimes as the pregnancy progresses.
• Avoid lifting heavy items.
• During sexual intercourse find a comfortable position which does not apply significant pressure on the abdominal region and do not allow air to be forced into the vagina at anytime.
• Avoid any elevation of core body temperature, including prohibition of swimming in heated pools, using a sauna or taking long baths in hot water.
• Avoid contact with sick animals. Also avoid cleaning cat litter boxes and having contact with reptiles because the faeces of both cats and reptiles can carry bacteria.
• Ensure the proper cleaning of hands, food preparation areas and utensils to avoid exposure to bacteria.
• Avoid all illnesses, particularly herpes. Avoid contact with sick people if possible.
• Avoid x-rays.
• Consult with an obstetrician or midwife regularly throughout pregnancy.
• Consult an obstetrician or midwife before travelling on an aeroplane, especially during the third trimester.

Health promotion messages after giving birth
• Exclusively breastfeed the infant for the first six months after birth.
• After the infant is six months of age introduce solid foods and continue breastfeeding.
• Do not consume alcohol or illicit drugs while breastfeeding.
• Monitor mood to detect signs of postnatal depression.

Of the health promotion messages that I have listed, the ones that appear most frequently in the health education resources and the medical literature are those that prohibit cigarette smoking and consumption of alcohol. The importance of taking folic acid tablets and breastfeeding are also mentioned numerous times across the sources.

Mothering a child with congenital health problems
Before I begin to explain some of the practicalities associated with parenting a child who has congenital heart disease, congenital naevus or spina bifida it is important to acknowledge that considerable diversity exists in the experiences of individuals who have these health problems. This means that there is also considerable diversity in the experiences of people who parent children with these health problems. As a result there is no singular or typical experience and my aim here is not to homogenise. Instead in the following descriptions I intend to give a general insight into the practicalities, prognoses and everyday implications that face not only the children living with these health problems but also the parents who care for them. The variation between individual children born with a particular health problem adds
to the uncertainty experienced by those caring for the child and demands the development of skill and continual vigilance in interpreting the signs of the health problem in their particular infant or child.

**Congenital heart disease (CHD)**

While experiences associated with CHD are influenced strongly by the type of cardiac problem that an infant is born with, almost all children affected by CHD require treatment (Kurt & Schumacher, 2009). Some heart problems can be treated with medications or by the insertion of a catheter into a chamber or vessel of the heart to reduce pressure (US National Institute of Health, 2009). However, the majority of children require more extensive surgical procedures, either immediately after birth or in the early years of life.

In Australia paediatric cardiac surgery is performed at the Royal Children's Hospital, which is located in Melbourne, Victoria. Children born outside of Victoria must travel interstate to receive surgical treatment and their parent(s) need to travel with them and remain in Melbourne until their child is well enough to travel to their home state. Following surgery, children return to a hospital in their home state and they must remain there until they are well enough to live in the family home. Following the child’s recovery from initial surgery, further operations may be necessary and medications are usually prescribed to maintain heart function. The cardiac surgeries performed on children with CHD leave characteristic scaring down the centre of the chest as shown next in the photo$^{29}$ of one of the interview participants’ children.

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<td>This photograph is included on page 97 of the print copy of the thesis held in the University of Adelaide Library.</td>
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Each time a child has a surgical procedure, the incision can introduce bacteria into the bloodstream. Although the white blood cells in the body usually destroy these bacteria before

$^{29}$ All photographs included in the thesis were offered to me by the children’s mothers to assist readers of the thesis to gain an understanding about the physical manifestations of their child’s congenital health problem.
an infection can develop, the rough surfaces that usually exist within a congenitally malformed heart may allow some bacteria to survive and this can result in an infection of the heart lining (Moore & Persaud, 2003; US National Institute of Health, 2009). This infection is called bacterial endocarditis and it is a serious (potentially fatal) illness which requires lengthy treatment with intravenous antibiotics in a hospital (Moore & Persaud, 2003). In order to reduce the risk of bacterial endocarditis children can be treated with preventative antibiotics before surgery. To reduce the risk even further parents are instructed to ensure that their child maintains good oral health because high levels of bacteria in the mouth can increase a child’s risk of developing endocarditis. Therefore, good dental hygiene is particularly important for children with CHD and parents are advised by medical professionals to monitor this vigilantly, even at times when surgery is not planned for their child.

The other everyday practicalities associated with parenting a child with CHD are, again, determined by the type and severity of cardiac problem. However, all children with CHD require consultations with cardiac specialists and possibly also with a paediatrician. The regularity of these consultations can range from once a week to once a year and the frequency of consultations can fluctuate during the life of a child depending on their stage of treatment and depending on the severity of their health problems. Parents of children with CHD are usually instructed to closely monitor their child’s health status and alert medical professionals immediately if any of the following symptoms develop since they can be signs of cardiac problems:

- a blue tinge to the skin around the child’s mouth or on the lips or tongue,
- a poor appetite,
- fast breathing,
- fatigue,
- unexplained sweating, and
- unexplained fever.


Parents are also encouraged by medical professionals to be mindful of the difficulty that many children with CHD have with gaining weight (US National Institute of Health, 2009). As a result, parents may be instructed to, or resort to, giving their child foods that are high in calories in order to promote weight gain and to avoid their child being classified as ‘underweight’ for their height.

Another important consideration for parents is that children with CHD may experience impaired function of their immune systems throughout life (US National Institute of Health,
2009). This can result in more frequent and more severe illness. Therefore, parents of children with CHD are also encouraged to take all possible precautions to prevent their child getting an infection.

**Congenital naevus**

As explained in Appendix 1 congenital naevus is characterised by the formation of dark areas of pigmented skin which can be associated with excessive hair growth. Therefore, the main issues associated with congenital naevus relate to cosmetic disfigurement. In order to reduce the impact of this there are a range of treatments available. Some naevi can be surgically removed depending on the location and extent of the naevus. Often this will involve multiple operations and will leave scarring. However, most commonly naevi cannot be removed totally because of the extent to which naevi cells are embedded within surrounding tissue (Schwartz, 2010b). Therefore, other methods of treatment may be necessary to reduce the appearance of the naevi. These include dermabrasion, which involves the abrasion of the upper layers of skin, and the use of skin expanders, which involves inserting small inflatable sacks under the skin surrounding the naevus to stretch the non-affected skin so that it can cover the space previously occupied by the congenital naevus (Schwartz, 2010b). Both of these treatments inflict considerable pain and there is no guarantee that they will result in an improvement in appearance even after ongoing follow-up treatments. Other methods of treatment, such as laser treatment and chemical peels, may lighten some naevi and reduce hair growth; however they do not remove the naevus cells or reduce the potential for more naevi to develop on the skin as the child grows (Dave & Mahaffey, 2004; Schwartz, 2010b). Therefore, given the associated pain and potential lack of effectiveness, some parents choose to leave the congenital naevus intact and monitor the skin closely for signs of irritation, problems with sweating or the development of further naevi.

Apart from the cosmetic issues, people with large congenital naevi have an increased risk of developing melanoma (Barnhill, Piepkorn & Busam, 2004). Because of this increased risk, children need to exercise vigilant sun protection on a daily basis and parents need to ensure that their child is protected from the sun. Also, the same naevus cells that appear on the skin can form within the central nervous system. This condition, called neurocutaneous melanosis, is largely untreated (Barnhill, Piepkorn & Busam, 2004). It is potentially fatal and can cause neurological problems, such as hydrocephalus (i.e. fluid on the brain, refer to Appendix 1 for further details), developmental delay, seizures and melanoma of the central nervous system (Barnhill, Piepkorn & Busam, 2004). In order to reduce the risks posed by this condition, children with large congenital naevi can have regular Magnetic Resonance Imaging (MRI) scans to detect internal naevi before they cause severe problems. There is no known way to inhibit the development of further naevi on the skin or in the central nervous system.
system after birth, so proactive monitoring by parents is strongly encouraged by medical professionals.

The daily practicalities of parenting a child with congenital naevus mainly involve vigilant sun protection. However, because many naevi are associated with excessive hair growth parents may also need to remove hair from the congenital naevus site regularly in order to avoid their child overheating or developing skin irritations. Methods of hair removal involve shaving or plucking, which can be painful and confusing for children since their siblings or peers do not undergo similar hair removal routines. Furthermore, given that congenital naevus is so outwardly visible on the skin, daily life involves dealing with other people’s stares or questions about the pigmented sections of skin, which can involve accusations of child abuse because some naevi have a similar appearance to a bruise.

Next I show some photographs of the son of one of my interview participants. This child was born with large congenital naevi on his head and his parents decided to leave it untreated. The photos\textsuperscript{30} show the appearance of the naevi when he was an infant and when he was one year old.

\begin{center}
\begin{minipage}{0.5\textwidth}
NOTE:
These photographs are included on page 10 of the print copy of the thesis held in the University of Adelaide Library.
\end{minipage}
\end{center}

\textsuperscript{30} All photographs included in the thesis were offered to me by the children’s mothers to assist readers of the thesis to gain an understanding about the physical manifestations of their child’s congenital health problem.
Spina bifida

Following the birth of an infant with spina bifida, medical professionals will determine whether surgery is required to reposition any tissue or structures protruding from the spinal cord back inside the body. If surgery is required a neurosurgeon will repair the lesion in order to reduce the risk of further spinal cord damage. However, surgery cannot repair the spinal nerves that are already damaged or malformed (Saladin, 2001). Typically, this means that children with spina bifida will experience impaired nerve function throughout their lives, resulting in varying degrees of incontinence, immobility, a lack of skin sensation and possibly a lack of sexual function or sensation (Saladin, 2001).

The majority of children born with spina bifida also develop complications in the form of hydrocephalus (refer to Appendix 1 for further details). In order to avoid severe brain damage following the onset of hydrocephalus, a shunt device must be surgically implanted to allow excess cerebrospinal fluid to drain from the brain to another area of the body (Lewis, 2003). A shunt consists of two catheters and a valve. The shunt regulates the pressure and direction of cerebrospinal fluid (Lewis, 2003). As the pressure of cerebrospinal fluid inside the brain increases, the valve opens and the excess fluid drains out of the brain (Lewis, 2003). Before leaving the hospital after insertion of a shunt, or following the surgical repair of a spina bifida lesion, parents are given information about any special needs that their child has, such as education about how to detect signs of shunt malfunction or infection.

A child with spina bifida, and particularly hydrocephalus, usually requires ongoing treatment and management which involves frequent visits to hospital and possibly home-based therapy (Lewis, 2003). This management and treatment is carried out by a multidisciplinary team, including a neurosurgeon, urologist, orthopaedic surgeon, physical and occupational therapists and other professionals as needed. As the child grows they will require further evaluation of bladder, motor and sensory function in order to determine the effects of the spinal nerve damage and to gain early intervention if additional problems develop.

Depending on the severity of the spina bifida, children may experience paralysis or problems with walking. Therefore, while some children will walk without assistance, many require leg braces, a walker, crutches or a wheelchair. Given that spina bifida involves damage to the spinal nerves, many children will also experience little or no sensation in some areas of their skin (Lewis, 2003). Therefore, children with spina bifida may not feel discomfort or pain from heat, cold, sharp objects, pressure, scrapes or excessive moisture and may be unaware of damage to their skin (Lewis, 2003). This means that parents must be vigilant in monitoring their child to help them avoid injury and they must also check their child’s skin regularly for signs of damage, irritation or infection. Parents must also attend to the continence needs of
their child if the spina bifida has affected the nerves that control bowel and bladder function. This requires parents to teach their children how to self-catheterise and generally manage their continence aids as they become old enough to understand and cope with managing the effects of their health problem.

Throughout this preface I have identified two aspects of the context in which the interview participants live and through which their maternal responsibility is interpreted—those of the antenatal advice about how to prevent congenital health problems and the practicalities of life with a child who has one of the selected congenital health problems. I now move on from providing the background to my findings to concentrate on an analysis of the ways in which medical and public health discourses inform the construction of maternal responsibility for congenital health problems.
CHAPTER 4

Understandings of causation: Decontextualising self-governance

This Chapter is the first of the five which examine the findings of my research and establish and develop the main arguments that form the foundation upon which the thesis is based. In this Chapter I begin by exploring discourses that construct understandings about the cause and prevention of congenital health problems. In doing so, I highlight how women and men are positioned within the discourses, while also explaining the relevance of concepts such as risk, medicalisation and technologies of the self. This Chapter is intended to establish a basis for the more focused analyses that I develop in subsequent chapters by providing insight into how congenital health problems are understood by the women and medical professionals and represented within the medical literature and health education resources.

Dominant constructions of cause: Decontextualisation and the centrality of women

Information about the cause and prevention of congenital health problems emerged from all of the sources that I analysed for this research. The most explicit and detailed information about these issues was present in the medical literature.31 The majority of the interview participants also articulated beliefs about cause and prevention. In addition, information about the participants’ understandings emerged implicitly during the interviews, particularly when I asked women who mother children with health problems to reflect upon what they would have liked to have been different about their experiences before, during and after pregnancy. Similarly, information about cause and prevention emerged from my analysis of the health education resources. Such issues were identified explicitly in the resources as well as emerging implicitly from the advice that was (and was not) included. I now provide an overview of the main ways that the causes and prevention of congenital health problems were constructed in the research data. This overview draws primarily upon the findings from my analysis of the medical literature; however, I also include examples from the other aspects of the research.

Several sources of the medical literature included detailed descriptions of current medical evidence regarding the causes of congenital health problems. These descriptions were relatively consistent across the sources. An example of the ways in which the causes were

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31 This was anticipated given that I selected literature which included a specific focus on the causes and prevention of congenital health problems.
categorised in the university prescribed textbook *Before We Are Born: Essentials of Embryology and Birth Defects* (Moore & Persaud, 2003) is provided in Figure 4.1.

**Figure 4.1**

**The causes of congenital health problems**

![The causes of congenital health problems](image)

Source: Moore & Persaud (2003:118)

The data in Figure 4.1 suggests that two of the categories of causes, those in pink and blue, are associated with the genes that exist within the bodies of parents, which are then passed on to their children. A third category, the one in green, relates to environmental causes of congenital health problems. These environmental factors are both those that are present in the immediate human environment that exists during pregnancy (i.e. within the woman’s body) as well as in the wider physical environment. The large section in purple relates to causes that arise from a combination of genetics and environmental influences. The yellow section is particularly interesting because it indicates that the causes of 50 to 60% of congenital health problems, that is, over half, are currently unknown. This shows that uncertainty pervades medical knowledge (Fox, 2000:409) about the causes of congenital health problems.

While analysing the medical literature and interviewing the medical professionals I noticed that instead of such uncertainty being conveyed clearly, a reader or listener may easily get the impression that medical ideas about causation are based on comprehensive, conclusive and uncontested facts. It is important to highlight this early in the thesis because de-emphasising uncertainty is one of the means through which medical discourses about congenital health problems become legitimised as credible sources of knowledge about causation. Without such legitimisation it would not be possible for medical discourses to operate as such a powerful force in influencing broader ideas about child health, and therefore, about the roles of women and men in relation to it. Given the importance of such legitimisation, I now introduce some of the basic processes through which this may be
achieved. I elaborate further on processes which have this effect in Chapter 7 as part of my more detailed analysis of the research findings.

**Citations: Reinforcing authority and truth claims**

Within Western societies the field of medicine in general, and medical texts in particular, are associated with (ideologies of) authority and status. It is partly this authoritative image that contributes to the dominance of beliefs about the total reliability of, and comprehensiveness of, medical information (Carron, 1999:82; Fraser, 2003:40-41). Given this, it is less likely that the medical professionals and authors of the medical texts will want to, or feel the need to, clearly convey the incompleteness or uncertainty of current medical understandings. Such authority also makes it less likely that general readers of the literature will question the comprehensiveness of the information that is presented because of its perceived status.

The representation of medical information as authoritative, ‘scientific’, conclusive and reliable is reinforced explicitly through statements in the medical texts, such as this example from the introduction to the *Nelson Textbook of Pediatrics*:

> For nearly three quarters of a century, Nelson Textbook of Pediatrics has been the world's most trusted resource for best approaches to pediatric care … this New Edition continues the tradition, incorporating a wealth of exciting updates and changes—ensuring you have access to today's authoritative knowledge to best diagnose and treat every pediatric patient … Nelson Textbook of Pediatrics is your comprehensive guide to providing the best possible care. (Kliegman *et al.*, 2007:i)

The impression that the existing medical information is complete and uncontested is also reinforced by the systems of referencing that are used in the medical literature. In the majority of the sources, the names of researchers or authors do not appear. Instead numbered referencing systems are used. In several of the sources, however, no specific references were provided at all. Instead non-specific phrases such as “research shows” or “studies demonstrate” were used to support the claims made. Both of these strategies have the effect of de-personalising medical evidence, which distances the information from the authors and researchers who produced it. This process of reification (Turner, 2006:503) also contributes to the representation of medical knowledge as objective, unbiased fact because it appears to remain uninfluenced by the opinions or selection practices of human researchers or human authors. The use of homogenising terms such as “research shows” also has the effect of representing the findings of medical research as consistent and conclusive.

However, closer analysis of medical information indicates that considerable contestation does exist within the field of medical research about congenital health problems. I return to examples of such contestation during Chapters 6 and 7.
On a more practical level, the citation practices that are used in medical and public health information also obscure the uncertainty that exists within these fields. This is a further aspect of the texts that contributes to the authoritative power of medical and public health understandings, and to their role in constituting particular belief systems. One study which highlights this was undertaken by Steven Greenberg.

Greenberg (2009) undertook a study to understand how certain scientific claims become validated through the patterns of citations that appear within the papers that report those claims. For Greenberg (2009) citation provides a public record of the belief system that is shared within a community. Therefore, analysis of citation patterns in relation to particular claims allow for understanding about not only what is written but also how it is supported (Greenberg, 2009:6). Greenberg’s (2009) findings reveal that citation is not simply an impartial scholarly method. Instead, it can be used as a tool of persuasion and as a way of gaining acceptance for particular claims (Greenberg, 2009:6). Greenberg (2009) suggests that the certainty of claims within medical research are constructed through citation in several ways, two of which he refers to as citation bias and amplification. Citation bias refers to the ways that authors of medical research papers exclude or ignore primary data that weakens or contests the claims that they aim to represent as valid (Greenberg, 2009:6). Amplification occurs when a small number of papers, regardless of whether these are influential or peripheral papers, are cited repeatedly in support of particular claims without the concurrent presentation of new data (Greenberg, 2009:4). There are varied forms and effects of such persuasive citation techniques. However, importantly they both result in systematic support of particular claims and the loss of potentially important, but alternative, data, such as research which challenges the validity of claims being made.

The research of David Armstrong also suggests that citation is an important process through which scientific uncertainty becomes obscured. Armstrong (2009) studied the processes by which the notion of health related quality of life became established as a valid concept in medical practice. Armstrong (2009:114) explains that in the 1970s quality of life existed as a vague and highly contested concept within medical literature. By the year 2000 quality of life had become a respected, and measurable, tool in the treatment of patients (Armstrong, 2009:114). The materialisation of quality of life as a ‘real’ phenomenon emerged partly through the repeated application of it in medical research and the validation of it through the proliferation of empirical papers that supported its utility (Armstrong, 2009:106, 109). The empirical nature of the evidence combined with the citation bias that became inherent within the evidence base also assisted in the establishment of quality of life as a valid concept (Armstrong, 2009:106).
During my research I found that a similar process is evident in relation to alcohol whereby the consistent use of particular research, namely empirical studies, establishes and re-establishes the validity of information about alcohol consumption during pregnancy having a negative effect on foetal development. Yet despite the degree of stabilisation that is achieved through this process, there are elements of this evidence which remain contentious and for which consensus appears difficult to achieve. This is particularly because of inconsistencies in the measurements that are used in the existing research base. In this sense, alcohol consumption during pregnancy remains a ‘loose concept’ but also one that is represented as fact, particularly since it is supported by some empirical research (Armstrong, 2009:114). The image of certainty that surrounds this topic, despite the considerable underlying uncertainty in the actual evidence, was demonstrated during an interview with Jordan who is a neonatologist:

**Toni:** You mentioned alcohol as being an important factor in terms of congenital health problems. I understand that if you look at the research there’s a lot of contestation and uncertainty about alcohol during pregnancy, particularly …

**Jordan:** Is there? I don’t think so.

**Toni:** Ok, why don’t you think so?

**Jordan:** Why do you think there is?

**Toni:** I’ve read reviews of evidence and it seems there’s different measurements about what is low, medium or high consumption during pregnancy …

**Jordan:** Oh well that’s a different thing that you’re talking about. You’re talking about alcohol. Does alcohol have an influence on the development of the foetus? Unquestionably, and with … uh very strong proof, yes. The next question is what degree and what it does. That’s, that’s a question that differs, so it relates to a dose effect.

**Toni:** OK. So given that there is a dose effect do you still advise total abstinence?

**Jordan:** Yes, yes.

**Toni:** Why?

**Jordan:** Well I think it’s because we’ve identified that there is a dose effect and we don’t know what is a safe dose. And it’s easy to go without! It’s also cheaper [laughs]. And it’s temporary.

It is clear that Jordan relies upon a risk discourse to support his advice of total abstinence despite there being insufficient (and conflicting) evidence to support this because it is unclear at what level alcohol consumption becomes potentially harmful. At the same time, Jordan’s comments suggest that because of the continuing uncertainty surrounding medical evidence relating to the effects of alcohol use during pregnancy, the ‘facts’ themselves are susceptible to being framed and reframed (Dumit, 2006:578). Facts, in other words, become deployed in
different ways and are influenced to some extent by personal interpretation and preference, yet in the professional context of medicine they are relied upon as objective, credible statements of knowledge. This reflects the power of medical discourses to posit authority in its claims (Foucault, 1976), and I expand on this idea later in the thesis when I focus on exploring the implications of a denial of uncertainty within medical and public health discourses (refer to Chapter 7).

Another reason that medical discourses do not convey uncertainty about the causes of congenital health problems is that there is a consistent and dominant focus on some factors related to causation and a relative omission of other, potentially relevant, factors. I now explain this further as I return to a broader discussion about how the causes of congenital health problems are understood.

Decontextualisation from the social and the environmental
During my analysis of the research data it became clear that, in general, most explanations of cause related to factors that are associated with the behaviours and biology of individuals rather than with broader social or environmental influences. This pattern is highlighted in Figure 4.2 where I have included data from my content analysis of the 15 medical journal articles (refer to Appendix 3 for further details about the articles).

**Figure 4.2**

Factors identified as causing congenital health problems in the medical journal articles

<table>
<thead>
<tr>
<th>Cause</th>
<th>Number of articles (Total=15)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual behaviour</td>
<td>13</td>
</tr>
<tr>
<td>Genetic inheritance</td>
<td>4</td>
</tr>
<tr>
<td>Biological processes</td>
<td>3</td>
</tr>
<tr>
<td>Maternal infection or medical condition</td>
<td>1</td>
</tr>
<tr>
<td>Physical environment</td>
<td>1</td>
</tr>
<tr>
<td>Social circumstances</td>
<td>1</td>
</tr>
<tr>
<td>Shared behaviours</td>
<td>0</td>
</tr>
</tbody>
</table>

As shown in Figure 4.2 most of the attention in the journal articles was focused on explaining how the behaviours and biology of individuals may lead to them having a child with a congenital health problem. Some of the behaviours that were linked to congenital health
problems include women’s consumption of alcohol during pregnancy (Diekman et al., 2000; Green & Stoler, 2007; Henderson, Gray & Brocklehurst, 2007), women delaying pregnancy until they are aged 40 or more (Carvalho, 2005), women consuming an inadequate amount of vitamins and minerals before or during pregnancy or ‘failing’ to maintain a ‘healthy’ body weight before pregnancy (Michals-Matalon et al., 2002) and the ‘failure’ of pregnant women to control their blood sugar levels (Schaefer-Graf et al., 2001). There were very few references made to social factors that may contribute to these behaviours, however, or to the potential influence of social factors, such as economic circumstances, in influencing individuals’ decisions about when to have a child. As part of this, there was little consideration of the potential influence of factors that are located outside of the bodies of individuals or that are understood as existing outside of their control, such as social inequalities or environmental factors. Furthermore there was no consideration made of the behaviours that are shared between men and women in heterosexual relationships as having a potential influence on their reproductive outcomes. These findings are consistent with themes that emerged from the other components of the research which reflect a relatively restrictive and contained focus on particular factors which may cause congenital health problems rather than a focus on the broader social, environmental and relational contexts in which reproduction occurs.

The centrality of women and the absence of men

The discussions about the causes of congenital health problems that appeared in the medical journal articles are particularly gendered. The gendering of these medical discourses is highlighted in Figure 4.3 which identifies the number of articles in which women, men, couples and families were mentioned in the context of discussions about congenital health problems.

Figure 4.3

Number of articles in which women, men, couples and families are mentioned (Total=15)

<table>
<thead>
<tr>
<th>Category</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Women only</td>
<td>6</td>
</tr>
<tr>
<td>Men only</td>
<td>0</td>
</tr>
<tr>
<td>Women and men</td>
<td>4</td>
</tr>
<tr>
<td>Couples only</td>
<td>1</td>
</tr>
<tr>
<td>Women and couples</td>
<td>3</td>
</tr>
<tr>
<td>Families only</td>
<td>0</td>
</tr>
<tr>
<td>Women and families</td>
<td>1</td>
</tr>
</tbody>
</table>
As shown in Figure 4.3 women were consistently linked to discussions about congenital health problems, and in some cases, were the only people mentioned apart from the affected children. In contrast, men were largely absent from the medical discourses. When men were mentioned this occurred consistently in conjunction with discussion about their female partners and the broader family group. Similarly, the gendering of the medical discourses was also apparent in my earlier analysis of Figure 4.2 because discussions about the links between individual behaviours and congenital health problems related only to the behaviours of women. Considering the gendered hierarchy that is reflected in the way that the causes are understood within the medical journal articles (as shown in Figures 4.2 and 4.3) is important because there is no category available for the cause to be linked to men instead of women, apart from perhaps in terms of their genetic contribution. The possibility of such paternal genetic linkages were rarely canvassed in the medical texts, however, and in the few cases in which they were, responsibility for overcoming the influence of genetics was placed upon women (I explore this in Chapter 6). Furthermore, the potential for shared behaviours between men and women to influence reproductive health is not considered within the medical discourses. This is even despite the possibility that these behaviours and the dynamics that exist within heterosexual intimate relationships, such as those relating to the distribution of finances, shared dietary practices, shared living arrangements and domestic violence, may be important factors in influencing both the behaviours of women during pregnancy and the social environments to which pregnant and pre-pregnant women are exposed. Instead, the current hierarchy of causation mainly reflects a focus on the individual woman as if she exists and reproduces independently of broader social, environmental and relational contexts.

The absence of men constructs reproduction almost as if it results from ‘virgin births’ in which women alone are responsible for producing children and, therefore, also solely responsible for children’s health. I return to focus on the implications of the generalised exclusion of men from the reproductive context throughout Chapter 6.

Overall, my analysis of medical discourses suggests that even where medical knowledge about the causes of congenital health problems is inconclusive (or contested) there is a tendency for medical researchers to focus consistently on particular factors—namely those related to the individual and the behavioural—and to direct far less attention to factors that have not yet been thoroughly explored. The generalised omission of consideration about social and relational factors creates the impression that individual women wield considerable

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32 The term *virgin birth* refers to the Christian belief that Jesus was conceived through the action of the Holy Spirit or a miracle rather than via sexual intercourse with a man (Delaney, 1986; Geurts, 2006; Myers, 2009:18).
influence and power over their reproductive outcomes. This representation occurs concurrently with representations of women as biological organisms, devoid of social contexts and for whom behaviours before and during pregnancy are a matter of free choice.

This trend in current medical discourses is potentially detrimental for two reasons. First it decontextualises understandings about the causes of congenital health problems by ignoring the potential influence of the social, the relational and the environmental. In doing so, this trend renders women responsible for particular reproductive outcomes because of the way that they behave. Second, the decontextualisation of medical understandings about the causes of congenital health problems may mean that knowledge about causation and effective prevention will continue to focus on women and not broader, possibly contributory influences. The current limited and decontextualised foci in medical understandings about causation became particularly apparent during an interview with Robert, who is an obstetrician. Robert made the following comments in response to me asking about what he believed were the main causes of congenital health problems:

Robert: If we’re talking about specific causes then um ... chromosomal variations would be by far the most common and they’re increasingly being identified. Uh in terms of environmental toxins the only one I believe has any significance ... is alcohol. But that’s the only one. There are other chemical toxins in the environment but none of them are ... very few of them are specifically proven ...

Toni: So do you get many questions about the potential influence of things in the physical environment causing congenital health problems, like pollution for example?

Robert: It might be in the back of people’s minds and it’s usually dealt with and dismissed. It’s a far bigger um ... media ... common press, popular press issue than it is in reality, far bigger.

Toni: Ok so do many couples ask you about it?

Robert: No.

Toni: You said it’s easy to dismiss, how would you dismiss it?

Robert: No evidence.

Toni: No evidence in the research?

Robert: Mmm, no evidence for it.

This highlights that the absence of evidence is used as a rationale for neglecting consideration of factors which may, potentially, contribute to the cause of congenital health problems. Yet our current commitment to focusing on particular factors—namely those related to the individual and the biological—in our search for understanding about causation limits the potential for alternative understandings and alternative forms of evidence to be explored.
Reproductive health as ‘risk’
Within all sources of data that I analysed it also became clear that discourses of risk provide a strong foundation for current understandings about congenital health problems. This is particularly apparent because the medical and public health discourses that relate to congenital health problems are dominated by the identification and discussion of potential threats to foetal development. Within these discussions particular substances, processes and bodies become constructed as ‘risky’ and, as such, are labelled as potential threats to healthy foetal development. The concern about risks shapes understandings of prevention and, in turn, frames the advice that is directed at controlling and managing potential threats. Such pervasive discourses of risk are not only contained in these research data; but they extend more broadly to shape general understandings about the factors that influence health within contemporary society (Bunton & Petersen, 2005:5; Gabe, Bury & Elston, 2006:87). As such, understandings of risks provide a central basis for modern conceptualisations of health, and these understandings extend throughout personal and expert discourses, which, in turn, become expressions of power and status (Gabe, Bury & Elston, 2006:87; Possamai-Inesedy, 2006).

In applying a risk society perspective to an analysis of the research data I now explain how women’s bodies may be constructed as sites from which risks to the imagined future of child health emerge. Following this I return to a discussion of the socio-cultural perspective on risk by exploring and applying Foucault's (1991a, 1991b) concept of governmentality.

Constructions of ‘risky’, ‘terror-togenic’ bodies
In considering the applicability of Beck’s (1992, 2000) notion of a risk society to dominant ideas of the causes of congenital health problems it is evident that an anxiety about future harm (to children) shapes much of the impetus to monitor, regulate and change factors that are believed to pose a threat. The anxieties inherent in a risk society extend throughout medical discourses to support particular understandings about the cause and prevention of congenital health problems. This is evident because the language that is used in the medical texts operates to convey anxieties about perceived threats to the future health of children and also to encourage the implementation of strategies to prevent an imagined future of child harm. Importantly though, understandings of risk are not presented in a neutral way within the medical texts. Instead it is particular bodies and behaviours that are identified as posing the greatest threats to the future health of children. More specifically, the designation of risk is located within the bodies and behaviours of women. To explain this further I now explore
the potential meanings and discursive implications of ideas about *teratogens* within the medical literature.

The words *teratogen* and *teratogenic* are frequently used throughout the medical literature in discussions about the causes and prevention of congenital health problems. A teratogen is any agent (such as a drug, chemical or disease) that can disrupt the development of a foetus and, therefore, cause a congenital health problem (Moore & Persaud, 2003:127). The root of the word, *terato* is Greek for *monster*, which when taken literally, means that a teratogen is a ‘creator of monster’ (Jauchau, 1997:30). The use of a word meaning ‘monster’ to describe the causation process highlights the emotive and generally negative context of medical discussion surrounding congenital health problems. Implicitly, and more broadly, the use of such terminology also highlights the emotive context in which women experience their pregnancies (Forbes, 2008:87) and in which the outcomes of a pregnancy are interpreted, both medically and socially. Furthermore, the association between pregnancy and the potential creation of a ‘monster’ or ‘monstrous effects’ could be interpreted as a producer of fear, adding further impetus for adherence to public health and medical advice in order to avoid ‘terror’—or more scientifically, teratogenesis.

Deeper exploration of the ways that teratogens disrupt foetal development indicates that they must be consumed by a pregnant woman or that she needs to be physically exposed to them before they can take effect. For example, if a woman consumes certain medications, such as Valproic Acid to stop epileptic seizures, these drugs may produce a teratogenic effect by disrupting foetal development (Jauchau, 1997:29; Moore & Persaud, 2003:133). Similarly, if a woman is exposed to environmental pollutants, such as mercury, these may enter the woman’s body by her consumption of fish for example, and disrupt foetal growth (Moore & Persaud, 2003). Furthermore, if particular diseases, such as Herpes or the Human Immunodeficiency Virus, are present in a woman’s body these may impede the development of foetal organs (Moore & Persaud, 2003:128).

On the basis of such medical understandings it is widely accepted that women’s bodies have an important role in the exposure of a foetus to teratogens. This understanding has important discursive implications. In particular, it constructs women’s bodies in an inherently contradictory way—as both the source of nurture and development of a foetus but also as posing potential risks to, and being a barrier to, healthy foetal development. This also means

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33. According to the work of Marilyn Francus (1994), in the West, female reproductive bodies have often been associated with images of monstrosity. This association has a long history and is linked to Christian theology and perpetuated through literary and filmic representations of the powerful, uncontrollable and, therefore, potentially dangerous and threatening nature of femininity and female sexuality (Creed, 1993; Francus, 1994).
that women’s bodies themselves, rather than just the teratogenic substances, become constructed as sites from which ‘monstrous’ effects, such as congenital health problems, may emerge (Ussher, 2006). So rather than the bodies of women being understood foremost as sites of nourishment which make foetal growth possible, women’s bodies are located within discourses of risk, through which they are seen to pose dangers to the imagined future of child health (Maher, 2002). This also represents the demonisation of female reproduction as danger or threat.

It is not only the bodies of women that are associated with danger within the medical texts; women’s behaviours are also directly implicated. Throughout the majority of the sources of medical literature it is stated that particular behaviours, including the use of illicit drugs (Kliegman et al., 2007), taking particular medications (Kozer et al., 2002; Schaefer-Graf et al., 2001) and having unprotected sex (Roberton & South, 2006) can increase a woman’s exposure to teratogens and, therefore, increase her potential to produce a child with congenital health problems. The contribution of behaviour to the ‘riskiness’ of women’s bodies is conveyed through the following quote, which was included in the Australian orientated textbook Practical Paediatrics:

Epileptic women must accept some additional risk of birth defects in their infants, but the risk can be minimized if epileptic control can be achieved with a single drug at the lowest possible dose … Periconceptional folic acid supplementation at a dose of 5 mg daily should be recommended for women on anticonvulsant medication because of the increased risk of neural tube defects in their offspring. (Roberton & South, 2006:286)

This quote suggests that risks are an inherent part of the female body and that additional risks are located within particular bodies. However, it is the behaviours of women that are identified as an appropriate focus of intervention within this discourse. Therefore, because women’s bodies are labelled as inherently ‘risky’ women are encouraged to behave in ways that will minimise the risks that their bodies pose. Such minimisation requires women to act reflexively in order to, first, acknowledge the risky potential of their bodies and, second, to manage that risk. In the previous quote such management is presented as being possible through behaviours such as consuming folic acid before and throughout pregnancy and also by managing and minimising medication.

The construction of women as ‘risky’ combines with the idea that they are responsible for managing risk to suggest that women have control over the level of risk that a foetus is exposed to. This construction has clear implications for how the causes of congenital health problems are understood and for who is made responsible following the development of such problems. In particular, in the context of individualism, it renders congenital health problems
as due to a failure by individual women to be reflexive and disciplined enough to offset the risks faced by their foetus. In addition, the simple attribution of responsibility for risk management to individual women obscures the complex intersections of the social, relational, environmental and biological pathways that influence reproductive wellbeing. This is particularly evident since much of the discussion about the causes of congenital health problems is located within a definitive, simplistic discourse of cause and effect, which provides little space for acknowledgment of the multiple, broad factors that have a potential influence on reproductive health. These ideas also excuse some groups from responsibility, which I explore further in Chapter 6. In the case of the discourses that I am analysing it is also clear that such ideas construct hierarchies of ‘low risk’ and ‘high risk’ and, from this, lead to the labelling of women as ‘good’ and ‘bad’ reproducers based on their behaviours and bodily status (Forbes, 2008:87). However, again, these are both things that women have varying degrees of control over depending on their social positioning, occupation and general health circumstances (I also explore these ideas further later in the thesis). I now return to a discussion about another socio-cultural perspective on risk, which is articulated through the concept of governmentality.

**Governmentality**

Whereas risk society theorists apply a weak social constructionist approach to argue that risks exist objectively but that the meaning of these are constructed, governmentality theorists apply a strong social constructionist perspective. In doing so, these theorists propose that there is *no* such thing as an objective risk (Gabe, Bury & Elston, 2006:90; Lupton, 1999:25). Instead within a governmentality approach risks are understood as social products that are constructed through the operation of discourses and institutions which work to produce understandings about the existence of threats on a population basis (Ewald, 1991:202-203). While Foucault did not focus on the topic of risk in great depth, the understandings that he applies as part of his theory on governmentality provide useful tools for understanding the constructed basis and social implications of risk. In particular, Foucauldian (1991a, 1991b) theory on governmentality encourages an understanding of risk construction as a practice of social surveillance, discipline and control, which influences individuals, and which operates to define norms of social behaviour.

According to this perspective, risk may be understood as a strategy of regulatory power through which individuals, social groups and populations come to be (self) monitored and managed. Foucault (1988:18) explains that people attempt to “transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality”. In doing so, they seek and adopt advice from a wide and diverse network of institutions and experts who
claim to be able to reduce risk (Lupton, 1999:87). The activities of medical researchers, statisticians, epidemiologists, sociologists and many more authorities in collecting evidence of and analysing ‘risk’ also contribute to its validation. The accumulation of such ‘evidence’ makes risk ‘real’ in the sense that it becomes calculable and governable. So too, through such efforts, particular individuals or social groups become identified as being ‘at risk’ or ‘high risk’ and, as such, become understood as requiring particular forms of surveillance and intervention.

Importantly in the context of the remaining sections of this Chapter, strategies of governmentality include two main forms. The first are direct, coercive strategies of social regulation and the second are less direct strategies that are contingent on individuals’ voluntary compliance with established social norms (such as attending antenatal care during pregnancy) (Lupton, 1999:87). These strategies of risk management are diverse, multifaceted and they emerge from various social institutions, such as the mass media and as, I argue next, also through the process of medicalisation. In this sense, expert opinion about impending risk contributes to a powerful web of social control that is taken on and perpetuated by individuals as they control the ways they behave and use their bodies (Bartky, 1988:62).

In applying the perspective of governmentality to an analysis of my research data I argue that one of the ways in which medical and public health discourses construct, reinforce and perpetuate maternal responsibility for child health outcomes is by constituting a complex web of mechanisms of regulatory power. This web is made possible by the medicalisation of reproduction. I now turn to an analysis of how medicalisation has contributed to heightened perceptions of reproductive risk.

My analysis revealed that medicalisation has a strong influence in shaping knowledge about the ‘appropriate’ roles of women in relation to reproduction. In the medical literature, health education resources and during the interviews, discussions about reproduction and reproductive risk were located within an abundance of expert medical and public health advice. Through this advice women were instructed about how they should behave in order to protect the health of their future child. Much of this advice was centred on the regulation of women’s bodies, such as what they should consume and ‘allow themselves’ to be exposed to. Women were also consistently instructed to engage with expert medical and public health advice in order to learn about their reproductive capacities and about how they could optimise their reproductive health (Longhurst, 1999). Through the provision of advice, and the surveillance that this entailed, women were constructed as vessels for a foetus and it
appears that it was the wellbeing of the foetus that was the primary concern of the advice givers (Longhurst, 1999:78). In addition, in support of the findings of Rosalind Petchesky (1987) the research data highlighted that women are encouraged to take up various forms of medical surveillance, such as scans, measurements and blood tests because such surveillance is posited as integral to obtaining healthy outcomes for children. In fact it was clear that women who did not willingly engage with all the recommended forms of medical surveillance were likely to be made responsible by health care professionals for their child’s health problems. An example of this is demonstrated by comments made by Laura, one of the mothers who has a son with congenital heart disease:

I could hear the doctors talking about Billy [Laura’s infant son], they’re going “Oh its failure to thrive, he’s fully breastfed it could be something to do with that.” And I knew that it wasn’t my breastfeeding. When they said that I just felt really insulted, like they were saying it was my fault. And because he wasn’t growing they wanted to weigh him after every feed to make sure he was getting enough fluid, but I was like “No! After he feeds he needs to sleep, that is what will help him grow.” But they weren’t happy with this and they wanted to keep weighing him. When I wouldn’t let them they told me I had a few more days to keep trying to breastfeed before they said we would seriously have to consider putting him on formula. But I knew it wasn’t my breastfeeding. (Laura, 30 years old, 5 month old son with congenital heart disease)

During the interviews it also became apparent that the medicalisation process had a strong influence on shaping medical professionals’ understandings about the cause of congenital health problems. This was reflected in their expression of understandings about the individualised nature of understandings about causation. It was also reflected in the general assumption that if women ignored medical and public health advice then they were putting the health of their foetus at risk and could therefore be held responsible if the pregnancy should miscarry or if the child was born with a congenital health problem. This idea was conveyed clearly by a neonatologist, Peter, when he said:

It’s generally the mother that talks about feeling responsible not the father. I guess it’s because the woman’s borned [sic] the baby, she’s carried it, so her health is directly linked. And so if something’s happened with her or she hasn’t had scans or something so we haven’t found [the congenital health problem antenatally], then she will feel guilty, and you know, that’s just the nature of it.

These findings, particularly in the context of theory about governmentality, highlight the role of medicalisation in constituting a web of surveillance and regulatory power which influence the way that women’s reproductive bodies are represented and also the way that women experience their bodies. The location of public health and medical discourses within a context that is shaped by medicalised understandings may lead to these discourses also forming part of a coercive web of social regulation. From this position, it is likely that such
discourses will operate to regulate maternal bodies in ways that are consistent with norms of
social behaviour, and through this, also designate particular responsibilities to women on the
basis of their reproductive capacities. Medicalisation enables the first form of governmentality,
which Foucault (1991b) suggests is based on coercive strategies of social regulation. The
second form of regulatory power, which is based on individuals’ voluntary compliance with
established social norms (Foucault, 1988) furthers the potential for congenital health
problems to be deemed a maternal responsibility.

The importance of self-surveillance, self-regulation and control
Given societal preoccupation with risk, pregnant women are now expected to undertake all
activities within their power to avoid ‘known risks’ to ensure that their child is born healthy.
Medical and public health discourses reinforce the idea that it is possible to avoid all
behaviours that are defined as ‘risky’. This belief results in women’s bodies being placed
under constant surveillance, particularly by women themselves (Forbes, 2008:87). For
Foucault (1988), such self-surveillance can be understood as constituting technologies of the self.
Through technologies of the self, people aim to transform themselves to achieve a
positive state, such as general wellbeing, happiness and perfection. In doing so, they seek
out and adopt advice from institutional governmental agencies, from experts who have
problematised areas of life as being dominated by risk (Lupton, 1999:87). Although women
were encouraged to engage with technologies of the self even before medicalisation, with the
medicalisation of reproduction, discourses and expectations around the need for women to
engage with technologies of the self have proliferated (Apple, 2006).

My analysis of the research data suggests that pregnant women and those seeking to
become pregnant are very willing to engage with forms of regulatory power which encourage
them to attend to their bodies in particular ways in order to promote their reproductive health.
My analysis of the health education resources and medical literature in particular suggests
that women must engage in considerable ‘work’ on themselves in order to fulfil medical
expectation. This includes attaining and maintaining a ‘healthy’ weight, not smoking, eating a
‘balanced’ diet, abstaining from alcohol, not consuming too much sugar or fat and avoiding a
range of other things such as pre-prepared foods and soft cheeses which have been
identified as potential sources of bacteria. Yet despite the high level of attentiveness that is
required and the associated pressures that this places on women, all of the mothers who I
interviewed had embraced this advice willingly, because they wanted to maximise the health
of their future child both before and after they became pregnant. This willingness and attentiveness was expressed by Jo:

I started taking folate probably a year before I was pregnant. They recommended, when I was trying to fall pregnant, that you take it up to 3 months before falling pregnant, but it ended up being a year for both my pregnancies. And then I took it during the pregnancy. I also didn’t drink any alcohol, I didn’t smoke any cigarettes, I took no drugs, I didn’t eat any pre-processed anything, any pre-made salads, I was so careful with following all of the advice, and I followed all of that to a ‘tee’. I wanted to give both my babies the best possible chance of being healthy. (Jo, 35 years old, 5 year old daughter with congenital heart disease)

It is likely that such a willingness to engage with regulatory strategies is connected to women’s positioning as the people who are most able to influence reproductive health. On the basis of this presumed influence, the women whom I interviewed voluntarily engaged in multiple risk-avoidance strategies and in doing so implicitly accepted that they were ultimately responsible.

The current medical and public health discourse also represents reproduction as something that women need to commit to not just during pregnancy but right up until menopause if healthy outcomes are to be assured. Numerous examples of the perceived need for women to prepare and maintain their bodies in particular ways throughout their lives were present in the health education resources. Clear examples of this were provided in the resource entitled What should I eat? Nutrition for pregnancy and breastfeeding, which is produced by the South Australian Government and distributed by several of the main public hospitals. The introductory paragraph of the booklet includes the following statement:

Good nutrition is important for your baby, even before conception. Aim to lead a healthy lifestyle before becoming pregnant. This includes being active and working towards a healthy weight. (Government of South Australia, 2007b:2)

This quote highlights the importance of women engaging in self-surveillance around what is the undefined concept of “good nutrition” throughout their reproductive life cycle if they wish to promote the health of their future children. Further reinforcing the need for such vigilance before pregnancy is the following quote which encourages self-surveillance around body weight in a way that conveys anxiety about the potential risks associated with women leaving it ‘too late’ to maintain an ‘appropriate’ body weight:

If you are overweight, pregnancy is not a safe time for trying to lose weight. It is best to tackle this either before the pregnancy or as a long term goal after your baby is born. (Government of South Australia, 2007b:9)
The need for women to continue engaging in self-surveillance *after* pregnancy in order to ensure child health is also conveyed. The following quote provides an example of this. The quote was included above an illustration of a woman sitting at a table with one child; both are holding pieces of broccoli. No other people are present in the illustration:

> Good nutrition is also important after pregnancy and breastfeeding to ensure good health for yourself and your family. Food preferences and eating habits developed early in childhood are often carried into adulthood. To make sure children grow up to be healthy adults we need to teach them healthy eating habits as early as possible. It is also important to be a good role model, show your children how much you enjoy eating healthy foods and they will want to follow. (Government of South Australia, 2007b:20)

An analysis of these discourses in conjunction with consideration of the broader findings of the research reveals important tensions. In one sense reproduction and mothering are defined as the *natural* roles of a woman, however, in another sense the discourses infer that reproduction and the maintenance of an appropriate mothering capacity are things that women have to constantly 'work at'. This suggests, in a powerful contradiction, that while the belief remains pervasive that reproduction is an innate function of women, a concurrent message also defines *healthy* reproduction as not something that women can automatically expect. Instead it has to be 'achieved' through appropriate maternal behaviour, through exercising self-surveillance across the life cycle and also through adhering to explicit and detailed antenatal medical advice in order to limit risk. This idea is expressed eloquently by Adrienne Rich:

> Throughout patriarchal mythology … two ideas flow side by side: one, that the female body is impure, corrupt, the site of discharges, bleedings, dangerous to masculinity, a source of moral and physical contamination, "the devil’s gateway." On the other hand, as mother the woman is beneficent, sacred, pure, asexual, nourishing; and the physical potential for motherhood—that same body with its bleedings and mysteries—is her single destiny and justification in life. (Rich, 1976:34)

Therefore, women’s compliance with, and submission to, forms of regulatory control are presented as necessary precursors to achieving reproductive ideals in contemporary society. However, as the findings that I present throughout this thesis show, sometimes self-regulation and individual’s efforts to adhere to medically defined technologies of the self do not allow them to achieve desired outcomes. Consideration of what happens when technologies of the self fail has not been provided in the relevant literature, however. Therefore through my research I address this gap in knowledge. I do so by exploring how responsibility for child health becomes interpreted by women and medical experts in contexts where women believe they have done all they can to ensure their child’s health and where
medical professionals offer advice based on the neo-liberal ideal of individual responsibility for ensuring desirable health outcomes.

The abundance of advice and the impossibility of ‘getting it right’

Adding further complexity to the technologies of self that are associated with pregnancy is the vast amount of advice that is targeted at women before, during and after pregnancy (refer to the Preface of Part 3). Not only does the sheer amount of advice increase the pressures on women but it also makes it difficult for women to adhere to all the advice in a way that would be regarded by medical professionals as achieving total compliance. The difficulty associated with this is compounded by women’s social experiences where they report being inundated with advice, not only from health professionals, but also from members of their social networks and, in some cases, from the media. The vast amount of advice that women are exposed to as well as the practical difficulties that may prevent them from applying such advice were highlighted by Sinta who made the following comments in response to me asking whether she received any advice about things she should do before or during pregnancy:

Sinta: Ooo … heaps and heaps! [laughs] Well … obviously I got told to start taking your folic acid you know a couple of weeks before you know you start trying [to become pregnant], which I did. I think you shouldn’t, you’re not supposed to eat like deli stuff, that would make you very sick or could cause problems with the foetus. Alcohol, not that I drink alcohol, but alcohol, smoking, that kind of thing. What else? Exercise. I tried my best, not that I got much exercise, but a little bit of walking here and there. Um … some stretching that kind of thing. But with work, and with already having to care for my first child, I just didn’t get much time. That was enough exercise for me already! [laughs] I had no time to actually sit down! Um … what else? … Yeah um in terms of medication, do not have medication unless it’s prescribed by a doctor and make sure it’s safe to have. I didn’t need any medication at all. What else? …

Toni: Where did you get this advice from?

Sinta: Ooo everywhere! But because she is my second child I had been through it once so I have that Pregnancy and Child Birth book that I went through the first time and I browsed through again the second time. Um websites, baby centre.com. Um … yeah a few websites and speaking to people mmm … like everyone has something to tell about what you should do when you’re pregnant. (Sinta, 30 years old, 17 month old daughter with congenital heart disease)

Sinta’s comments suggest that in the context of busy and pressured lives, which, for the majority of the women I interviewed, involved paid work as well the additional domestic responsibility associated with having a child with a congenital health problem, women may struggle to adhere to the abundant advice that they receive. Sinta’s comments also highlight further the considerable burden of responsibility that is placed on women by such a vast
amount of advice about the need to prepare and maintain their bodies in particular ways. However, my analysis of the health education resources found that the advice that is provided rarely considers the social pressures that are faced by women in contemporary society. For example, several of the health education resources suggested that women eat only freshly prepared rather than pre-prepared meals during pregnancy and that they avoid high risk foods such as cold, deli style meats (Government of South Australia, 2006:12; 2007b:10; Johnson & Johnson, 2007:9). In effect, this means that it is safest for pregnant women to consume home prepared meals. Such advice not only has the effect of heightening anxieties by redefining certain food items as 'risky' but it also ignores the many factors faced by many women which may restrict the extent to which they are able to prepare nutritious meals at home, such as time constraints and possibly a lack of skills, resources or knowledge relating to the preparation of meals. Therefore, through their positioning within the context of such an abundance of advice, and the generation of this advice from many sources, pregnant women become constructed as 'public property' who can be legitimately inundated with advice about how to promote the health of their foetus, even though this advice may not be congruent with their circumstances.

Also, in an important contradiction, some of the current advice requires particular behaviours of women even before they know they are pregnant. Therefore, even when women believe they have tried their best to comply with the specified technologies of the self, there remains some lingering doubt on behalf of women themselves and those around them about whether in fact total compliance was achieved before pregnancy and whether some part of the advice that women did not or were not able to comply with provided the basis for the development of their child’s health problems. In this sense health promotion messages around pregnancy have dual effects for women. In one sense they operate to empower women by assisting them to make choices that increase the likelihood that they can achieve the desired outcome of their pregnancy, yet they also provide a mechanism of blame for women through establishing the potential for interpretations of their non-compliance.

As an extension of this, the health education resources appear to represent all women as having access to the resources that are deemed necessary to foster healthy reproduction. Such resources include fresh food and adequate financial resources. This idea is clearly demonstrated in the following quote from a health education resource for women about nutrition during pregnancy:

It has been shown that extra folate in the very early stages of pregnancy can reduce the chance of having a baby with a neural tube defect. Spina bifida is the most common neural tube defect. This defect occurs when the spinal cord and brain are forming. This can happen before you know you are
pregnant. Even if you eat well it is difficult to get enough folate. So although it is worthwhile increasing folate in your diet, it is also a good idea to ‘top up’ with a folate tablet. You can do this by taking a 0.5 milligram (mg) folate (folic acid) tablet, for at least ONE MONTH BEFORE pregnancy and the FIRST THREE MONTHS of pregnancy. Folate tablets are not expensive and are available from your local pharmacy without a prescription. (Government of South Australia, 2007b:2) [Emphasis in original]

This presumes that all women will be able to tolerate and absorb folic acid in pill form and be able to afford folic acid tablets since they are not “expensive”. It also infers that all women have the opportunity to plan their pregnancies and, in doing so, can prepare their body in ‘appropriate’ ways by taking folic acid to promote reproductive health. This ignores the economic and social pressures that exist for many women in Australia (Coveney, 2009). The assumptions that are reflected and perpetuated in this quote also ignore the effect of relations of power, such as gendered inequalities, in influencing the extent to which a woman may be able to plan for a pregnancy. Ironically, this information about the need for women to take folic acid before pregnancy and during the first three months of pregnancy was included as part of an information pack that is routinely provided to women at their first antenatal appointment. This appointment usually occurs once a woman is already approximately three months pregnant. However, the advice is framed in a way that places the exclusive burden of responsibility on women to know of and to follow this advice. This again demonstrates the way in which reproduction and reproductive health become decontextualised in the public health and medical literature and infers that women are able to act as autonomous beings free from social constraint or environmental influences.

In addition, the pressures on women and the difficulties associated with applying all of the suggested strategies are worsened because of the ambiguous, confusing and conflicting nature of some of the advice. In one of the health education resources the following complicated information is provided to educate women about how much and what types of fish they can eat while pregnant or preparing for pregnancy:

If you are pregnant or planning a pregnancy, you can eat up to:

2-3 serves of any fish or seafood not listed below
OR
1 serve of sea perch/orange roughy or catfish per week and no other fish consumed that week
OR
1 serve per fortnight of shark or swordfish/broadbill/marlin and no other fish consumed that fortnight. (Government of South Australia, 2007b:11) [Emphasis and formatting in original]

The guidelines around fish consumption for pregnant women are strict and complex. The reasoning is that some fish contain mercury which can have a detrimental effect on
pregnancy and foetal development. However, on page 3 of this same booklet pregnant women and women preparing for pregnancy are encouraged to adhere to *The Australian Guide to Healthy Eating*, the diagram of which is provided next as Figure 4.4.

**Figure 4.4**

*The Australian Guide to Healthy Eating*

NOTE:
This figure is included on page 124 of the print copy of the thesis held in the University of Adelaide Library.

Source: Government of South Australia (Government of South Australia, 2007b:3)

The Guide recommends that all Australians aged over four years of age consume moderate amounts of food from the 'Meat, fish, poultry, eggs, nuts and legumes' group, which consists of approximately **two servings of foods** from this group each **day** (Children's Health Development Foundation, 1998:12) [Emphasis added]. This highlights a point of conflict in the advice that is provided which may confuse women and therefore act as a further barrier to women's ability to negotiate and implement the vast amount of advice that they receive.

**Conclusion**

Throughout this Chapter I have provided an introduction to discourses about the cause and prevention of congenital health problems as they have emerged from the research data. In doing so I have begun to build two arguments. The first of these is that medical and public health discourses have a role in constructing, reinforcing and perpetuating women’s greater
responsibility for reproductive and child health in a way that extends beyond women's biological functions. The second is that medical and public health discourses construct, reinforce and perpetuate maternal responsibility for child health outcomes through constituting a complex web of externally imposed and internalised mechanisms of regulatory power. A central focus in this Chapter has also been on introducing the relationship between risk and governmentality. I will return to these two concepts as I explore the research findings, and their implications, further. Throughout the next four chapters I focus on explaining, in greater detail, the findings that relate to each of the four themes that shape the thesis (stated in the thesis Introduction). In the next Chapter I turn my attention to the first theme to examine the ways in which the ideology of individualism shapes maternal responsibility for congenital health problems within the discourses of public health and medicine.
CHAPTER 5

Individual responsibility: The power of choice and the irrelevance of social structure

This Chapter extends the findings that I presented in Chapter 4 to explore more deeply some of the most pervasive discourses that emerged from the analysis. These discourses are based on understandings about the power of individuals, their behaviours and their choices in creating particular realities for themselves and their children. In this Chapter I argue that the ideology of individualism permeates medical and public health discourses about congenital health problems. Consistent with the broader focus of the thesis, I explain how the operation of these ideologies within public health and medical discourses construct and perpetuate maternal responsibility for congenital health problems within neo-liberal society. To begin, I explore how the individualisation thesis is reflected in the interview data, health education resources and the medical texts. I then focus specifically on the implications of constructions of ‘choice’.

Women as both inside and outside social context

The tension that underlies the individualisation thesis between the supposed freedoms of individuals to make choices freely and the persistence of potentially constraining structural inequalities was evident in the interview data. Several of the women acknowledged the potential role of social inequalities, particularly low socioeconomic status, in contributing to the cause of congenital health problems. However, some of these participants also constructed themselves and their own experience of having a child with a congenital health problem as being largely uninfluenced by social inequalities. This was demonstrated by Liz’s response to a question about whether she had sought support from other mothers who also have a child with spina bifida:

I just really haven’t come into contact with someone I could really sit down and discuss things with because um … each kid’s different, the situation’s different, we’re from a bit different socioeconomic backgrounds um … you know people are dispersed geographically so all of those sorts of things make it a bit difficult to find someone you could really sit down with and say well we’re in a similar situation … I’ve noticed the socioeconomic thing too, I mean a lot of times spina bifida happens to poorer people and that makes it … like we’re different from a lot of the other families so it is hard to relate. (Liz, 40 years old, 3 year old son with spina bifida)

Socioeconomic status is a measure that is derived from an assessment of income, occupation, educational attainment and wealth (Mukherjee, 1999). Therefore, socioeconomic status provides an indication of the relative advantage or disadvantage of an individual or of the social and economic characteristics of groups of individuals who live in a particular geographic area such as a suburb or region (Mukherjee, 1999).
Liz’s comments highlight that while she understands that there is a relationship between low socioeconomic status and spina bifida, she also understands herself, and her child’s health problems, as being outside such an influence. For Liz, class based inequalities impact on the experiences of other people and not on her own. Instead of being constrained by class, Liz constructs herself as an autonomous agent who can choose who she will relate with and choose who she can present herself as being like or unlike. Liz also infers that she is independent enough to relate with no other person given the perceived difference between her own biography and that of others. It may also be that Liz’s assumptions about low socioeconomic status causing spina bifida in children of women who she has nothing in common with reinforces her desire to maintain distance from these women and their biographies.

A perceived difference in class based biographies was also reflected in comments made by Mike, an obstetrician who also specialises in fertility treatments:

**Toni:** So if it’s male factor infertility do you ever see the same sort of guilty feelings?

**Mike:** In that the bloke blames himself? Yeah you see that. You see that but um … they’ll sometimes laugh it off by saying “I’m shooting blanks” as though “I’m no good.” But not once have I seen the female member of the couple then accost the bloke. Instead they say “Right well we’re together so we’ve gotta work this through.” I think also at Flinders [Medical Centre] and in the south of Adelaide, the demographic is a little bit better. I’m sure you’d get different answers, oh I don’t want to sound nasty, but if you went to the Lyell McEwin you would get a different opinion I’m sure. It’d be “Ok you’re shooting blanks, I’m out [of the relationship] and I’m gonna find a new bloke.” I have worked for one year at the Lyell McEwin so I know a little bit of what I’m talking about there; um … they’ve just got a different mentality.

While drawing upon class based differences Mike discounts the operation of social inequality in shaping the experiences and attitudes of individuals of low socioeconomic status. Instead he reduces his observations to the level of biological essentialism to argue that people living in low socioeconomic areas, universally, have a “different” or less noble and more self-interested mentality to those living in more affluent areas. This obscures the disempowering effects of class based structures and provides a mechanism through which individualised blame can be targeted at those who experience the effects of these structures, effects which can be exacerbated further by contact with health professionals who unreflexively perpetuate the values that uphold these structures.

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35 The Lyell McEwin is a publically funded hospital that is located in a low socioeconomic, disadvantaged area of Adelaide, South Australia. Flinders Medical Centre is located in a southern suburb of Adelaide, which is characterised by a relatively higher economic status.
During the interviews four of the women acknowledged and highlighted the effects that various aspects of social inequality had within their lives. Yet in doing so, these four women also invoked discourses of individualism to explain that they had the responsibility, and ability, to overcome the effects of inequality by expressing their personal agency in particular ways. This idea was reflected clearly in the experiences of Melanie.

It was evident that Melanie had spent considerable time and effort developing strategies to reduce the possibility that she would be treated poorly or differently by the medical profession. Melanie was concerned about such treatment because aspects of her personal biography appeared to render her as lacking or deficient. Melanie gave birth to her first child at the age of 19 and then gave birth to her daughter with spina bifida at the age of 22. At the time of the interview Melanie lived in a government provided house and was reliant on government welfare as well as low paid, low skill part-time work. While talking about her experiences Melanie recalled frequent occasions where she felt judged and discriminated against during her contact with health professionals because she was a “young mother” who “did not have a lot of education or money.” Despite her experiences of social inequality providing the basis for such judgement, Melanie believed that it was possible, and also her duty, to escape such judgement by masquerading herself and her children in particular ways while interacting with medical professionals:

I’m doing the best that I can like, you know; every time we go there we always dress nicely, like my son is always dressed nicely, so I never give them the impression that I am any different than any other mother in there but yes I do feel … different, yeah, considering what my file reads compared to any other healthy, normal pregnancy. And like he’s [her partner] as scruffy as all hell. He’s always rocking up in his work clothes, like you know, at least he’s got a job type thing. But yeah I just prefer it now when he doesn’t come because like you can’t go in there scruffy because they look down on you. (Melanie, 26 years old, 4 year old daughter with spina bifida)

Melanie’s comments further highlight the strong influence of principles of individualism in encouraging women to believe that they can overcome the effects of class by expressing their agency in particular ways. For Melanie this involved dressing ‘up’ and deciding who will and will not be present at her child’s medical appointments. However, Melanie’s comments add another layer of complexity by highlighting the influence of individualistic discourses in reinforcing maternal responsibility.

Melanie believed that her efforts to overcome the effects of her inequality were an important part of her role as a responsible mother. This is because she believed that her efforts had the potential to override the perceptions of failed maternal responsibility that she had experienced as being constructed by others on the basis of her age and socioeconomic
status. Furthermore, Melanie believed that her efforts to disguise her lower class status protected her daughter from being regarded by the medical professionals as a lower class patient, and, therefore, receiving a lower standard of care. However, Melanie's belief in her power to overcome the effects of class inequalities, and the strategies that she used to do this, necessitated the exclusion of her male partner. Therefore, in an effort to overcome the effects of class based inequalities through adhering to the principles of individualism, Melanie reinforced the operation of gender inequality in her parenting relationship by positioning herself as solely responsible for her child's health care. This highlights the influence of individualism in encouraging a belief in the freedom of the individual but, at the same time, operating to strengthen the constraining effects of inequality within women's lives.

Contributing further to the tensions that permeate experiences of maternal responsibility, Melanie's comments raise other questions about why it is that her partner does not recognise, in the same way that she does, the importance of appearance and demeanour in interacting with medical staff in an attempt to reduce negative judgements. Perhaps Melanie's concerns about “them” looking “down on you” reflect that she feels it is herself and her skills as a mother that are judged negatively, rather than her partner, if he appears “scruffy”. I explore the complexities that underlie these possibilities in Chapter 6 where I consider the gendered processes through which women become positioned as the most central figures in relation to their children's health.

More positively, the comments made by both Melanie and Liz also demonstrate that a belief in the power and ability of an individual to construct themself in any way that they choose may operate to provide women with a sense of empowerment (in addition to their feelings of frustration or alienation). This is particularly important for the group of women who I interviewed because several reported feeling that they had little or no power when engaging with medical professionals. A belief in their ability to define themselves in any way that they choose provides women with an opportunity to regain a sense of agency, particularly if they feel as though they are constantly being negatively defined by others, as was inferred by Melanie. It is necessary to exercise caution when celebrating benefits that may emerge from a belief in the power of individual agency though, because as I now explain, such beliefs can also provide a basis for individualised blame.

**It's all about ‘free choice’ but making the ‘right choice’**

Underlying beliefs about the power of individuals are understandings about the strong influence of free choice in the construction of personal identities and personal realities. Dominant understandings, based on neo-liberal ideologies, about the power of individuals to
choose and define their own realities have emerged strongly and frequently from my analysis of the health education resources and medical texts as well as from the interviews.

Within the medical literature and health education resources, individual women are consistently represented as having considerable power and influence over their reproductive health. This representation is achieved, in part, through a lack of acknowledgement about the strong influences that social and relational factors may have on reproduction and child health. I identified the absence of social and relational considerations in Chapter 4. I now return to consider how this decontextualisation relates to the concept of choice.

As I highlighted earlier, in the medical literature and health education materials there are many different messages about things women should and should not do to achieve healthy pregnancy outcomes. On the surface it appears as though these messages reflect some consideration about the potential for environmental and social factors to influence reproductive health. For example, the advice for pregnant women to avoid soft cheeses appears to provide implicit recognition about the potential for some foods, which are part of the external environment, to have a detrimental effect on pregnancy. Similarly, the advice for pregnant women to avoid alcohol and smoking appears to implicitly recognise the potential impact of women’s social behaviours on the outcomes of their pregnancy. However, I argue that only token consideration of relational, social and environmental influences on reproductive outcomes is evident within the discourses which permeate these texts.

Rather than extending consideration to the broad range of factors that may contribute to congenital health problems, current thinking within mainstream medical and public health discourses is limited to a preoccupation with the individual female body, and in particular to what women consume. Little attention is given to macro- or micro-social and economic factors that may influence reproductive health. The generalised omission of social, environmental and relational factors, and the corresponding dominance of individualistic understandings about the power of people to construct their own biographies, leads to understandings of reproductive health as something that can be freely chosen, or avoided, by individuals. Furthermore, the availability of an abundance of advice within the fields of public health and medicine renders the achievement of healthy reproduction to be something that is available to all who make the ‘correct’ choices. Importantly, these ‘choices’ are constructed as being free or unmediated by social context or power relations. Within this context the potential for individualised blame for ‘less than desirable’ reproductive outcomes is considerable (Lippman, 1999). This is especially so since health promotion messages are presented in a way that infers that all recommended behaviours are equally achievable by
women. For example, the framing of these messages equates the avoidance of soft cheese with the elimination of smoking. This framing obscures the social conditions and biological addiction that may constrain women’s attempts to follow some recommendations over others. The construction of reproductive health as equally achievable, choice based and individually controlled also renders any failures to be necessarily a matter of individualised failure to adhere to the rules governing responsible motherhood and responsible citizenship for women.

These kinds of understandings were expressed frequently by the interview participants. For many of the women, claims of total equality and complete free choice provided a basis for understanding their reproductive experiences. For example, when I asked Kelly if she believed that, in general, women were given more responsibility than men to decide about their child’s medical treatments she said:

I don’t know whether I was given that responsibility, I think I took it. I guess because my daughter was a girl and I had grown up a girl and my experience was as a girl, I took that responsibility. Um … whereas my son … when we were making the decision about circumcising or not, I left that to my husband. It was his choice, what he wanted … I guess that’s how I would describe it. No I wasn’t forced to make any decisions that I wasn’t comfortable with, we’re pretty equal like that, we just decide together how we want it to be. (Kelly, 34 years old, 6 year old daughter with congenital naevus)

This quote and other parts of Kelly’s narrative highlight the persistence of gender as a dynamic within her relationship. In particular, gender appears to have had a strong influence on her experiences of mothering her children and in the division of care for her child with a health problem. However, she invokes an egalitarian discourse to explain the decision for a gendered division of care. She also adheres strongly to beliefs about the power of the individual to define their own realities and in doing so, implicitly, to choose, to some extent, the health outcomes of their child. In understanding this it is useful to reflect on the ideas of Canadian social theorist Jennifer Nedelsky (1999) who suggests that problems related to mothering are understood as intensely personal yet in a contrast which often remains unquestioned they also appear to be structured in ways that are “beyond our immediate control” (Nedelsky, 1999:304).

The attitudes and opinions expressed by several of the medical professionals also reinforce understandings about the power of individuals to control reproductive outcomes, and the power of individuals to construct their experiences in any way they choose. The expression of such beliefs has the effect of reinforcing and reproducing individual responsibility for child
health outcomes and, importantly, this responsibility is also gendered. This was clearly highlighted by the comments of Mike, an obstetrician, when he said:

Women do feel responsible [for their child's health problems]; they do feel guilt, um ... because they are responsible. I mean they created this child. But uh ... whether it's perfect or imperfect, if you want to consider a handicap as imperfect, a lot of people wouldn't. Um ... and so some might have a pathological feeling [of guilt] to that matter which then would need to be handled. But uh ... but I think that extends to other things in life too. If you have a car accident you wish you were driving 5 kilometres per hour slower, or weren’t driving at all or you walked, that’s life … people make choices and sometimes you have to live by the outcome.

While Mike’s comments provide quite an explicit attribution of responsibility, I found that it was more common for the reinforcement of individual responsibility for child health outcomes, and the explanation of this as choice based, to be expressed implicitly though medical practice. For example Robert, an obstetrician, explained that:

Parents usually ask why did [the health problem] happen? Can you tell me what the basis of it is? Sometimes we can, sometimes we can’t and ... uh they’ll ask did we do anything? Oh actually they don’t usually ask that directly but we [the medical team] would always ask about possible things they were exposed to in the pregnancy, you know alcohol, cigarettes, medicines, illnesses all those sort of things that might, in their mind, but usually don’t, cause the problems in the child. And the aim of that is to cover all their thoughts about those things so that you can dismiss them as best you can so they don’t feel guilty about it.

The logic Robert applies when making this comment is central to my thesis. Robert’s comment is driven by assumptions that parents, and implicitly mothers, will automatically assume that their child’s health problems arose from their behaviours. In an effort to counter these beliefs and, therefore, avoid parents blaming themselves, Robert introduces the topic of personal responsibility early in his explanation to parents about the origin of the health problem. This introduces parental responsibility in order to dismiss it. Rather than having the desired effect of dismissing blame, however, it is likely that this could operate to reinforce the culturally imposed, individualistic association between the behaviours ‘chosen’ by parents, or especially mothers, and child health problems.

The discourse of parental responsibility that underlies Robert’s comment is particularly important because comments such as these are usually expressed in the absence of a concrete explanation about cause. Consequently, the main, or only, factors considered are those that relate to the behaviours and environmental exposures of women during pregnancy. The strong use of choice based and individualistic explanations of reproductive outcomes establishes a basis from which individual women may be blamed for their behaviours and, in doing so, this deflects responsibility from external factors and social structures. Consistent
with this is the work of Jane Edwards (1994:2) who suggests that in the absence of a conceptual framework that extends beyond the individual, guilt becomes deflected from an externalised to an internalised moral discourse. This results in congenital health problems becoming experienced as a private trouble that can then be explained in terms of personal failure (Edwards, 1994:2).

‘Choice’ becomes NO choice
Reflecting back on the individualisation thesis, Beck and Beck-Gernsheim (2002) propose that a belief in a freedom to choose dominates contemporary societies. However, the findings of my research suggest that public health and medical discourses operate to restrict women’s choices through an inferred need to select particular ‘right’ choices. Such right choices include things like breastfeeding and consuming folic acid tablets before and during pregnancy to optimise child health and reduce the risk of some congenital health problems. While women are not forced to breastfeed or take folic acid, and many participants emphasised that doing these things was their free choice, the moral value systems that exist within the fields of medicine and public health operate to impose sanctions on those who fail to make these ‘right’ choices. Such sanctions result in the labelling of women who ‘choose’ to deviate from (or who are interpreted as having deviated from) the ‘right’ choice as ‘bad’ mothers, implicit in which is an attribution of failed maternal responsibility. This means that in the context of reproductive health a supposed freedom to choose becomes entangled with pressures to make particular ‘right’ choices (Valentine, 2010:955), which, in effect, offers no real choice at all.

Given the contradictory operations of choice, the women’s strong and enduring commitment to this discourse could be said to reflect what Georg Lukacs (1967, 1971) calls a false consciousness. A false consciousness develops when individuals unwittingly adopt ways of thinking and understanding that perpetuate their own oppression. In this case such oppression involves, and is perpetuated through, self-blame. The women’s acceptance of the presumed power of individual choice in shaping their reproductive health and the outcomes of their pregnancy renders them blameworthy. It also operates to maintain the systems of power through which the range of options available to them to ‘choose’ is restricted to those approved by medicine and public health. In conjunction, women’s strong commitment to ideals of free choice perpetuates the individualised focus that is reflected in medical and public health discourses which further discourages consideration of the social, relational and environmental influences on child health outcomes.

36 This concept is derived from Marxist theory.
From the analysis that I have presented so far it is clear that ‘free’ choice is a deeply political discourse. It is imbued with strong power relations which operate to attribute reproductive responsibility, to denote failed responsibility and to deflect responsibility from existing social structures, institutions and knowledge positions. The power of a supposed freedom of individuals to define their personal realities is strengthened by the unwitting commitment of individuals to the ideas that surround the notion of choice. In addition, my analysis so far has revealed that the complex operation of ideals of choice work in conjunction with gendered ideas about mothers rather than fathers being the ones to most strongly influence the health of their children (I introduced this idea in Chapter 4 and I develop it further throughout Chapter 6). A reliance on choice discourse also operates to uphold the status quo and the social constraints and imperatives that emanate from it, while providing an illusion of unbounded personal freedoms (Sherwin, 1998). In upholding the existing nature of gender relations, choice operates to legitimate and make possible maternal responsibility for ‘less than desirable’ child health outcomes, which creates the conditions necessary for individualised maternal blame. This is highlighted clearly by the following two quotes from Maxine. In the first quote Maxine expresses self-blame based on her perceived personal failures:

I have a lot of guilt … if I could take the condition away from her, even five years down the track, I'd do anything to take it away from her. My mind goes through 1000 different scenarios all the time and I can reassure myself that I was taking folic acid and there was nothing I could have done differently to prevent it. But I still wonder did I do this? (Maxine, 28 years old, 5 year old daughter with spina bifida)

In the second quote, as a way of relieving herself from the painful effects of self-blame, Maxine applies an individualistic discourse to defer blame to other women without consideration of the social context in which these women live:

A friend of mine has a baby with urinary troubles and she's one of those women that has everything right; the right husband, the right job, the right house, everything right, and then the perfect baby that isn't quite so perfect and it's almost reassuring that I'm not the only one. I get angry sometimes, that I did everything right, I was living a healthy lifestyle, I'm good to people, I do the right thing day in, day out, and I see women who abuse their children, and smoke and drink and carry on when they're pregnant and take drugs, and they have these beautiful children, how come I didn't get one of them, how come I got one with special needs? (Maxine, 28 years old, 5 year old daughter with spina bifida)

The second quote highlights Maxine’s use of individualistic blame as a strategy for shifting emphasis from herself and for renegotiating the blame that emerges from the neo-liberal relationship between individual choice, individual behaviour and life outcome by highlighting other women’s ‘failed’ responsibility. Maxine’s comments, and the other findings that I have
presented in this Chapter, also support Beck and Beck-Gernsheim’s (2002) proposition that individuals have been liberated from ‘old’ systems of social constraint but have become re-embedded into new systems of social limitation, social disapproval being one form of such limitation. However, contradicting the liberating effects of choice that are described by Beck and Beck-Gernsheim, my findings reveal that choice is one of the main tenets upon which modern forms of social control are now reproduced in the lives of women, both in a deterministic way and through their own beliefs about maternal responsibility. I now elaborate further on the mechanisms of individualised responsibility and blame that operate through a supposed freedom to choose.

**Choice versus necessity**

My analysis revealed that rather than the characteristics of particular congenital health problems having a particularly important influence over the amount of self-blame and guilt that is experienced by the women, differentiations made between choice and necessity had a stronger influence. During the interviews several of the women distinguished between particular decisions that they had made about their child’s treatment by explaining whether they were based on choice or necessity (in the sense that the treatments were necessary to save the life of their child). On the basis of this distinction, women whose child had congenital naevus, in particular, expressed considerable self-doubt and anxiety about the treatment choices they had made. For example Tina explains that she decided to allow her daughter to undergo several treatments that were intended to lessen the pigmentation of the congenital naevus and improve skin function:

**Tina:** So I guess the way I describe the journey of her naevus removal, it’s a little bit like you’re in a running race I guess and I felt each time we’d come to this hurdle we’d just have to jump it. And at times I’ve felt like I want to bow out of the race [here Tina began to cry but said that she wanted to continue].

**Toni:** Does the visibility of the naevus on the skin influence how you think about treatment?

**Tina:** Yes absolutely and ... I feel also that it’s a choice I’ve made to ... I could have chosen to leave it and that has been a struggle for me. If it was a problem that was going to risk her life, then I would have been able to justify the decision, although the melanoma risk is there with naevus if she vigilantly wears sun block and other things that risk is very minimal. Um … but I guess that’s what I’ve struggled with is this ‘I've made a decision and now I’m seeking perfection’ feeling and sometimes I feel like I should have left it a long time ago, but I’m still compelled to do what I think is best for her. And that’s very difficult [Tina begins to cry again] (Tina, 38 years old, 5 year old daughter with congenital naevus)

Based on these comments, it may be that Tina’s feeling of responsibility is not so much related to causing her child’s congenital naevus but in making the ‘right’ decision about
treatment, particularly given the pain associated with removing a congenital naevus that will not “risk her life”. As Tina’s comments reveal, however, decisions about treatments that were not life saving were perceived by the women as choices they themselves had made. This interpretation was made without much recognition of the contexts in which they made these choices, which usually involved considerable external pressures. Such pressures emanated from societal factors such as potential discrimination on the basis of bodily difference and also pressures from medical professionals or family members to have certain treatments performed. Medical professionals, and the system of medicalisation in which they operate, have a particularly powerful role in advising parents of what choices are available and not available to them and also in constructing necessity when necessity may not otherwise exist. This is explained by William, an obstetrician, in relation to the tensions underlying screening tests:

I guess the thing that I’ve observed over a long period of time is that the whole process of screening for birth defects, birth abnormalities, call them what you will, has taken on a life of its own which, to some extent, has been directed by laboratories and professionals rather than necessarily by a request on behalf of the community … And uh so in that sense it’s an interesting dilemma and sometimes people in the community say “Well I believe I have to have this test” without understanding they’ve got a choice in the matter. There’s almost a sort of assumption that somewhere out there there is somebody who’s making all these decisions ‘this is what you have to do to have good antenatal care.’ This belief is problematic when you’re screening for abnormalities because you are potentially leading to the ability to disrupt a normal pregnancy … and so that whole process can be challenging and not necessarily something people always think through from all angles. So it’s a different concept in terms of how we are dealing with pregnant women because you know they’re responsible for their child’s wellbeing obviously, understandably, but also not necessarily being aware that in trying to perhaps make good decisions they may actually have to make decisions which jeopardise the wellbeing of that child, a normal child, and that’s always the dilemma of all of the tests.

William’s comments highlight that the medicalisation of pregnancy provides parents with so many more supposed ‘choices’ but with this comes many more pressures to make the ‘right’ choice based on the available information. This understanding, which can be equally applied to the plethora of treatment options available to parents, requires individuals to trust medicine and medical surveillance and accept new technologies even though these technologies may provide more confusion than clarification. So, as Ettorre (2002:67) explains, because the technology exists, parents, and implicitly mothers’ choices become shaped by pressure from others to utilise these technologies as well as by the technologies themselves. Therefore, the distinction which was made by Tina as well as other participants between choices based on necessity or those that are optional may not be as simple as they appear. While the women do have agency in selecting particular treatments, these options are not selected on the
basis of total ‘free choice’, which is the rationale being used for self-blaming by these women. This tension highlights how important it is to explore how women interpret the basis of their choices in neo-liberal society since this is an important factor in how they view themselves, and are viewed by others, to have fulfilled their maternal responsibility appropriately (Valentine, 2010). These findings also, again, highlight the conflicting effects of choice in women’s lives as it operates to both empower and entrap.

This duality of effects was not intended by those who campaigned strongly for the greater availability of choice through the women’s health movement however. Choice has a strong relationship to the women’s health movement, which was in turn linked to the consumer rights movement in the 1970s and 1980s. Campaigns for greater choice emerged most clearly and publicly in relation to abortion during the early stages of the Women’s Health Movement. In the context of abortion, the provision of choice was intended to provide women greater control over their bodies (Johnstone, Brown & Beaumont, 2001; Lippman, 1999). The demand for greater choice was in fact a demand for greater autonomy to allow women more control over their own lives (Tuana, 2006:2). This movement towards greater choice was based on an idealised understanding of what choice could offer, that is, opportunity for women’s personal self-determination, which mirrored the contemporary liberalism of the time (Lippman, 1999:282).

The ongoing availability of choice to women, in its idealised form, remains a necessary part of ensuring women’s wellbeing and access to appropriate health care. However, within the current neo-liberal climate a gap has emerged between the idealised principle of choice and the way that it functions in practice (Lippman, 1999:282). In particular, choice now operates within the context of a risk society and this has the effect of rendering women’s choices to be potential threats to their health, and in the case of pregnancy, to the health of the unborn. On the basis of this, the availability of choice and its power in allowing women to be self-determining legitimises the imposition of medical surveillance over women to ensure that ‘correct’ choices are made. In addition, the perceived power of choice in the lives of women renders them responsible for selecting their reproductive outcomes. This contributes to a legitimisation of maternal blame for ‘less than desirable’ child health since it is interpreted as the result of a misplaced and misdirected enactment of personal agency (Diprose, 2008:269).

**Conclusion**
Throughout this Chapter I have highlighted some of the ways that discourses of individualism have manifest within the research data. In particular, I have demonstrated that discourses of
individualism operate to obscure the social basis of reproductive health and, therefore, render the achievement of healthy outcomes as possible for all providing that women select the 'right' behaviours. This provides a context for the education of women and men about reproductive responsibility that can then be internalised and manifest in particular understandings about the origins of child health. Importantly these are understandings that can provide a basis for individualised and gendered blame for child health problems. The discourses at work here are made more powerful by widespread societal acceptance of neo-liberal understandings about the power of the individual in defining personal realities.

The pervasiveness of individualism within the interview data highlights the ways in which the women and medical professionals utilise broader social discourses as a basis for their understandings about reproductive experiences. The unquestioning manner in which individuals appear to internalise such discourses is an important part of the process through which medical and public health discourses become effective reinforcers of dominant ideologies relating to mothering and child health. I now continue to explore the findings of the research throughout Chapter 6, particularly in relation to the second theme of the thesis which is focused on the gendering of responsibility for congenital health problems.
Chapter 6

“His job is already done”: Excluding and excusing men from reproductive responsibility

The title of this Chapter emerged from my interview with Emma. Emma has a son with congenital heart disease and she believes strongly that men lack influence in promoting reproductive health and in creating healthy pregnancies. For Emma, men’s role is limited in that “once the sperm’s got in, that’s it; his job’s sort of finished.” Emma was not alone in this belief. It was dominant throughout many of the interviews. Such understandings also pervaded the medical literature, health education resources and the supplementary research data that I collected. In this Chapter I explore how the perceived lack of male influence on child health is constructed and reinforced. Throughout the Chapter I examine the deeply embedded assumptions that support understandings about men’s distanced and women’s centralised roles in relation to creating child health. In doing so I argue that current discourses operate to exclude men from the context of reproduction following conception and, concurrently, excuse them both from blame for congenital health problems and from responsibilities for parenting. In support of this I demonstrate how men’s role in relation to reproduction becomes constructed as limited and sexualised, therefore, negating their influence following conception. I also extend the ideas that I presented in Chapter 4 to show how women become represented as inherently more ‘risky’ than men and, therefore, constructed as the most legitimate targets for public health messages and medical intervention.

Men as sperm, health as virility and women as ‘risky’

To begin exploring how men’s reproductive influence is constructed I analyse the public discourses that surround a nutritional supplement for men called Menevit. As part of my collection of supplementary data I gathered information on the range of vitamin supplements that are available and recommended in Australia to promote reproductive health. Examining Menevit as a case study is important because it has been widely advertised through the Australian print and television media and it is also now formally recommended to men by some health professionals. This became evident during the interviews that I undertook with women who have a child with a congenital health problem. Two of the women told me that Menevit had been recommended for their male partners when they sought medical advice from obstetricians prior to conceiving. The marketing campaign for Menevit has promoted the idea that it is not only women who should attend to and maintain their reproductive health but

37 For the purposes of this thesis I define conception as the point at which a pregnancy is identified as established following intercourse.
also that men can and should also do so. This idea is central to the topic of this thesis, which makes further exploration of the discourses surrounding Menevit an important inclusion. By examining the discourses that operate within information about Menevit I will identify some of the dominant ways in which men’s relationships to reproduction are represented. Following this, I explore more deeply how similar representations also emerged from my analysis of the interviews, the medical literature and the health education resources.

‘Iron man food for sperm’: Menevit

Menevit is marketed by the pharmaceutical manufacturer Bayer Health Care and it first became available in Australia in 2008. The supplement is sold in capsule form and it is recommended that men take one capsule per day. According to the product website, Menevit is “suitable for men in couples planning pregnancy who are interested in supporting sperm health” (Bayer Health Care, 2007) [Emphasis added]. The Menevit capsules contain ingredients which are “specifically formulated to maintain sperm health for pregnancy” (Bayer Health Care, 2007) [Emphasis added]. I have emphasised some of the words in the previous quotations to show that, at least on the surface, the marketing materials for Menevit suggest two important ideas. First, that there is a supposed link between the “health” of men’s sperm and pregnancy and second, that it is couples, rather than individuals, who are involved, seemingly equally, in the planning of pregnancies.

The specific associations that are drawn between men’s health and pregnancy within information about Menevit are theoretically interesting because, as I make clear throughout this Chapter, men and discussions about their health are largely absent from mainstream public health and medical discourses about congenital health problems. The apparent disparity between discourses surrounding Menevit and mainstream reproductive health discourses prompted me to explore the information that is presented on the Menevit website more deeply. In particular I aimed to understand how men’s health was seen to influence pregnancy and also to learn about how men’s role in preparing for pregnancy was constructed. I now explain the complexities that are associated with the messages that are transmitted through the Menevit website which, contrary to a surface level reading, actually operate to distance men from responsibility from child health rather than implicating them within it.

An analysis of the Menevit website makes clear that instead of men having a role in pregnancy in a general sense, men’s role is represented as contained to specific stages of pregnancy. This meaning is conveyed through the content of the sections on the website that
are entitled *The man’s role in planning pregnancy* and *What else can you do?* These sections contain specific advice for men about ways that they can increase their chances of achieving conception; however, there is no mention of anything else related to pregnancy. This means that through the operation of discourse, the role of the man in planning pregnancy actually becomes the role of the man in facilitating conception. Through the absence of information about stages of pregnancy following conception, men become constructed as having no legitimate place or responsibility in preparing themselves for these stages of reproduction. In fact the isolated focus on conception renders men as largely irrelevant to, and legitimately absent from, the reproductive context beyond conception.

The inferred link between men’s *health* and pregnancy is treated in a similarly reductive manner. Throughout the information that is included on the website under the heading *Men’s Health & Pregnancy* the only mention of health pertains to the health, and subsequent reproductive viability, of sperm. This constructs the link between men’s health and pregnancy as based only on the success or failure of a man’s sperm to meet with and fertilise an egg and does not consider the potential for men’s health to influence the health of a pregnancy or the health of the child that is produced from a conception. As I show later it is assumed within the discourses that I have analysed that only *healthy* sperm are viable, which suggests there is no possibility that sperm, or men’s general health or behaviour, contributes to congenital health problems (Daniels, 2001; Delaney, 1988; Fausto-Sterling, 1987). Therefore, despite the surface level meanings that are conveyed, a deeper analysis of the discourses surrounding Menevit shows that male health and male reproductive health are represented as synonymous with sperm health. In addition, it is clear that sperm health becomes measured only by its ability to conceive and not by its location within a healthy male body or by the production of a healthy child.

The reduction of men’s health to sperm health, and the related construction of men’s limited role in reproduction, has the effect of disembodying men from the reproductive process. Disembodiment occurs because sperm become the focus of attention and intervention while men become reduced to the mere carriers and producers of sperm. The disembodiment of men within discourses relating to Menevit is further demonstrated through the relative absence of photographs or other representations of men on the website. Sperm and diagrams representing their role in the fertilisation process are pictured frequently, however, particularly in the Menevit logo.
A rare image of a man does appear on the opening page of the website for Menevit. The image is presented in Figure 6.2.

Even though a male figure is present, this image has the effect of further disemboding men from the context of reproduction. One reason for this is that the man is pictured facing away from the viewer. This positioning detracts from his identity as a person, or a potential father, by making him ‘faceless’. As such, the man appears to exist in the image not in a nurturing capacity but instead in a metaphoric capacity where he is represented as a purpose built, action orientated body with a sole, distant focus. His focus is centred on an imagined path or journey, which is represented by a photo of the Atlantic Ocean. The attire of the man also makes clear that he is a swimmer who is preparing for action. Overall, the man’s appearance and positioning suggests that he is used as a metaphor for a sperm. The reduction of the man to a sperm in this image further reinforces the event-orientated purpose that men are
represented as occupying in relation to reproduction. Their presence and usefulness is reduced to that of biological fertilisation only rather than being constructed as inhabiting multiple reproductive roles, such as first producer of the sperm, then pregnancy support and eventually father.

Such imagery is in stark contrast to that provided on a website that promotes Bayer's parallel vitamin supplement for women called Elevit. Elevit is designed to support the reproductive health of women before, during and after pregnancy, particularly during lactation (Bayer Health Care, 2005). The Elevit website, which is directly linked to the website for Menevit through an active hyperlink, provides clear and multiple depictions of women in their role as mothers, rather than as people who are confined only to a biological role during pregnancy or conception. This contrast is highlighted in Figure 6.3 through a comparison of some of the images that are presented on each website.

**Figure 6.3**

*Images shown on the websites for Elevit and Menevit*

NOTE:
These figures are included on page 143 of the print copy of the thesis held in the University of Adelaide Library.

Sources: Bayer Health Care (2005); Bayer Health Care (2007)

On the basis of the discourses surrounding Elevit women as whole beings are represented as having a reproductive role before, during and after pregnancy. The imagery that is included on the website also indicates that women embody an identity as a loving carer for their children. Women's biological material (eggs) are also as absent from the Elevit website just as men’s roles as fathers are absent from the Menevit website. The act of ejaculation is the only thing associated with ‘love’ by men on the Menevit website as is depicted in Figure 6.4.
These images appear as part of an interactive quiz on the Menevit website in which men are asked to select the correct answer about how often they should have sexual intercourse in order to maintain the health of their sperm. The number of hearts on each diagram represents the suggested number of occasions of sexual intercourse each week. The ‘correct’ answer is that men should have sexual intercourse, or as it is represented in this context, spread their love through ejaculation, two to three times per week (Bayer Health Care, 2007). This will ensure optimal sperm health and maximise men’s chances of conceiving (Bayer Health Care, 2007). The inference that men express love through ejaculation—indeed they are depicted as ejaculating from ‘the heart’—further reinforces the biologically essentialist ways in which men are represented and it also distances them further from a role as a loving, nurturing father, containing them only to a role in producing virile sperm.

I now return to an analysis of the image of man as swimmer that appeared on the first page of the Menevit website (Figure 6.2). In doing so, I identify some additional messages that are conveyed about men, women and their roles in relation to reproduction.

As I argued earlier, the imagery and wording that is shown in Figure 6.2 represents the journey of a sperm rather than the journey of a man embarking on fatherhood. When thinking about reproduction as an embodied process, however, it is clear that this journey of the sperm takes place within a woman’s body, which is represented metaphorically by the Atlantic Ocean. Within this metaphor a woman’s body is shown to be a hostile, unstable, dark and cold environment that has hidden dangers (represented as rocks) lurking below the surface (Ussher, 2006). The wording “If a sperm were human it would need enough stamina
to cross the Atlantic” (Bayer Health Care, 2007) suggests that the sperm’s journey is one filled with difficulty given the harsh, dangerous and precarious body in which it must swim.

The sheer size of the Atlantic Ocean in comparison to the man pictured also operates to convey the fragility of sperm and further reinforce the dangers posed to it by the environment it must conquer. This metaphoric meaning combines with the message that men should care for their sperm by taking Menevit to make it strong in order to swim the ocean. This emphasises that sperm need to be strengthened and nurtured. Through these processes sperm are imbued with a level of personhood and rendered in need of protection. The personification of sperm in this way also makes them akin to the ‘little ones’ produced by men, which links with societal beliefs about the sacred and precious value of children (Daniels, 2001:320). This, therefore, adds further moral imperative for women to create healthy rather than hostile intrauterine environments in order to protect these ‘little ones’. These processes also distance men even further from understandings about child health because rather than their sperm being viewed as potential transmitters of risk, the sperm become rendered ‘at risk’ from the dangerous and hostile environment that exists within the body of a human woman. These representations, and those which I identified in my earlier analysis of the image, contradict (or unsettle) the advertisers’ surface level assertion that men and women have an equal role in preparing for pregnancy. This is clearly not the case since the operation of the metaphor and broader discourses around Menevit makes clear that it is women who plan for pregnancy and women who have responsibility for creating a healthy intrauterine environment to foster healthy foetal growth while men plan for the event of conception only.

My findings in relation to Menevit echo those documented by Emily Martin (1991) in an influential paper entitled The Egg and The Sperm: How Science has Constructed a Romance based on Stereotypical Male-Female Roles. Martin (1991) argued that scientific accounts of how reproduction occurs are imbued with metaphors of conquest which rely on gendered stereotypes. These stereotypes imply that reproduction occurs through conquest by male sperm and the submission of female eggs (Martin, 1991). Further to this, Martin (1991) suggests that the dominant scientific construction of reproduction reinforces cultural associations between men, productive ability and overall positivity. In contrast women become represented as having a passive role in conception while at the same time possessing the ability to threaten reproductive success (Martin, 1991). Similarly, the representations that emerge from discourses around Menevit involve the stereotypical construction of the female body as a risky reproductive vessel that is, potentially, impregnated by an active, strong swimming sperm. What I add to this observation is a further
understanding of the social effects that flow from such representations of reproduction and also improved understanding about the attributions of reproductive responsibility that emerge from them. I explore both these issues as the Chapter proceeds. Before moving on from a discussion of Menevit, however, I briefly examine how discourses of ‘choice’ are evoked within the website. This examination is relevant to a discussion of men and women’s relationship to reproductive health. It also provides further development of the arguments that I presented in Chapter 5 about the pervasiveness of individualism within discourses about reproductive health.

**Menevit and choice based fertility**

Much of the information that is presented on the Menevit website demonstrates the underlying assumption that individuals’ reproductive capacities result from their choices. The existence of such an assumption can be highlighted through consideration of the ingredients in Menevit, which are shown in Figure 6.6.

**Figure 6.6**

**Ingredients in the Menevit capsules**

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<td>This figure is included on page 146 of the print copy of the thesis held in the University of Adelaide Library.</td>
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Source: Bayer Health Care (2007)

Close examination of this list of ingredients reveals that Menevit consists of common micro-nutrients, such as Vitamin C and garlic oil. It is inferred that men’s increased consumption of these ingredients can eliminate, or at least reduce, their fertility problems. The promotion of the ingredients in Menevit in this way, almost as a ‘magic bullet’ (Diesendorf, 1976) to address fertility problems, is a basic marketing strategy to sell the product. However, on closer examination it becomes clear that the promotion of the idea that taking vitamins and minerals is necessary to avoid fertility problems also conveys an implicit message about where the ‘problem’ is likely to originate (Bacchi, 1999; Keane, 2002). The message is that men’s problems with fertility result from their consumption of a diet that is inadequate to
supply sperm with the micro-nutrients necessary to support their proper function. Problematic sperm become symptoms of a problematic male diet which, in turn, becomes linked discursively to the poor food choices of individual men. In the current neo-liberal era this individualised construction of the ‘problem’ then leads to a call for men to take Menevit as a means of improving their ‘choices’.

Such an individualisation of ‘the problem’ becomes reinforced when considered in conjunction with the other advice that is included for men on the Menevit website. To improve chances of conceiving, men must take Menevit and also engage in other behaviours that are conducive to sperm health. These behaviours, such as reducing smoking and alcohol intake, are presented in a simplistic discourse which appears to again locate the solutions to fertility problems at the level of choice. Fertility becomes a choice because it is represented as available to all men who decide to support the health of their sperm through choosing particular behaviours over others. A similar discourse of individual choice permeates the advice offered to women through the Menevit website in a small section in which particular behaviours are recommended to women suggesting that they have the ability to control reproductive and child health through the choices that they make before, during and after pregnancy.

The representation of male fertility and female reproductive health as things that can be chosen, and ultimately controlled, through individual behaviour ignores the broader factors that influence reproductive health and restrict the opportunities of individuals. In particular, the representation of fertility problems as arising from the failings of individual men, such as a failure to eat healthily or resist dangerous substances, ignores the strong relationship between risky, health threatening individual male behaviours and pervasive, enduring forms of masculinity (Beasley & Elias, 2006). Despite this, the simplistic advice offered to men highlights an assumption on behalf of the makers of Menevit that it is necessarily men’s inadequate intake of micro-nutrients and their normative engagement in risky behaviours, such as smoking and drinking alcohol, that cause the problems with their fertility. This reflects knowledge of an assumed socially dominant model of masculine behaviour, but at the same time this model of behaviour is linked implicitly with the individual decisions of individual men.

I now shift my focus from the discourses surrounding Menevit to consider in greater depth how discourses of male exclusion following conception, particularly in relation to issues surrounding child health, have emerged within my analysis of the interviews, health education resources and medical literature.
Reinforcing male exclusion through a lack of information

Discourses that support men's exclusion from the reproductive context following conception emerged particularly strongly from my analysis of the health education resources that are distributed to pregnant couples. My findings reveal that in South Australia there are currently no health education resources that are routinely offered to men about reproductive health or pregnancy. Instead, during antenatal appointments all routine information is provided to women. There are some pamphlets available for distribution to male smokers at the discretion of health care providers which include information about the dangers associated with smoking in the presence of pregnant women and infants, however, even these pamphlets are not offered routinely.

The exclusion of men from health information and practice also became evident during the interviews that I undertook with all 28 mothers. I asked all the women if their partner was given advice about how he could promote the health of their baby before or during pregnancy. Most indicated that their partner received none or only limited advice. Instead information was consistently directed at the female member of the couple. For example Jenny, said:

> My husband came as well to a lot of the appointments, I think the advice really was targeted at the female ... I can't remember anything being targeted at him. Oh, they did say some things like if you're trying to conceive the male should try and cut down alcohol and things like that, but they didn't say stop, they said cut down, whereas for the female, it's like no—forget it! Forget it for the whole nine months after too actually.

(Jenny, 30 years old, 5 month old son with congenital heart disease)

As inferred by Jenny, when women recalled advice being offered to their partners this advice was consistently related to ways that the man could ensure his fertility rather than promote the health of his partner or child. This trend, which is consistent with discourses emerging from Menevit, is highlighted again here by Kate in response to me asking whether her partner received any reproductive health advice:

> Kate: Nothing. He would've got nothing. Oh no hang on ... undies\(^3\) [laughs]. I remember something to do with the undies or the boxers you know, that thing, that was the only thing I've ever heard to do with yeah the whole pregnancy thing.

Toni: So do you think that he was expected to be involved in helping you to keep yourself healthy during pregnancy?

Kate: No. No. I don't think so. And I felt like it was just my job sort of thing and I guess he just felt the same.

Toni: Why did you think that?

Kate: Um ... just because it's me ... I don't know ... me looking after the

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\(^3\) Kate is referring to advice for men to wear loose fitting underwear in order to protect the virility of their sperm.
Kate’s quote also highlights that the relative exclusion of men from advice and practice around reproductive health has the effect of reinforcing women’s responsibility for pregnancy and reproductive health. This is particularly important when reproductive outcomes are ‘less than desirable’ because it establishes the potential for women to be blamed or to blame themselves.

Furthermore, men’s generalised exclusion establishes a basis from which men can be excused from taking responsibility for the health of their child. The discursive construction of men’s bodies as legitimately absent from the reproductive context following conception has the effect of reinforcing the expected distance of men from child care and their role as fathers. This idea is supported by the following quote from Bianca:

**Toni:** Did your partner ever receive any advice about what he should do to encourage the healthy development of the foetus?

**Bianca:** No, no. They spoke at me and half the time he was thinking ‘why am I even there?’ like ‘does anybody care?’ ‘I’m not literally giving birth to her, but I’m still freaked out!’ Nobody asked him at that time “How do you feel about it? What do you want to do about it?” That was only for me. And that added a bit more pressure on me, all that focus. There’s nothing he could have changed in the whole situation anyway, but it left him out a bit, which left that bond out a bit. I mean I think she only discovered that she had a father when she was about two, she just turned around and said “Daddy” like she thought ‘oh yeah that’s who he is.’ (Bianca, 28 years old, 5 year old daughter with spina bifida)

**Men’s exclusion from antenatal spaces**

Similar discourses of male exclusion also emerged during the antenatal appointments that I observed. As I explained in Chapter 3 I attended antenatal appointments with a couple throughout their first pregnancy. During the six month period that I attended the appointments I consistently noticed the lack of men in the waiting room of the hospital clinic. Initially I dismissed the importance of this observation accounting for men’s absence on the basis of structural factors which may prevent their attendance, such as inflexible working arrangements or strong financial pressures which may not allow them to take time off work. However, as I became more deeply immersed in discourses surrounding reproduction I reflected more closely upon the absence of men in the antenatal clinic since it was consistent with broader patterns that were emerging from the analysis. In particular, I began to question what broader factors were reinforcing men’s relative exclusion from antenatal spaces and consultations.
Apart from the absence of men in the waiting room, other aspects of the antenatal appointments also stimulated such questioning. In particular, I noticed that Chris, the male member of the couple with whom I attended the appointments, was rarely addressed directly by health professionals. Instead he was mainly spoken about (as if he was not present) or excluded from the discussion completely. An example of this arose when the female member of the couple, Amy, was asked to provide an account of Chris' family history of health problems, despite his presence next to her.

In addition, the spatial arrangement of the room in which the antenatal appointments were held also provided a physical basis for Chris’ exclusion. The chairs that were offered to the couple were positioned against a wall alongside the computer and desk where the midwife sat. This spatial arrangement resulted in a situation where Amy was positioned directly next to the desk of the midwife while Chris sat beside Amy further along the wall. This meant that Chris had to look past Amy to see the midwife and, similarly, the midwife also had to look past Amy to communicate directly with Chris. Such positioning detracted from the effectiveness of communication between Chris and the midwife and it also positioned Chris as a peripheral, rather, than central member of all discussions. Therefore, even when men are present at antenatal appointments they can experience a degree of exclusion through the spatial and discursive practices that operate. This is a problem because men’s inclusion in antenatal appointments provides an important, and early, opportunity for their broader inclusion both in the reproductive context generally and specifically in regards to taking responsibility for the health and outcome of a pregnancy. Their relative exclusion, however, establishes a trend which can continue throughout and following the pregnancy as men learn their role as parents.

**Men as peripheral to reproduction**

The representation of men as occupying only a peripheral role in pregnancy and reproduction is not confined to the discourses that operate during antenatal appointments or through the Menevit website. The marginalisation of men from understandings and practice around pregnancy is pervasive. It has the effect of rendering men as people who lack a legitimate or important position in the reproductive context following conception. The perceived illegitimacy of men’s relationship to reproduction is demonstrated in the following quote from the textbook *Llewellyn-Jones Fundamentals of Obstetrics and Gynaecology*:

> Many women want their partner or some other support person to be with them during childbirth. The presence of an informed loved one during labour gives the woman familiar and personal support to reduce the clinical environment of a delivery ward. (Oats & Abraham, 2005:51)
Through this quote fathers become represented as supporters or as people who are not central to the birth of their child. Instead they are rendered interchangeable with any other person who may provide a pregnant woman with support. Furthermore, it is made clear in the textbook that only *some* kinds of men are able to fulfil an effective supportive role, which is highlighted here:

> In terms of antenatal depression the vulnerable women tend to have poor social support, to have either a partner who is unemployed or none at all. (Oats & Abraham, 2005:40)

This quote equates the value of unemployed men with that of absent men. The marginalisation of men within discourses pertaining to reproduction and reproductive health is an important phenomenon because the exclusion of men produces important effects. These effects have the potential to influence how comfortable, able and willing men feel about taking a significant role in preparing for fatherhood, such as by attending antenatal appointments with their partner in order to share the experience of pregnancy or by demonstrating an interest in, and responsibility for, promoting their own health before conception.

**The absence of relationality**

Part of the reason that men become excluded from the discourses that I have analysed is that the importance of the relational nature of reproduction and pregnancy is rarely acknowledged. In particular, as I highlighted earlier, the potential for shared behaviours between men and women to contribute to the cause or prevention of congenital health problems remains largely unconsidered or explored.

Instead of reproduction being constructed as a shared process, women become the main focus of explanation and intervention relating to congenital health problems. Women are thus discursively constructed as existing outside social context, and outside of reproductive relationships with men (Keane, 1996:265). Reproduction is framed as a biological process that occurs inside the bodies of women only. As such it is represented as largely uninfluenced by social or relational factors. This is particularly evident in the medical literature in discussions about the link between teratogens and congenital health problems. I introduced the discussion about teratogens in Chapter 4 where I argued that women’s bodies are presented as posing risks to a foetus because they provide the conduit through which it becomes exposed to teratogens. However, teratogens can also affect eggs and sperm before a child is conceived. This means, therefore, that men *may* also be responsible for transmitting the effects of a teratogen if it has affected his sperm at the time of conception (Lie, Wilcox & Skajaerven, 2001:755). Despite this, during my analysis of the medical
literature I observed that almost all of the discussion about teratogens focused exclusively on maternal exposures by linking these to various congenital health problems while the role of men in transmitting the effects of teratogens was rarely identified.

I considered that one possible reason for this is that some of the textbooks that I analysed were drawn from the field of obstetrics. This field originated from a focus on women’s health rather than on the health of men. However, this did not explain why textbooks and journal articles from the field of paediatrics did not consider the possible influence of men’s teratogenic exposures. The absence of detailed consideration about men led me to question whether any medical research existed that supported a link between men’s exposures to teratogens and a change in the quality or structure of their sperm.

In order to explore this possibility I searched for literature on a teratogenic behaviour that is engaged in by both men and women. I selected cigarette smoking as one example of such behaviour. The aim of my literature search was to determine whether research had been undertaken and reported which examined the effect of cigarette smoking on the reproductive cells (sperm and eggs) of males and females. If this literature existed, I wanted to find out whether smoking had been identified as having any influence on the reproductive cells (sperm and eggs) of smokers or on the development of foetuses they conceived. I conducted the search using the medical database PubMed which I subjected to a comprehensive search strategy that would allow me to locate relevant medical journal articles if they existed. Surprisingly, the search located 460 potentially relevant sources. I examined these and excluded 336 articles that examined the effects of women’s passive or active inhalation of cigarette smoke during pregnancy. I excluded these because I was interested in the influence of smoking on women’s eggs and men’s sperm prior to conception. By examining the remaining 124 relevant sources, published between the years of 1979 and 2008, I found, surprisingly, that the majority of the research actually focused on the teratogenic effect of cigarette smoking on sperm rather than on eggs (refer to Figure 6.7).

39 The search strategy that I used was: (germ cells OR germ cell OR semen OR sperm OR ovum OR ova OR oocyte*) AND (smoking OR smoker* OR tobacco use disorder OR nicotine) NOT animal AND english[lang]
As shown in Figure 6.7, 79% of the 124 articles reported the effects of cigarette smoking on sperm. This is compared with 17% that examined the influence of cigarette smoking on eggs and only 4% that included a combined focus on both sperm and eggs.

My analysis of the results of these studies revealed that men’s smoking can influence the quality and structure of their sperm. In addition some researchers have found a link between such changes in men’s sperm and chromosomal defects in children born to male smokers (Rubes et al., 2009). Paternal smoking before and at the time of conception has also been correlated with an increased risk of offspring developing childhood cancer, even in cases where the mother never smoked (Ji et al., 1997).

Despite the existence of this medical evidence, men’s smoking is rarely addressed directly within the mainstream discourses that I analysed (such as in textbooks, health education resources or medical practice) about reproductive health or about the cause and prevention of congenital health problems. Discussions about men’s smoking where it exists at all is typically framed in a way that positions women’s bodies as the conduit for transferring
teratogenic effects to the foetus by passively inhaling the cigarette smoke of their male partner. The omission of evidence about direct links between men's smoking and other forms of male exposures which may lead to teratogenesis is consistent with broader patternings of male exclusion from thinking about child health outcomes.

It is clear that the unacknowledged and largely unquestioned omission within mainstream medical and public health discourses of factors that are outside the maternal body reinforces traditional gendered stereotypes. These stereotypes position women as most closely linked to their children's health when, in fact, factors outside the maternal body may have as important an influence in determining child health outcomes. The dominant focus on women also reinforces stereotypes that render men irrelevant to reproduction following conception and which, therefore, legitimates their exclusion. In this sense pregnancies which result in children with congenital health problems become constructed as if they were virgin births, which are completely outside the influence of a man or his reproductive health, despite the existence of evidence which suggests otherwise.

Therefore it is clear that the stereotypical absence of consideration about men's influence on reproductive health and pregnancy outcomes has resulted in important omissions from medical and public health discourses. Further insight into this anomaly is provided by the work of Daniels (2001) who proposes that the type of questions that we can ask and the kinds of information that we focus on create a particular frame which enables some considerations while disabling others. This creates a selective attention in which the frame that we are using to understand a particular issue becomes invisible and our thinking becomes framed within it, which makes it difficult to think outside of the discourses upon which we become reliant (Daniels, 2001:312; Foucault, 1972). This theory has clear relevance to the gendered focus that dominates literature on reproductive health since women are consistently, and often exclusively, rendered as central to reproductive processes while men's potential influence is negated. The pervasiveness of such a framing process in terms of understanding the cause of congenital health problems is demonstrated by the experience of Natalie:

**Toni:** Previously, you said that you worked in the mines and the doctors thought that maybe you had been exposed to something that might have caused the health problem.

**Natalie:** Yes, that’s right, they thought it may have caused something to go wrong with her heart. I kind of believe that too actually.

**Toni:** You said your partner also worked in the mines?

**Natalie:** Yes for ages.
Toni: Did the doctors consider that his experience may have contributed to the health problems?

Natalie: Oh no! No [laughs]

Toni: Why do you think that is?

Natalie: Well they don’t think of the 50/50, you know, it takes two to tango. But then I think with parenting in general it just seems that the sole … a lot of the focus is just on how the mother raises the child or brings the child into the world, it’s nothing to do with the father. (Natalie, 30 years old, 11 month old daughter with congenital heart disease)

Up to this point in the Chapter I have focused broadly on identifying some of the ways in which men are discursively excluded from the context of reproduction. I want now to explore more deeply the processes through which men’s exclusion from thinking about reproductive health becomes both possible and legitimised. This focus on how processes operate is important because as Christine Beasley and Juanita Elias (2006) suggest, much of the existing research does not explain how particular gendered divisions and stereotypes become legitimised and supported in society. This is particularly true in relation to stereotypes that are formed on the basis of masculine ideals since the influence of masculinity often remains unstated and unacknowledged because it is based on the banal position of the norm (Kimmel, 1997). While exploring how men’s exclusion from thinking about reproductive health becomes both possible and legitimised I extend my argument that men’s exclusion is based upon the construction and perpetuation of gendered stereotypes which naturalise and legitimise gender divisions in responsibility for congenital health problems and child care more generally. In support of these arguments I address three main topics. The first relates to the understanding that women are more suited to promoting the health of their children than are men. The second topic involves consideration of the cultural meanings that operate within reproductive health discourses to influence how sperm and eggs and their potentialities for risk are understood. The third topic is based on the dominant conceptualisation of women as reproducers while men are regarded as having a primarily sexual identity.

‘This is a woman’s job’

Reflecting back on Emma’s comments in the introduction to this Chapter, it is clear that some of the women I interviewed expressed views which actively legitimised men’s absence from the context of reproduction following conception. Several of the women also expressed the belief that women should carry greater responsibility for child health because they do have
more influence on the health of their children than do men. This belief was expressed clearly by Jane:

**Jane**: I did everything right during the pregnancy, before and during, I just can't explain [the congenital health problem].

**Toni**: And you said earlier that when you think about things that could have caused the health problem you usually think about things you did or didn’t do but you don’t think about factors beyond yourself.

**Jane**: Yes.

**Toni**: Is there a reason for that?

**Jane**: Well … I think that all the 9 months that you carry a baby you are in total control and … you're the one person who does have control over your baby’s life. I think women are … they have that responsibility.

**Toni**: Do men also have that responsibility?

**Jane**: Oh no. Men can be supportive [laughs] but I think ultimately it’s the woman who can not only make these decisions but execute them as well. (Jane, 35 years old, 2 year old son with congenital heart disease)

Jane’s comment is important because it shows that she believes strongly in the exclusive ability of women to determine the outcome of their pregnancy yet she also believes that she did nothing to cause her child’s health problem (I reflect further on this tension during Chapter 8 and explore its basis and implications). Considering Jane’s comments, and her role in internalising and reinforcing men’s exclusion, extends the discussion within this Chapter because prior to this point I have explored the ways in which **structural factors** reinforce gendered divisions and contribute to the exclusion of men from the context of reproduction. However, as I explained in Chapters 4 and 5, it is also important to consider how particular discourses become internalised, embodied and replicated by individuals in addition to focusing on the ways in which a broad external network of power, knowledges, institutions and practices contribute to particular realities (Foucault, 1991a, 1991b). Applying such a dual focus allows for a more nuanced understanding of the ways in which discourses operate to create and reinforce particular social realities, such as the dominant exclusion of men from discourses of reproductive and child health.

Lisa made a comment during her interview that demonstrated her subscription to dominant beliefs about the appropriateness of men’s marginalisation from pregnancy and child health outcomes. When Lisa was describing her daughter she said:

She's quite a beautiful looking girl, I think she is anyway, people often remark on what a beautiful girl she is, and she's got impeccable manners and I'll say to her dad “I don't know what you're taking credit for.” I probably shouldn’t say this on tape, but I do say to him “All you did was have an orgasm, I'm the one who made her!” And then I still get, still now, I get that little twinge that I didn’t quite make her right, so that's tough. (Lisa, 29 years old, 5 year old daughter with spina bifida)

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Lisa’s comments actively reinforce the stereotypical assumption that creating and raising children are mainly the responsibilities and appropriate roles of women. Lisa’s admission of guilt also highlights the way that the perpetuation of understandings about men’s lack of influence on child health contributes to the responsibility experienced by women.

It was not only in relation to pregnancy that the interview participants expressed beliefs which legitimised women’s greater responsibility for ensuring the health of their child. Women also expressed this belief in the context of child care activities. Several of the women stated that it was appropriate that they carry the majority of the burden for the care of their children since, for the most part, they were better at providing care for them than were their male partners. I examine this idea further in Chapter 8 where I discuss how congenital health problems influence the ways that women understand and interpret their child care responsibilities. However, in the context of this Chapter it is important to highlight that ideas about women being ‘better’ at child care further legitimate and extend men’s absence from caring relationships with their children even after they are born.

Similar findings also emerged from the research of Hays who provides an important insight into the social basis of the belief that women are ‘better’ at child care. Hays (1996) interprets this belief within the context of the pervasive social ideology of intensive mothering (refer to Chapter 1). Intensive mothering teaches women and men that it is the responsibility of women to care for their children because women are better suited to this role while men are better suited to, and more competent at, working outside the domestic sphere. In the interviews that Hays undertook to inform her book *The Cultural Contradictions of Motherhood* (1996) several participants justified the unequal distribution of parenting responsibilities in their relationship as based upon the fact that they provided ‘better’ care for their children than their partners did. In addition, Hays (1996) asserts that it is likely that women and men remain committed to the belief that women are better at child care since, through the traditional, socially acceptable division of parenting roles, women have more experience in caring for their children than men. This highlights the social basis of the stereotype which women use to legitimise and perpetuate their greater engagement with child care and which operates to legitimise the relative exclusion and excusing of men on the basis of entrenched assumptions about sexual difference.

Apart from being reinforced by women themselves, the idea that women are better at or more legitimate carers for their children, was also reinforced through medical practice. It appears that even when couples attempt to engage in more egalitarian parenting relationships, the discursive construction of men’s bodies as legitimately absent from
reproduction has the effect of furthering and normalising men’s expected absence from child health care. This idea is illustrated in the following quote from Tamara:

   Even when we try to share the responsibility it’s hard to do so. Like one time I was really tired and we had to take Harry into the emergency room at the hospital to get checked. And like I just didn’t want to deal with it. Anyway so my husband talked to the nurses and stuff and I stayed behind him. But then I found them looking around my husband at me! Talking to me, like I should be the one dealing with it and not him. All the time it’s like it’s my responsibility and not his. (Tamara, 30 years old, 5 year old son with congenital heart disease)

Despite some women actively committing to, and replicating, beliefs about the exclusion of men, the majority of the women did not do this. Instead most of the women I interviewed expressed a desire for equality in their parenting relationships. Some also inferred that they had successfully achieved such equality both during their pregnancy and in the early years of their child’s life. For example, Wendy said:

   Yeah we are pretty equal. Like we always try to include each other in things and also share things about our kids. And I mean we even did that during the pregnancy because we shared feelings, I’d tell him what I was feeling and what was going on. So he was very supportive and really good. (Wendy, 32 years old, 3 year old son with congenital heart disease)

This quote highlights Wendy’s desire to share parenting roles equally with her partner. However, it is clear that such equality was limited even during pregnancy because when the couple “shared feelings”40 it was she who expressed her own feelings and he responded supportively yet did not express his feelings. This provides an example of pseudomutuality which I explained in Chapter 1. While it is clear that only women can experience pregnancy in a biological sense, I argue that men also have a legitimate position from which they could experience pregnancy as a relational process with their female partner so long as they are not disabled in doing so through the discursive construction of pregnancy as the exclusive preserve of women.

Wendy’s quote also highlights another important discourse which emerged powerfully during the interviews. In biological terms aspects of initial care for infants places demands upon women that cannot be easily shared with men. This means that no matter how strongly the couple desires an egalitarian relationship in relation to child care they tend to be forced into complying with rigid gender roles (Swanson, 2004:4). Apart from its biological basis, pseudomutuality also becomes ingrained in current gender relations because individualist ideas stimulate a desire and a sense of opportunity to achieve egalitarianism yet the current

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40 I acknowledge that sharing feelings does not equate to an equal sharing of parenting. However, during the pregnancy it may have provided the basis for Wendy’s partner to assume a more active and involved role had such sharing occurred in a more participatory and mutual way.
unequal and gendered basis of current systems places structural constraints on the extent to which egalitarianism is possible in practice.

**Safe sperm and risky eggs**

A further discourse which makes possible men’s exclusion from advice and practice around reproductive health is the presumption within public health and medical discourses that sperm is a ‘safe’ substance that cannot transmit the potential for congenital health problems.41 Beliefs about the safety of sperm are underpinned by its representation as a flowing substance that is continually produced by men, therefore, remaining fresh for each conception. The flowing and fresh nature of sperm contrasts with representations of women’s eggs as stagnant, ageing and limited. The stagnation of women’s eggs is used as a basis for assumptions about women’s greater susceptibility for carrying (and transmitting) the effects of their lifelong exposures, as I highlighted earlier though my discussion of teratogens. The perceived safety and untainted nature of sperm was reflected clearly by a genetic counsellor, Maureen:

**Toni:** We’ve talked about women expressing feelings of responsibility or guilt, do you find that similarly with men?

**Maureen:** I probably haven’t had anywhere near the number of conversations with men. And I mean there’s virtually nothing that can affect sperm ... we don’t know of anything really that affects sperm that can then affect a conception. So I don’t think that men do feel at all the same level of … uh and they’re not the ones that have carried a pregnancy so I don’t think it is anywhere near the same issue for men as it is for women.

The presumed safety of sperm was also reinforced in one of the medical textbooks, where the authors implied that the origins of childhood health and illness develop only after conception. This inference is highlighted by the quote:

*The task of paediatricians is not limited to childhood. It is increasingly to promote health and prevent disease from the moment of conception forward.* (McMillan *et al.*, 2006:174)

However, as I have demonstrated in this thesis, the presumed safety of sperm is not necessarily accurate. In further support of the idea that sperm are not impervious to damage which can be transmitted to their offspring, I note recent medical evidence of the associations between sperm damage and air pollution (Rubes *et al.*, 2009) and occupational exposures (Hsu *et al.*, 2006).

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41 I argue that sperm is represented as ‘safe’ in the context of the discourses that I am analysing. However, I also recognise that in other, different, theoretical contexts sperm are regarded as dangerous, particularly since they can penetrate the body of a woman and cause unplanned pregnancy and seminal fluid can also transmit infection. Therefore, the construction of sperm as a safe substance is context-specific and cannot be considered universally applicable.
The understandings that support the risky eggs versus safe sperm dichotomy have a history. As explained by Martin (1989:27) it is useful to reflect on ideas from the past, particularly ideas that now seem primitive or wrong, to understand how cultural and gendered assumptions shape contemporary scientific understandings. According to work by Daniels (2001), debates over the origins of foetal harm have been consistently based upon understandings of male virility and female vulnerability. Historical understandings of male virility render sperm completely invulnerable to harm from the toxicity of particular agents and exposures or to, conversely, be rendered completely infertile if damage does occur (Daniels, 2001:313-314). These ideas reflect stereotypical assumptions about the strength of the male body and its self-containment. In addition, the belief that damaged or ‘tainted’ sperm will be rendered completely infertile conveys the idea that any sperm which successfully fertilises an egg is necessarily ‘normal’ (Daniels, 2001:317). This equates an ability to penetrate an egg with a measure of normality, meaning that sperm which succeed in achieving conception are assumed to be strong, undamaged and, therefore, healthy.

Contributing to the power of the safe sperm and risky eggs dichotomy are early, but enduring, understandings about sperm as the seed of life. According to early theories of reproduction, which were not challenged scientifically until the turn of the twentieth century, men were seen to provide the ‘seed’, or entire genetics, for reproduction whereas women provided only the incubator, or womb, in which that seed grew (Stonehouse, 1994:1; Tuana, 1988:39). This means that the seed was understood as giving life whereas the woman, as the field in which the seed was planted, was understood as providing nurturance (Delaney, 1988:85; Tuana, 1988:38-39). Therefore the womb of a woman, like soil, was regarded as the medium responsible for supporting life, rather than giving life, and for influencing how a child grew (Delaney, 1988:62; Fausto-Sterling, 1987). This idea interacted with those surrounding the safety and positive (life-generating) power of sperm to explain problems with the health of a child as necessarily the result of a defective, and possibly, immoral female body. Stemming from this, problems such as ‘barrenness’ (an inability to conceive) or the birth of a child with health problems were all blamed on women (Stonehouse, 1994:60). The soil was blamed if conception could not occur, as if it was regarded too acidic or too barren to support life (Stonehouse, 1994:61). Deformities and health problems were blamed on women’s impure thoughts while the baby grew inside the body or seen as punishment for her sinfulness in general (Stonehouse, 1994:61). Such ideas had the effect of naturalising women’s responsibility for reproductive health problems while establishing the legitimisation of men’s exclusion from understandings about child health problems. It is clear that such past understandings influence the enduring and gendered constructions that are reflected in current public health and medical discourses.
Women’s responsibility to control genetics

Further negating men’s influence on reproductive health, and reinforcing the perceived safety or untainted state of viable sperm, are discourses which attribute responsibility to women for overcoming genetic threats to foetal health. Given that it is now known that men and women contribute equal genetic material to a foetus one may assume that each member of a couple could be held equally responsible for any genetic congenital health problem that arises. However, this is not the case. Instead my findings show that women are attributed with greater responsibility for genetic problems based on understandings of possible interactions between the genetics of the foetus and its environment, that is, a pregnant woman’s body. In order to explore this I return to discourses relating to foetal alcohol spectrum disorder (FASD).

As stated in Chapter 3, several of the medical journal articles that I analysed included information about the cause and preventability of FASD. One of these articles (Green & Stoler, 2007) was a review paper that documented existing evidence about the causes of this congenital health problem. Throughout the review the authors made clear that the primary cause of FASD is women’s consumption of alcohol during pregnancy (Green & Stoler, 2007). However, the authors also explain that foetal genetics have a role in predisposing a foetus to the effects of FASD. Such genetic factors may explain why women of a similar age can consume comparable amounts of alcohol during their pregnancies and some will give birth to a child with FASD while others will not (Green & Stoler, 2007:13,19). Furthermore, links between ethnicity and genetic susceptibility to FASD were proposed in the review. In particular, the authors referred to research that has shown that African American people appear to be more genetically susceptible to FASD than people from other ethnic groups in the US (Green & Stoler, 2007:19). Importantly in the context of this Chapter, the authors also highlight that some forms of genetic predisposition to FASD are present only within the male genotype (Green & Stoler, 2007:14). This means that men may have a greater likelihood than women of having a genetic susceptibility to the effects of FASD. This also means that, theoretically, men may be more likely than women to pass on such a predisposition to their offspring.

Despite the complexities that are associated with the known causes of FASD, the tone that permeates the review article constructs women as entirely responsible for preventing and causing the health problem. This is made clear since most of the risk factors and all of the preventative strategies that are identified relate to the behaviours and characteristics of women. Women’s responsibility for FASD is constructed on the basis that genetic susceptibility, regardless of its origin, can only contribute to the development of FASD if a
woman consumes alcohol during pregnancy. Therefore, on the basis of such a simplified cause and effect relationship, which ignores the social context and even aspects of the biological pathways to FASD, women are rendered exclusively responsible. The way in which responsibility for FASD is constructed infers that individual women have the power to mediate (and even mitigate) the effects of genetic factors through the behaviours that they choose to engage in. Similar discourses are also replicated in the medical literature in relation to other congenital health problems, particularly spina bifida. In regard to spina bifida, exclusive responsibility is attributed to women on the basis of the belief that a woman’s consumption of folic acid during pregnancy may overcome a genetic susceptibility to spina bifida. In this case, even if genetic susceptibility for spina bifida is passed to the foetus by the man, women still carry the burden of responsibility for causation.

Through the analysis of discourses relating to FASD, and briefly, spina bifida, I have highlighted another process which legitimises a failure to consider male contribution to the factors that influence child health. The establishment of only superficial links between fathers and the genetics of a child means that almost no inheritance of harm becomes attributed to them on the basis of either their genetic contribution to a pregnancy or their behaviours (Daniels, 2001). The absence or marginalised position of men in discussions about genetic influences on child health has important consequences for women because it means that women alone are positioned to bear the burden and blame. Thus, women become entirely responsible, not only for any direct genetic contribution they make but also for recognising and moderating the effects of the genetic contributions of the man with whom the child was conceived. In addition I have made clear that the construction of women’s bodies and behaviours as inherently more risky than those of men establishes their greater influence in producing congenital health problems and, therefore, positions them as more legitimate targets for medical intervention and regulation.

**Men are sexual, women are reproducers**

Another reason that men are excluded from attention following conception is that they are primarily constructed as sexual, rather than reproductive, beings. According to Beasley, the ideals associated with hegemonic masculinity are central to the construction of an enduring and stereotypically gendered division between men and women. This division is based upon the conceptualisation of men as having strong, virile bodies, whereas contrasting ideals around femininity construct women as sexually passive (Beasley, 2008:157). Such stereotypical representations are pervasive in contemporary society and they influence the ways in which men’s and women’s roles in relation to reproduction are constructed (Connell, 2005; Keane, 1996). The social validity of these constructions is strong since they are based

The stereotypical understandings which support such gendered divisions are also reinforced through academic research. This is evident since extensive social science research has explored women’s reproductive lives, their use of reproductive technologies and their experiences as mothers and nurturers of children (Inhorn, Tjornhoj-Thomsen, Goldberg & Mosegaard, 2009). Meanwhile, there are relatively few works that have explored the reproductive concerns of men or the ways that they could contribute to their own reproductive health or to that of their female partners. This infers that men are viewed as the less important sex in relation to reproduction and reproductive health partly because it is assumed that their biological ‘drive’ is toward copulation rather than parenthood (i.e. towards fathering rather than fatherhood) (Inhorn et al., 2009). In contrast, socially dominant ideas about women’s sexuality revolve around their desire and ability to reproduce. Therefore, reproduction is viewed as integral to women’s sexual function, with sexual desire being regarded as secondary (Beasley, 2008). The findings of my analysis suggest that such stereotypical and dualistic assumptions have an influence on discourses around reproductive health. This influence became particularly apparent during the analysis of the medical literature in which men’s enduring association with sexual intercourse appeared to form a basis from which they were legitimately included or excluded from discussions about particular topics related to reproductive health.

An example of this was found in the medical textbook Llewellyn-Jones Fundamentals of Obstetrics and Gynaecology. This book was similar to the others in that there was scant consideration of men and men’s reproductive responsibility. However, men were the focus within a section relating to sexual intercourse during pregnancy. Throughout this short section of a chapter the authors made clear that men have a responsibility to care for the needs of their pregnant partner during sexual intercourse (Oats & Abraham, 2005:52-53). Given the topic, it appeared that men were regarded by the authors as having a more legitimate presence within the context of this discussion of sexual intercourse. This was highlighted by the way that the authors addressed men directly while providing advice about how they could still engage in sexual intercourse without compromising the health of the pregnant woman or the foetus. For example:

> Men should be aware that certain positions may be uncomfortable and they should not force air into the vagina because it is associated with embolism in pregnancy. (Oats & Abraham, 2005:52)
Men’s explicit inclusion in this discussion, as well as their attribution with responsibility, highlights assumptions about the appropriateness of men being considered within discourses relating to sexual intercourse. Interestingly it also locates men’s sexual desire as not relating to reproduction given that conception is impossible through sex during pregnancy. Furthermore, men’s inclusion in this discussion presumes that they have considerable control over sexual intercourse by initiating it and determining the position. In contrast, the relative exclusion of men from discussions about other topics canvassed within the medical literature infers that men occupy a lesser role, and have less control, in relation to aspects of reproduction that precede or follow sexual intercourse. However, it appears that women’s construction as most closely associated with stages of reproduction following sexual intercourse legitimates them being the primary focus of pregnancy advice.

Similar discourses also operated during the antenatal appointments that I observed. As I explained earlier, men were largely absent and excluded from the context of the antenatal appointments. However, on one particular occasion, Chris, the male member of the couple, was addressed directly by the midwife. At this time the midwife was informing the couple that her role was to care for the health of women in an overall sense during pregnancy. In fulfilling this role the midwife asked Amy, the female member of the couple, whether she undertook preventative health measures, such as having pap smears and performing self-examination of her breasts. It was during this discussion that the midwife suggested that Chris adopt the role to assist Amy to examine her breasts, inferring jokingly that this could be an enjoyable practice for him. This was the only time during the antenatal appointments that a health professional suggested that Chris take part in, or take responsibility for, ensuring the health of his pregnant partner. The potential inclusion of breast examination as part of sexual activity or as an activity that men can gain sexual pleasure from, however, was the motivation for Chris’ invitation to become involved with the health care of his wife.

The strong relationship between the men’s social identities and sexual intercourse, rather than reproduction more generally, was further reinforced by research which was conducted by Gordon (1995) with men who had survived testicular cancer. The physical consequences of testicular cancer often result in the surgical removal of a testicle. This can reduce a man’s ability to conceive and it can also result in problems with ejaculation (Gordon, 1995:246). By interviewing men who shared the experience of testicular cancer Gordon aimed to explore whether the loss of a testicle, the associated changes in sexual functioning and the potential loss of an ability to conceive influenced men’s sense of masculinity. The findings of the interviews revealed that experiencing testicular cancer created a transitional phase for men that encouraged them to reassess the priorities in their lives (Gordon, 1995:248). During this
reassessment men engaged with cultural meanings and social practices that reaffirmed their masculine identities (Gordon, 1995:248). Therefore, despite losing a testicle, and in some cases, the ability to conceive a child, the research participants maintained and strengthened their masculine identities (Gordon, 1995:248).

As their main way of reconfirming a masculine identity, the men focused on their remaining sexual functions and ability to still perform sexually as a way of validating their sexuality despite having compromised or absent reproductive capacity. However, given the effects of the treatments for testicular cancer many of the men felt sexually unattractive. In this situation they relied upon their female partners to reinforce their attractiveness by still treating them as desirable sexual beings. Therefore, for the men, achieving sexual performance became a central means through which they proved their continued manliness through their demonstrated ability to continue to satisfy their female partners’ desires and to perform a central role through which masculinity is expressed (Gordon, 1995:262). Continuing to perform sexually also provided men with a further means of preserving the quality of their sexual relationship with their partner by demonstrating that their body still functioned in a similar way to what it did before the cancer developed. Evoking all these strategies assisted men to satisfy the requirements of a masculine role and it also allowed them to cope with their experience of testicular cancer (Gordon, 1995:263). This suggests that masculinity is not conferred by or fixed to nature and biology exclusively, instead it is constructed, performed and made meaningful within the social context in response to life experience (Gordon, 1995:263). Gordon’s research also suggests that reproduction is not as central to the maintenance of hegemonic masculinity, to male identity or to men’s concept of their sexual performance. This suggests that negative outcomes in the area of reproduction are likely to have different, and perhaps less detrimental, social consequences for men since masculine identity is supported in other areas of life. In particular, masculine identity may be linked to a man’s fertility (ability to conceive a child) without regard to the health of that child which, as my research shows, is attributed to the woman’s body and behaviours during pregnancy.

**Uncertainty equates to no risk for men but potential risk for women**

Dominant ideas about men’s legitimate absence from the context of reproduction and their presumed non-influence on child health outcomes are consistent with the ways in which risks are presented within medical and public health discourses. On the basis of men’s distanced relationship to reproductive health it is assumed that their potential to pose a risk to foetal development is much less than that of women.
The different ways in which risks are presented within public health and medical discourses on the basis of parental sex is demonstrated by consideration of information about two pharmaceutical drugs: aspirin and Roaccutane. Throughout several of the medical textbooks, medical journal articles and health education resources women are advised not to take aspirin tablets during pregnancy. However, within some of the journal articles it is also stated that conflicting medical opinions exist about the effects of aspirin on the developing foetus and that, on the basis of current research evidence, aspirin cannot be confirmed as producing teratogenic effects (Kozer et al., 2002). Despite such uncertainty, and on the basis of contested evidence and an uncertain perception of risk, women are advised not to consume aspirin during pregnancy since it may result in child health problems. This highlights the way that the complexity underlying existing medical knowledge becomes reduced or simplified as it is translated into health promotion messages. This is the same kind of logic that is applied in relation to population based immunisation campaigns. That is, immunisation is provided at a population level on the basis of perceptions of potential risks. However, in order to simplify the health promotion message immunisation is recommended for population group at ‘potential risk’ without the complexity of this risk being communicated along with that message. In the case of immunisation as well as aspirin we can see that simplicity in the message, whether that be encouraging immunisation or discouraging aspirin use, is preferred in an attempt to gain compliance and achieve improved health outcomes. However, the effects of the message surrounding use of aspirin by pregnant women have more complex (particularly gendered) secondary effects than the approach used in relation to immunisation, which I now explain through the example of Roaccutane, a drug that is used to treat severe cases of acne.

Consumption of Roaccutane has been shown by some studies to influence the number and functioning of live sperm (Roche Australia, 2005:7). However, medical uncertainty about the extent to which Roaccutane may pose a threat to foetal development following conception still exists since few studies have been undertaken to explore this potential and those that have been undertaken have produced conflicting results. Despite such uncertainty and a relative lack of evidence, the potential risk associated with men’s consumption of Roaccutane before or at the time of conception is presented as unimportant within the medical textbooks or journal articles that I analysed. Instead the potential risk associated with Roaccutane is negated on the basis of dominant beliefs about the untainted nature of sperm and men’s overall lack of influence in contributing to congenital health problems. This is
demonstrated by the broad conclusion which appears in the Australian textbook *Practical Paediatrics*:

Drugs and chemicals taken by men have not been proved to increase the incidence of abnormalities in their offspring. (Roberton & South, 2006:287)

Consideration of this quote, and the general discourses surrounding men’s consumption of Roaccutane, suggests that, in contrast to the tentative approach adopted in relation to aspirin, when a drug that is associated with the same level of uncertainty and contestation is consumed by men, the perceived level of risk is presented as minimal, ignorable or non-existent. Therefore, the gendered basis upon which risk becomes understood operates to transfer an unequal burden of reproductive responsibility to women. Such a burden involves women avoiding exposures that are confirmed as risky as well as those that pose an unproven but potential risk, and given the high level of anxiety about the role of women’s bodies posing a threat to foetal development; these potential risks are likely to be limitless (Keane, 1996:265). In order to avoid both confirmed and potential risks women must impose a higher level of surveillance over their bodies and behaviours than is expected of men. It is clear that the implications that are associated with the gendered construction of risk are consistent with the ideas of feminist anthropologist Jeannette Kupfermann. Working under the guidance of influential theorist on purity and danger Mary Douglas in the 1970s, Kupfermann (1981:11) suggested that societal understandings about the physical body become reflective and reinforcing of structures of social relations. This means that within the context of unequal gender relations the physical body becomes a symbol through which particular inequalities are represented and legitimised (Kupfermann, 1981:12). The operation of understandings about the low and high risk status of men’s and women’s bodies achieves such legitimisation since, on the basis of it, women become represented at the most appropriate targets for control and intervention while men become excluded and excused from responsibility for congenital health problems. Therefore, it is not so much the nature of risks as it is the construction of understandings about groups from which those risks are thought to emanate that shapes current knowledge of, and responses to, the potential causes of foetal harm (Daniels, 2001:325).

Anne Fausto-Sterling (1987) proposes that two interrelated cyclic processes have an influence on how scientific knowledge is constructed and interpreted in society and I believe that these are useful in understanding the gendered perceptions of risk that are presented in the discourses. The first is the process by which scientist’s cultural understandings of gender, whether conscious or unconscious, influence the construction of scientific theory about a supposedly ‘objective’ human nature (Fausto-Sterling, 1987:61). The second is the process
by which scientific theory operates to shape the social concept of gender (Fausto-Sterling, 1987:61). The operation of these processes is evident in the research data because it is clear that social norms around gender have influenced the content of the medical and public health discourses. It is also clear that the naturalisation of particular norms through their inclusion in public health and medical discourses operates to shape and reinforce particular gendered assumptions, thereby increasing their power within society.

**Conclusion**

Throughout this Chapter I have argued that discourses surrounding reproductive health equate men with sperm, its production and conception and, in doing so, exclude them from the context of reproduction following conception. Men also become excused from reproductive responsibility on the basis of their presumed non-influence as well as through the positioning of women as more legitimate targets for medical and public health intervention. By exploring the discourses that operate to exclude and excuse men I have identified some of the processes through which gendered stereotypes and cultural norms around reproduction are constructed and maintained. I have also made clear that the dominant focus on women and the relative exclusion of men from thinking about reproductive health have resulted in potentially important areas of reproductive health remaining unexplored and even unnoticed (Fausto-Sterling, 1987:69). The dominant focus on women also renders men to be less important than women in the lives of their children. This finding is particularly important because this consistent exclusion of men has implications for the way that we think about the capabilities of men in relation to child care and also about the appropriateness of men taking an equal role in parenting. So while women may necessarily have a more central role in relation to pregnancy because of their biology, we must question the generalised exclusion of men. Such questioning is important because the exclusion of men early in their experiences of becoming a parent is likely to have ongoing effects for how men, and society in general, understand the role of fathers and on the quality of fathers’ relationships with their children.
CHAPTER 7

The power to construct: De-emphasising uncertainty and legitimising women’s greater responsibility

Throughout the previous three chapters of this thesis I have explained that public health and medical discourses operate to gender, individualise and naturalise responsibility for congenital health problems. I turn now to consider the third theme that shapes this thesis. In this Chapter I explain how medical and public health discourses become legitimised in a way that gives them the power to construct maternal responsibility for congenital health problems. Developing such an analysis is important within the context of this thesis because, as I explained in Chapter 4, medical and public health knowledge about the cause and prevention of congenital health problems remains incomplete and pervaded by uncertainty (Gifford, 1986:224). Such incompleteness has the potential to undermine the authority of the knowledge claims that are made within these fields. However, as I explain in greater detail throughout this Chapter, one way that the legitimacy of public health and medical knowledge is reinforced is through the discursive reduction or erasure of uncertainty.

While exploring how uncertainty becomes diminished or erased in medical and public health information, and in identifying the implications this produces, I draw on two examples: health promotion messages that encourage folate consumption during pregnancy and those which discourage consumption of alcohol during pregnancy. Through these examples I present two arguments. The first is that the erasure of uncertainty in public health and medical evidence is another process by which maternal responsibility becomes constructed. My second argument explains that there are several processes that convey authority to public health and medical information, thereby increasing its power. Through these processes, and the consequent representations of authority, medical and public health information becomes constructed as the most legitimate sources of understanding about the cause and prevention of congenital health problems. This primacy perpetuates dominant understandings about gendered attributions of responsibility for congenital health problems, despite underlying inconsistencies and contestation in the existing bodies of research evidence. I begin by exploring the framing and implications of health promotion messages about folate.

Blaming through framing: Spina bifida equals maternal deficiency

During the interviews with women who have a child with spina bifida, discussion frequently arose about the B group vitamin folate and the synthetic form, folic acid. This topic was usually raised by the participants early in the interviews. All of the women recognised that medical evidence links maternal folate deficiency to an increased risk of having a child with
spina bifida. Based on this evidence, the current health promotion advice, which was included in many of the health education resources that I analysed, encourages all women to increase their folate consumption before and during pregnancy:

Folate (or folic acid) is a vitamin which helps reduce the risk of birth defects such as spina bifida. It is recommended that a folate supplement be taken one month before and for the first three months of pregnancy. Folate supplements are available from pharmacies without a prescription. Folate is also found in: green leafy vegetables (eg broccoli, spinach), wholegrain breads and fortified breakfast cereals, oats, nuts, vegeemite [and] fruit (eg citrus fruits and berries). (Lyell McEwin Hospital, 2005:3)

... 

Your doctor will recommend you take a folate supplement until the 12th week ... [Folate] is very good for the development of the baby’s central nervous system. It plays a protective role against defects such as spina bifida (Johnson & Johnson, 2007:9-10)

During the interviews it became clear, however, that the framing of this advice, and its widespread distribution in the absence of other information about the cause or prevention of spina bifida, operated on a practical level to infer that spina bifida necessarily results from a woman not consuming enough folate. The pervasiveness of this understanding, which exists as part of the broader context of heightened maternal responsibility for reproductive health, led some women who have a child with spina bifida to blame themselves for their child’s health problems even though they took folic acid. This is illustrated by Jane and Mary:

You go through horrendous guilt because you know you’ve got the folate issue and you think well … I’ve caused this. Even though I took my folic acid tablets, but I think ‘Oh what if I could have done better?’ ‘What if I should’ve taken more than one tablet?’ Because I remember checking with my doctor and they said no you’re doing right. But it’s … really hard to let that go because you’re just feeling so much guilt and … you just feel like you caused it. (Jane, 34 years, 3 year old daughter with spina bifida)

...

You’re told that folate is important … and you think that that’s a cure and if it doesn’t work you must be deficient. You must have been doing it wrong or something. (Mary, 37 years, 4 year old son with spina bifida)

While the framing of the health promotion message about folate led Jane and Mary to assume responsibility for their child’s spina bifida, several of the other women refused to do this. The main reason for their objection was that, through their own research and personal experiences, they had learnt that there is considerable complexity and uncertainty existing within current evidence about the cause of spina bifida. For example, one participant had
discovered that a prescription medication that she consumed in early pregnancy had been associated with the cause of spina bifida. Other participants suggested that genetic factors or bad luck may be implicated, while they also acknowledged that in much of the medical literature they had read, the causes of spina bifida were regarded as largely “unknown”. Such uncertainty and complexity is not, however, reflected by the framing of the current health promotion message about folate supplements. As a result, this creates the impression of a linear, cause and effect relationship between spina bifida and women’s folate deficiency. This is an important consideration because even though the majority of the women I interviewed did not blame themselves for their child’s spina bifida, they believed that the current framing of preventative health advice was overly simplistic. Such over-simplification may encourage other people to blame women for their child’s health problems, which is a concern highlighted by Emma:

Sometimes I feel that people are judging me, that I did something wrong to cause it. Especially with all the advertising nowadays that says “Spina bifida, if you take extra folic acid it will reduce the risk”, but people don’t hear the reduce the risk part. So that’s probably where we’re not … to me the way that it’s sold is often not right. The reduce the risk bit should be made clearer … because I’ve done everything right, I probably did a bit better than most people but other people are still thinking that ‘Oh well she must have done something wrong to end up in this position.’ (Emma, 27 years, 3 year old daughter with spina bifida)

In particular, several of the women recounted feeling judged, either implicitly or explicitly, during their contact with health professionals. This judgement intensified their dissatisfaction with the framing of health advice and increased the potential for them to feel responsible for their child’s health problems, as Kelly explains:

I hate seeing new doctors because the first question is “Did you take folate during pregnancy?” It’s not until I explain, that we can get over that and they stop judging me. But it’s always assumed that you didn’t and that just makes me keep doubting myself. I have begun to hate the folate equals spina bifida message. It’s important, but the way it’s interpreted has some nasty effects. (Kelly, 32 years, 4 year old daughter with spina bifida)

These findings suggest that the framing of health promotion messages can obscure underlying uncertainties and complexities in the existing evidence and, in doing so, strengthen linkages between particular causes and particular outcomes. The presentation of health promotion messages in this way has the potential to increase women’s responsibilities for their children’s health problems and can lead to them feeling blamed. Such blame became legitimised in the examples that I have provided through the presentation of health information in a way that renders a child’s spina bifida as indicative of their mothers’ deficiencies. I now extend my analysis to consider in greater detail how uncertainty becomes diminished and simplified within public health and medical information. To do so, I focus on
examining how the uncertain and contested body of evidence relating to the effects of alcohol consumption during pregnancy becomes translated into a clear health promotion message.

**Disappearing uncertainty: Pregnancy and alcohol just don't mix!**

Through my analysis of chapters from medical textbooks I identified dominant messages about a causal relationship between alcohol and congenital health problems. Alcohol was a frequent topic of discussion in all of the textbooks and it was consistently represented in negative terms. Such negativity was conveyed in three ways.

The first involved the presentation of statements which attributed particular congenital health problems directly to women’s consumption of alcohol. For example intrauterine growth restriction (IUGR) is linked to maternal alcohol consumption in the following quote:

> Infants born to alcoholic mothers often exhibit IUGR as part of the *fetal* [sic] *alcohol syndrome.* (Moore & Persaud, 2003:85) [Emphasis in original]

The inclusion of this quote within a textbook assists in conveying, as medical ‘evidence’, the idea that “alcoholic” mothers are assumed to produce children with FASD which “often” includes retarded foetal growth. This quote reinforces the danger associated with alcohol since it links alcohol with foetal damage and also with the propensity to encourage women’s dependency and excess consumption, thereby contributing to the risky potentials presented through women’s behaviours.

The second way that alcohol consumption was discussed was through an interaction with other agents to cause particular congenital health problems:

> Maternal zinc deficiency has been implicated in abnormal fetal [sic] growth and enhanced susceptibility to such teratogens as alcohol (Uauy, Mena & Warshaw, 2006:175).

The establishment of such indirect relationships between alcohol and congenital health problems further reinforces the underlying danger associated with women’s consumption of alcohol during pregnancy (and here that danger extends to consumption of *any* amount rather than just excessive amounts). In this way, alcohol is constructed as a substance that is not *only* associated with inherent danger but also as something which may interact with other aspects of women’s biology in a *indeterminable, unpredictable* way to increase harm to a foetus.
The negative discourse that permeated discussions about alcohol consumption in the medical textbooks was reinforced by clear advice about the need for women to abstain completely from alcohol during, and in many cases before, pregnancy. Such direct advice also implicated pregnant and pre-pregnant women as responsible for, and capable of, preventing foetal harm. This is reflected in the following quote from a section of the medical textbook *Practical Paediatrics*:

The harmful effects of ethanol on the developing human are well documented:

- Teratogenic effects of alcohol are dose-related, ranging from clinically inapparent effects to the fetal [sic] alcohol syndrome of prenatal and postnatal growth failure, microcephaly, intellectual disability, a characteristic facial appearance, cleft palate, microphthalmia and heart defects.

- Heavy drinking throughout pregnancy is associated with a 10% risk of fetal [sic] alcohol syndrome and a 30% risk of observable fetal [sic] alcohol effects.

- No minimum safe dose has been defined.

- Consumption of a significant amount of alcohol prior to diagnosis of pregnancy is a frequent clinical scenario. It is difficult to estimate the risk of harm to the baby because of a lack of good data.

- Women should be advised to avoid alcohol during pregnancy. (Liebelt & Hotham, 2007:285) [Format in original]

Such direct advice about the importance of women abstaining completely from alcohol during pregnancy was replicated consistently in the health education resources. An example of the relationship that was established between alcohol and congenital health problems through the presentation of such advice is provided in the next quote. This quote appeared in a booklet that was included in the Bounty Bag\(^42\), which is distributed to most women who attend antenatal appointments in South Australia:

Can you drink when you’re pregnant? Of course you can—provided you’re drinking water, that is … As for alcohol, as no safe lower limit of alcohol consumption in pregnancy has been established, experts around the world believe it’s probably best to avoid it completely. Consumption of alcohol during pregnancy can lead to fetal [sic] alcohol syndrome or fetal [sic] alcohol spectrum disorder. Babies suffering from these syndromes may experience growth and development delays, brain problems and facial abnormalities. (Bounty, 2007:36)

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\(^{42}\) Refer to Chapter 3 for further information about Bounty Bags.
Interestingly though, as is reflected, but also de-emphasised, in both of the previous quotes, there appears to be continuing uncertainty about the medical evidence upon which the relationship between alcohol consumption and the cause of congenital health problems is based. This is clearly demonstrated in the last quote since the idea that “no safe lower limit of alcohol consumption in pregnancy has been established” could also be interpreted to mean that there may be an amount of alcohol that is safe for women to consume during pregnancy. This means that the underlying uncertainty, if conveyed, has the potential to lessen or problematise the perception of risk associated with women’s consumption of alcohol during pregnancy. The possibility that there may be an amount of alcohol that is safe for women to consume during pregnancy is not acknowledged within the texts that I analysed, however. Perhaps this is because such acknowledgement would challenge the legitimacy of advice about a need for total abstinence and also encourage questioning about why “experts” believe abstinence is “probably” necessary even though the current body of contested evidence may not support this claim.

The disparity that I have highlighted between the health advice that is being presented as almost, but not totally, definitive and the high level of uncertainty that exists within the relevant evidence further reinforces an argument that I presented in Chapter 6. This argument proposed that the dominant understanding of women’s bodies as inherently risky within medical and public health discourses operates to position women as responsible for controlling their behaviours in order to offset risks, even if these risks are unconfirmed and contested. This discourse is gendered, however, as is further reinforced here since no advice was included in the textbooks about a need for men to abstain from alcohol because of an unconfirmed, potential risk for it to have a teratogenic effect on their sperm. The discourse is also decontextualised because the social context in which alcohol consumption occurs remains largely unacknowledged, which contributes further to the construction of individual women and their bodies as the most important and most dangerous sites of risk.

The uncertainty that pervades evidence about the effects of women’s alcohol consumption during pregnancy became more apparent during my analysis of the medical journal articles. Three of the journal articles in the sample, two of which were systematic reviews, focused specifically on examining the effects of alcohol consumption during pregnancy. My analysis of the two systematic reviews revealed that there are even greater inconsistencies and disparities within the relevant evidence than was inferred in the medical textbooks. In particular it became evident that there are differences between research studies in how women’s alcohol consumption is measured and in what is classified as low and high levels of consumption during pregnancy. This is clear since the aim in one of the review articles was
to collate evidence from studies which compared the pregnancy outcomes of women who “abstain from alcohol or drink at low-moderate levels” (Henderson, Gray & Brocklehurst, 2007:243). For the purposes of this review “low-moderate intake” was classified as consumption of less than 12 grams of alcohol per day, which is the equivalent of one small glass of ordinary strength wine or three quarters of a pint of ordinary strength beer in the UK (where the review was undertaken) (Henderson, Gray & Brocklehurst, 2007:243). However, in the second review article the vague measure of “one drink per day” (Green & Stoler, 2007:19) was classified as heavy alcohol consumption rather than low to moderate.

Such inconsistencies in the classifications that are used, and the uncertainty that this has the potential to produce in medical practice, were also highlighted in the third journal article that I analysed. The authors of this article reported the findings of a qualitative survey that they undertook to examine the knowledge, attitudes and clinical practices of a sample of 600 obstetricians in the US regarding patients’ alcohol consumption during pregnancy. According to their findings 83% of respondents indicated that a lack of consistent information about the thresholds of alcohol consumption that are associated with adverse reproductive outcomes was a major barrier to their effective practice in this area (Diekman et al., 2000:756).

Importantly, the authors also identified corresponding uncertainty within the personal beliefs of obstetricians about alcohol consumption during pregnancy. In particular, they explained that while 97% of those surveyed reported asking their pregnant patients about alcohol consumption many also reported personal confusion about the potential effects of alcohol consumption during pregnancy (Diekman et al., 2000:756). Furthermore, the findings presented in the article showed that the majority of obstetricians surveyed were not convinced that total abstinence from alcohol was necessary for pregnant women. Despite this, a similar majority of respondents reported that they follow the advice of federal advisories and always advise abstinence (Diekman et al., 2000:756, 762). Reasons for this may be related to pressure from medical authorities who prescribe this message and also a desire on behalf of respondents to avoid litigation. However, regardless of the reasoning that informs it, the erasure of the uncertainty that surrounds advice about alcohol has important secondary effects for women in terms of reinforcing the importance of maternal responsibility as personal sacrifice during pregnancy as a precursor for foetal health and in establishing the potential for blame if total abstinence is not achieved.

Similar experiences of personal uncertainty were also evident in the narratives of the medical professionals whom I interviewed. In particular it appeared that several of the medical professionals experienced a tension between their personal experiences and the official medical advice that they give women about a need to abstain from alcohol completely during
pregnancy. For the professionals I interviewed this tension was based mainly on a lack of clear medical knowledge about what level of alcohol consumption may interfere with the growth and development of a foetus, as demonstrated in the following quote from Mike, an obstetrician:

The default is most of our patients automatically already say “Oh I never drink anything.” So you just reinforce “Oh that’s beautiful, that’s good, keep on doing that.” So I’ll never say “Oh you can have a drink.” But pre-Christmas people may say “Look I have an important Christmas function can I have a glass of wine?” So I say “Yes you can have one glass of wine” [shrugs]. “Have one glass and that’s it. That’s fine.” I try to, depending on … if it’s well educated people then I will say “Look there’s actually no data … there’s nothing, so if you do have the odd glass of wine [shrugs] there’s no data.” If you look at France where if they say ‘don’t drink’ they are really talking about three glasses per day, that for them that’s zero. One at lunch and one in the evening … so that’s at least two. In France no drinking means two glasses of wine. And I mean I don’t think they have many more problems with their babies, so it’s just unclear.

Further reinforcing this point, another obstetrician, William, stated that he routinely advises patients to abstain from alcohol during pregnancy. Yet he also stated that he had felt comfortable about his wife drinking alcohol while she was pregnant with their child. This tension between the certainty that William presents during his consultations with patients, and his differing personal beliefs, is demonstrated in his response to a hypothetical scenario that I posed which involved a pregnant woman named Karen asking whether her alcohol consumption could have caused the retarded growth of her foetus:

Karen would probably ask me about whether it’s appropriate to have that amount of alcohol. One or two standard drinks each weekend. I mean I would say to her that I don’t know that there is any evidence that that amount of alcohol would harm her developing child. Um, but the correct thing to do is to say that you should not have any alcohol through pregnancy, alcohol is known to damage developing cells. I guess the hard thing is to say well at what point does that [damage] kick in? And what we’re probably talking about is not so much birth defects but whether or not somewhere along the line that it’s going to have an impact on your child’s long term wellbeing. For example is your child going to have a lower IQ than it would have had otherwise? And how you’re ever going to measure that I have no way of knowing, but that’s probably the sort of measure you’re at. So I would tell her that no alcohol is best but, personally, say in my own personal life, in my own family, I know that my wife had the occasional drink at a party. I know that most of the people I know that have had children over the years have a drink socially every now and again and so I wouldn’t feel anxious if she said look “I’m going to continue to have a drink”; that wouldn’t worry me personally. But the scientific data is unclear on it.

These findings suggest that alcohol consumption is an area where medical professionals, and medical evidence, are marked by considerable uncertainty. However, importantly, even in the context of considerable inconsistencies and uncertainty, medical professionals adhere
strongly to advice regarding the need for pregnant women to abstain from alcohol completely. Discursively, the consistent replication of such advice by medical professionals operates to further diminish and obscure the uncertainty that surrounds understandings about the link between women's alcohol consumption during pregnancy and foetal harm.

Contributing to, and stemming from, this minimisation of uncertainty, some of the medical professionals appeared particularly anxious about the possibility that women's consumption of any amount of alcohol during pregnancy results in a high risk of infants being born with the congenital health problem foetal alcohol spectrum disorder (FASD). Such anxiety persisted even in situations where the medical professionals had no personal experience of diagnosing or treating an infant with FASD despite having patients who consumed alcohol. While such a lack of experience may have had the potential to increase the uncertainty of medical professionals about the dangers associated with alcohol, it did not appear to lessen their perception of risk. In fact, conversely, the uncertain nature of the evidence appeared to encourage several of the medical professionals to advise abstinence on the basis that any amount of alcohol may result in FASD. This is demonstrated in the response below which was provided by Robert who is an obstetrician working in a public hospital when I asked if he had professional experience with patients who have FASD:

> Not a lot, no. As much as there's the advertising about it um … the actual syndrome as such, the full blown syndrome, is pretty unusual. So I don’t … I can’t … I personally haven’t seen, certainly in my private practice, I didn’t ever see anyone that had foetal alcohol syndrome. I'm aware that the occasional child that's been born here in the hospital over the years, you know, definitely had foetal alcohol syndrome but it's pretty, uh, pretty unusual. And that’s the challenge to say what are the thresholds for which alcohol can be given and, you know, people often ask you that question and you have to say well look, you know, presumably no alcohol is safer. That’s all we know, so, yeah, no alcohol is probably best.

The findings that I have presented so far in this Chapter demonstrate that advice about alcohol is consistently presented in a way that reinforces its relationship to the cause of congenital health problems. The minimisation of uncertainty through medical practice and widespread distribution of overly simplistic health promotion messages has the important effect of strengthening links between women’s behaviours during pregnancy and negative influences on the development of their foetus. This also reinforces women’s responsibility to control their behaviours during pregnancy in order to protect their foetus from health problems. The heightening of responsibility, and potential blame, on the basis of uncertain or even inaccurate medical evidence is not restricted only to alcohol, however. Instead, as I explained earlier in the Chapter, similar findings also emerged from my interviews with women who have a child with spina bifida.
I now continue to consider how the uncertainty that emanates from contested evidence becomes diminished and simplified by considering further processes that convey authority within public health and medical information. I begin by explaining the role of evidence-based medicine (EBM) and the related process of standardisation.

**Evidence-based medicine: Standardising uncertainty**

Within the fields of public health and medicine in Australia there is a general acceptance of, and reliance on, the model of EBM. EBM is based on the systematic evaluation of scientific evidence and involves the standardisation of medical practice (Greenhalgh, 2010; Sackett, Richardson, Rosenberg & Haynes, 2000). Standardisation is achieved through the production of recommendations that specify how medical professionals should practice and what kinds of advice or treatments they should offer (Hester-Moore, 2005; Sackett *et al.*, 2000). These recommendations are presented in the form of practice guidelines. Practice guidelines function to summarise current scientific knowledge about a topic and to dictate how it should be applied in clinical practice (Hester-Moore, 2005:175). The main aims of practice guidelines are to generate uniformity within medical practice and to streamline medical care (Hester-Moore, 2005:175). The operation of practice guidelines in constructing certainty, and the implications of this in terms of positioning women as responsible for congenital health problems, is particularly evident in relation to issues surrounding alcohol consumption during pregnancy.

In Australia, standardised practice guidelines relating to alcohol consumption during pregnancy have been developed by the Government’s National Health and Medical Research Council and endorsed by the specialist professional organisation The Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG). I now consider the content of these guidelines, and the evidence that informs them, to provide insight into how the process of standardisation in EBM contributes to the production of health promotion messages which are framed in a way that diminishes the inconsistencies in underlying medical knowledge.

The Australian Government has produced two documents which provide current evidence-based information about alcohol intake, the harms associated with it and appropriate treatments. One is titled *Australian Guidelines to Reduce Health Risks from Drinking Alcohol* and it was produced by the National Health and Medical Research Council (NHMRC, 2009) and the second document is called *Guidelines for the Treatment of Alcohol Problems* (Haber, Lintzeris, Proude & Lopatko, 2009) and it was produced by the Australian Government Department of Health and Ageing. Throughout both of the documents it is made clear that
existing evidence about the effects of alcohol consumption during pregnancy is problematic, as explained here:

Interpretation of the published research is hampered by methodological problems, including:

- difficulties inherent with under-reporting of alcohol intake and accurate documentation of the quantity, timing and frequency of alcohol intake during pregnancy
- use of variable definitions for low, moderate and high levels of maternal alcohol intake
- failure or inability to identify and adjust for potential confounding factors such as maternal age and parity, body composition, nutrition, polydrug use, cigarette smoking, socio-economic [sic] status and education, and maternal and fetal [sic] genetics
- short duration of follow-up, loss to follow-up, or evaluation of only limited outcomes in exposed children
- difficulties in comparing studies from different countries and settings due to differences in how alcohol consumption is measured and reported
- the focus of some studies on high-risk population groups, the findings of which may not be applicable to Australia or Australians
- publication bias, in which studies with positive results are both more likely to be submitted and accepted for publication. (NHMRC, 2009:68-69) [Format in original]

The authors of both Government documents also acknowledge that the uncertain and contested nature of the existing evidence limits the extent to which accurate conclusions can be drawn about the effects of alcohol consumption during pregnancy, particularly in cases where only small amounts of alcohol are consumed:

While there is convincing evidence linking chronic or intermittent high level alcohol intake with harms, including adverse pregnancy outcomes and FASD, there remains uncertainty about the potential for harm to the fetus [sic] if a woman drinks low levels of alcohol during pregnancy. It is important that all women of child-bearing age are aware, before they consider pregnancy, of both this uncertainty and the potential risks of harm, so they can make informed decisions about drinking in pregnancy. (NHMRC, 2009:77)

However, interestingly, the uncertainty that exists within the evidence is also used as a basis for the framing of a definitive and restrictive directive within both documents. This directive is
that health professionals should advise women who are pregnant or planning a pregnancy that “not drinking alcohol is the safest option” (NHMRC, 2009:78):

A ‘no-effect’ level has not been established, and limitations in the available evidence make it impossible to set a ‘safe’ or ‘no-risk’ drinking level for women to avoid harm to their unborn children, although the risks to the fetus [sic] from low-level drinking (such as one or two drinks per week) during pregnancy are likely to be low. A conservative, public health approach has therefore been taken in recommending that ‘not drinking alcohol is the safest option’ for pregnant women and women planning a pregnancy. This decision was not based on the fact that substantial new evidence had emerged since the previous guidelines were published, but on limitations of the existing evidence. (NHMRC, 2009:68)

I am not arguing that public health should not advise women to avoid alcohol consumption during pregnancy, and I acknowledge that the inconsistencies in evidence make it difficult to establish a level of alcohol consumption that is safe during pregnancy, even at lower levels. Therefore, such a conservative public health approach may be appropriate in order to promote foetal health at the population level. However, what is important in the context of this thesis is to provide consideration of the underlying secondary effects that can emerge from such a definitive health promotion message, which is developed from an unsupported evidential base and yet, in practice, is extremely restrictive for women. Not only is the advice restrictive but it also operates to construct pregnant women as a ‘special’ ‘separate’ category of adults within society for whom alcohol consumption is prohibited and for whom the benefits of alcohol are denied. Such benefits include its effects as a mild relaxant and also the positive cardiac effects that can be achieved by the consumption of small and regular amounts of red wine (Szmitko & Verma, 2005).

The problematic nature of the evidence is made even more apparent since, despite the promotion of such strong advice, the contradictory nature of current understandings continues to be replicated within the documents themselves creating a context of confusion and furthering the uncertain basis upon which this advice is offered. This is demonstrated by the following two quotes:

Women who drank alcohol before they knew they were pregnant or during their pregnancy should be reassured that the majority of babies exposed to alcohol suffer no observable harm. (NHMRC, 2009:68)

However, later in the same document the following quote is presented:

The effects of alcohol exposure on fetal [sic] development occur throughout pregnancy (including before the pregnancy is confirmed), with the developing fetus being most vulnerable to structural damage during the first three to six weeks of gestation (NHMRC, 2009:71)
This quote suggests that the teratogenic effects of alcohol are likely to be most severe in early pregnancy. Yet, contradicting this, the previous quote advises that it is unlikely that alcohol consumption will have an effect in these early stages when women may not know they are pregnant. This evidence has the potential to absolve women from blame. However, the dominant authority that frames the standardised directive of total abstinence overshadows this potential and has the effect of rendering women and their behaviour potentially dangerous and, therefore, in need of surveillance. These ideas are further reinforced by the following practice guideline which was presented in the Guidelines for the Treatment of Alcohol Problems (2009), which problematises the regularity of women’s alcohol consumption, rather than the amount, and encourages surveillance on the basis of this:

Infants born to women who have consumed alcohol regularly during pregnancy should be carefully assessed for foetal alcohol spectrum disorders by a paediatrician aware of the maternal history, with further management directed by the appropriate experts. (Haber et al., 2009:xvi)

The need for medical surveillance over women, and the subsequent positioning of them as potentially responsible for congenital health problems, is further legitimised and confirmed in the documents in a way that infers that many women cannot be trusted to maintain abstinence throughout their pregnancy:

Recent data show that 59 per cent of Australian women drank alcohol at some time during their pregnancy (Colvin et al 2007). Furthermore, 14 per cent reported drinking five or more drinks on an occasion in the three months prior to pregnancy (Colvin et al 2007). However, many women choose to abstain from alcohol some time during pregnancy—58 per cent during the first and second trimester and 54 per cent in the third trimester (Colvin et al 2007). In the first trimester, 15 per cent of women surveyed drank above the NHMRC 2001 guidelines and this proportion decreased to 10 per cent in the second and third trimesters (Colvin et al 2007). In a recent national survey, “34 per cent of women had drunk alcohol during their last pregnancy and 24 per cent indicated they would drink in a future pregnancy, despite knowledge of the adverse effects of alcohol and the fact that 78 per cent believed that reducing or ceasing alcohol intake in pregnancy may benefit their baby” (Peadon et al 2007). (NHMRC, 2009:15-16) [References in original]

As reflected in this quote, the discourses surrounding alcohol consumption also have the effect of representing alcohol consumption as a choice for women. Importantly, this is a choice which is represented as uninfluenced by women’s social circumstances and as completely unrelated to the addictive potential of alcohol. This furthers the

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43 The 2001 Guidelines stated that pregnant women “may consider not drinking at all” but “if they choose to drink, over a week, [they] should have less than 7 standard drinks, AND, on any one day, no more than 2 standard drinks (spread over at least two hours)” (NHMRC, 2001:16).
decontextualisation of discourses which inform women’s responsibility for congenital health problems. It also establishes the potential for blame since, as highlighted in the previous quote, women can be demonised for ‘choosing’ to still consume alcohol despite knowing about the ‘dangers’ which, through such an individualistic framing, renders them negligent should their alcohol consumption be perceived as the cause of a congenital health problem.

During this analysis I have shown that through the process of standardisation, a definitive health promotion message about abstinence has emerged from a contested and uncertain evidence base. In relation to alcohol, standardisation has created a medically enforceable ‘fact’ that has become a device of clinical practice, particularly in legitimising a focus of clinical surveillance over pregnant women (Armstrong, 2009:104). The authority that underpins the standardised guidelines that relate to alcohol is increased, despite the acknowledged contestation, by the official position of RANZCOG which advises medical professionals to follow the guidelines produced by the Australian Government and to recognise the validity of standardisation practices in producing valid knowledge:

RANZCOG endorses the principles of evidence-based medicine and recognises the NHMRC levels of evidence and grades of recommendations. (RANZCOG, 2009:1)

This suggests that EBM has the effect of endorsing a particular position in a way that conveys power to that position despite underlying contestation between the individual experts who are then required to maintain that position. The effect of standardisation in overriding complexity and in contributing authority to medical and public health information is further demonstrated by the way that the need for total abstinence has become translated into the widely distributed health promotion message that now appears on posters in antenatal clinics in South Australia and in the pamphlets given to most women who attend antenatal appointments which states:

Pregnancy and alcohol don’t mix. There is no safe time to drink alcohol during pregnancy. There is no safe amount of alcohol. Alcohol can harm your baby for life. (Government of South Australia, 2007a) [Emphasis in original]

This quote also shows how evidence becomes over-simplified as it is translated into a health promotion message. Perhaps it is the over-simplification of evidence surrounding alcohol consumption that encourages some women to doubt the relevance of the health promotion message and continue to drink alcohol during pregnancy. This is possible since several of the women I interviewed reflected on their observations of other women either drinking alcohol or not taking folic acid during pregnancy and then giving birth to healthy children as a way of trying to understand the factors that do or do not cause congenital health problems.
Therefore, the erasure of uncertainty within health promotion messages may have the unintended effect of making people less inclined to follow public health advice because they understand that the current framing of these messages is likely to amplify and exaggerate the associated risks.

Consideration of some of the implications that are produced from the overly simplistic framing of health promotion messages also indicates that the erasure of uncertainty feeds a system of power which encourages the regulation of women’s bodies in particular ways, irrespective of whether such strong regulation is effective in improving child health outcomes. In understanding this system and its effects, the work of Foucault is useful. For Foucault, medical knowledge is a form of *bio-power*. Foucault understands bio-power as a socially and politically productive matrix in which medical knowledge and professionals occupy privileged positions of authority. I now explain Foucault’s theory of bio-power since it provides further insight into some of the findings that I have presented in this Chapter and the thesis more broadly.

**Bio-power and the reinforcement of medical authority**

Foucault understood medicine to be a powerful force within society which gains power through its claims to know the ‘normal’ body—and thereby its ‘disorders’:

> Medical power is at the heart of the society of normalization. Its effects can be seen everywhere: in the family, in schools, in factories, in courts of law, on the subject of sexuality, education, work, crime. Medicine has taken on a general social function … which is the major form of power. (Foucault, 1996:197)

Foucault developed two different, but related theories that are useful for understanding the forms of power that are manifest within the medical system. The first of these is a theory of bio-power (Foucault, 1976) and the second is his theory of governmentality (which was introduced in Chapter 4) (Foucault, 1991b).

In introducing his theory of bio-power, Foucault (1976) observes that since the seventeenth century there has been a shift in the way that governments manage populations. This has involved a change from a repressive approach to a constructive approach. Whereas sovereign power was once exercised by killing or by an abstinence from killing it has now been replaced by forms of power that promote and shape life (Gastaldo, 1997:114). Foucault (1976) suggests that this shift has resulted in the development and expression of what he labels bio-power, that is, a set of processes, techniques and technologies through which the biological features of humans become the object of political control (Foucault, 1976). Bio-
power works to analyse, explain, define and shape individuals and their behaviours (Danaher, Schirato & Webb, 2000:ix). In doing so, bio-power operates as an implicit yet highly pervasive and effective form of social regulation.

Foucault (1976) understands such regulation to emanate, in part, from the state. In this sense, the state encompasses the ensemble of coercive institutions of power that exist within society as well as the broader structures of power within which those institutions are located (Foucault, 1976:141). Foucault (1976:139) explains that in the exercise of bio-power the attention of the state is directed mainly toward regulating the reproductive capacities of bodies as well as people’s experiences of health, birth and death. It was not until the eighteenth century that the concern with the fostering and regulation of life, which underpins bio-power, emerged. According to Foucault (1976) this was the first time in history that power became concentrated on life instead of death and this resulted in attention being focused on people’s biological, political (access to power) and social realities.

The central focus of the regulation that is achieved through bio-power is the body. Through the processes involved in bio-power the body becomes constructed as a political field that is inscribed, shaped and constituted by power relations. For Foucault (1976) the emergence of bio-power resulted in the body becoming a focus of analysis as an individual entity rather than just as existing within the collective identity of the population (Foucault, 1976). Since this time, many techniques and mechanisms of power have been focused on the body and members of the medical profession have emerged as the legitimate holders and producers of knowledge about the body. The influence of disciplinary power over the body has had the effect of dividing it into parts and training it with the intention of transforming the body so that it becomes more efficient (and compliant) (Gastaldo, 1997:114). These processes of bodily subjectification and transformation occur in subtle and continuous ways as the body is located within a complex web of powers, each of which has a regulating force (Foucault, 1976). As a result, the body has become an object of knowledge—and in particular, medical and public health knowledge.

The exercise of bio-power in society has involved the emergence of many implicit and explicit apparatuses of power. Through these, bio-power is exercised in two main forms. One form operates at the level of the individual and it involves individuals being positioned within, and actively engaging with, a complex web of self-discipline and surveillance (Burchell, 1996:23). Part of this surveillance is executed through what Foucault terms the gaze (I introduced this in Chapter 2). Foucault (1979) explains that individuals’ continual exposure to the gaze of
authority within modern society constructs them as both subjects and objects of power and knowledge. Foucault (1979:155) theorises that individuals are exposed to:

an inspecting gaze which each individual under its weight will end by interiorizing to the point that he is his own overseer, each individual thus exercising this surveillance over, and against, himself [sic]. A superb formula: power exercised continuously and for what turns out to be minimal cost.

Individuals practice the self-surveillance that is encouraged through their exposure to the gaze by monitoring their own conduct and regulating their bodies and behaviours. Such a reflexive focus on the self and the potential effects of our own behaviours is driven by a fear of being observed, and judged, by a powerful authority (Foucault, 1979). It is also driven by a positive desire to protect against negative outcomes, such as disease. Such self-surveillance is a central component of the disciplinary power that emerges from bio-power. As suggested in the previous quote, self-surveillance results in a situation in which, within a society subject to relentless disciplinary power, individuals embrace, and apply, that power to discipline themselves (Foucault, 1979; Sawicki, 1991:68). The operation of self-regulation means there is less need for coercive apparatuses of power to impose direct monitoring over the population. Instead individuals monitor themselves in an attempt to maintain compliance with social ‘norms’ and, subsequently, avoid negative judgement from an imposing, surveying gaze (Foucault, 1975). Therefore, within Foucault’s (1976) model of bio-power, the individual body becomes recognised as both a site from which power emerges and also as a site within which disciplinary power operates to regulate the productive capacity of the individual.

The second form of bio-power is based on the more direct imposition of power and control through the policies and interventions that are used to govern the population (Deveaux, 1994; Foucault, 1976). This involves the ‘expert’ regulation of bodily processes and the ‘expert’ imposition of what such bodily processes mean within given cultural settings (Sawicki, 1991:68). The experts involved in this more direct operation of regulatory bio-power may include governments, public health professionals and also medical professionals who seek to define what is ‘normal’ and ‘necessary’ for individuals. Although Foucault did not apply theories of bio-power to women’s bodies directly, it is possible to use these to understand how women become both disciplined and represented as powerful individuals with considerable agency, and therefore, responsibility, in relation to reproduction.

It is clear that information, modern technologies and practices around reproduction constitute forms of disciplinary bio-power. This is evident because they are based on advanced techniques of direct and indirect surveillance, surveillance both from external (expert)
sources and from intense self-surveillance. These techniques, such as measurement, testing, classification and monitoring, operate to make female bodies and their contents (foetuses and reproductive processes) visible in ways that allow for the external imposition of intervention and labelling (Petchesky, 1987; Sawicki, 1991:83-84). Some of the categories that emerge and are applied to individual women through these forms of surveillance include ‘normal’ versus ‘retarded’ foetal growth and ‘healthy’ versus ‘unhealthy’ reproduction. On the basis of such binaries, women can be represented as ‘capable’ or ‘deficient’ reproducers or even pathologising agents (Donovan, 2006:398, 401; Sawicki, 1991:84).

The imposition of medical and public health surveillance operates to discipline women by encouraging their acceptance and expression of ideas about how they should behave in order to optimise their reproductive capacities and achieve what are defined medically as ‘normal’, ‘healthy’ outcomes (Reiger & Dempsey, 2006). Such understandings are relevant to theoretical discussions of medicalisation where the reconstruction of social issues as medical problems becomes an example of what Foucault (1975) labelled as medicine’s surveillance of the body. Such surveillance is exercised through the panoptic-like gaze, which is characterised by an asymmetry of power between those who survey and those who are surveyed or, relevant to this thesis, between doctor (or midwife) and patient. However, this process is not totally deterministic or top-down because, importantly, as I highlighted in earlier, within the context of reproductive health women are also particularly willing to engage in relentless self-surveillance consistent with the expectations of the ‘gaze’. The education of women through public health and medical discourses about the need for discipline and control encourages an individualistic, mechanistic view of women’s reproductive bodies and a gendered view of what makes ‘normal’, ‘healthy’ reproductive outcomes possible. This view is not new; in fact it is modelled on the basis of an understanding of the body as an innate machine-like object, which medicine has the power to fix (Ettorre, 2002; Martin, 1989). In this instance, however, the body as machine becomes invoked in an extra dynamic of gendered power since women are represented as having the power and obligation to regulate their bodies, through engagement with medical and public health advice and practices.

Further than this, and as an extension of Foucault’s ideas in the context of the contemporary risk society (Beck, 2000; Beck & Beck-Gernsheim, 2002), a woman’s self-surveillance and self-discipline is not only encouraged and embraced with the aim of offsetting risk for her particular foetus and her particular pregnancy. Women’s self-discipline is also enacted within a context of societal anxiety about the imagined, and uncertain, future of the next generation (Diprose, 2008:270). In this sense, during pregnancy women are not only engaging with responsibility for their own body and their own foetus, but they also come to embody the
future of the broader population. This means that women do not only bear responsibility to care for themselves and their foetus out of self-interest for a desirable outcome (and to avoid becoming the target of social disapproval) but they also bear a moral responsibility to care for the future of the population (Ettorre, 2002:68). This leads to a heightening of the perception of risk posed by pregnant women and their behaviours. Such a heightened perception of risk leads to pregnant women’s behaviour being policed by those around them, as well as by themselves, as they and others take on the role of societal supervisors and protectors of the future generation, in which there is deemed to be a collective interest (Longhurst, 1999:88). This differs to men’s responsibility to care for their own bodies because that responsibility is perceived to end at the level of self-interest and does not extend through a moral discourse equivalent to that which can be applied to women’s body through an imagined future of moral imperatives and imagined risk. Therefore, the weight of responsibility experienced by women through their positioning as the strongest predictor of their child’s future health is incomparable to that that could ever be imposed on men if they continue to be positioned as largely peripheral to reproduction and as outside the establishment of future health for their child or for the next generation.

Of particular relevance in this Chapter, it is also clear that health education has come to play an increasingly important role in the exercise of bio-power through its association with illness prevention and health promotion. In understanding the role of health education as a site from which bio-power is enacted it is helpful to draw on the ideas of Sandra Bartky (1997, first published in 1988). Bartky (1997) applies a Foucauldian perspective to explore how patriarchal standards of bodily acceptability operate as disciplinary practices for women. The premises on which her ideas are based also have applications here. Bartky (1997:139) explains that the strategies through which many forms of disciplinary power are exercised in society are based on the suggestion that the bodies of women are deficient. The promotion of a pervasive sense of bodily deficiency through axes of power such as beauty magazines and health education serves to educate women that they must engage in activities to transform their bodies to make them ‘good enough’. It also encourages women to seek ways of transforming their bodies to achieve change that will assist them in meeting what is regarded as desirable within society (Davis, 2003; Heyes, 2009). However, within this disciplinary project the majority of women are destined to ‘fail’ because the standards that are set for them require extensive compliance, the measures of which are also fluid and ever shifting (Bartky, 1997:139). Furthermore, in relation to reproductive health the standards that women are expected to meet are often unachievable by the time that pregnancy occurs because of the way that these standards require women’s lifelong commitment to healthy reproduction (refer to Chapter 4). This means that even if women try to meet the high level of
compliance that is required during pregnancy their past ‘deficiencies’ can still be interpreted as causing their child’s congenital health problems. This is particularly evident in relation to dominant health promotion messages about consumption of alcohol and folate because if women did not comply with these messages before realising that they were pregnant then their ‘failure’ to do so may form the basis of blame for their child’s health problems. Importantly this sense of pervasive and enduring bodily deficiency increases the power of medicine and public health because women learn that greater ‘management’ by science, and particularly doctors, is likely to have the greatest likelihood in overcoming potential problems or risks and, therefore, create the safest, healthiest outcomes possible for their child (Martin, 1989:64).

In this tendency to render women deficient there is little acknowledgment of social or economic context. Many women do not have the resources to comply with the standards and regimes that are imposed through health promotion messages. For example a woman may not be able to achieve what is constructed through health education as a ‘healthy’ diet during pregnancy and as such may bear the disapproval of health professionals and others should her pregnancy result in a less than desirable outcome. This possibility is particularly apparent for women in low income families whom, according to research by Coveney (2009), have to spend approximately one third of their income on food in order to meet their nutritional needs. However, the definitive and reductive framing of health promotion messages obscures the complexities that are introduced through factors such as class or inequalities in education. Therefore, since the standards of bodily acceptability are almost impossible to realise in relation to reproductive health, a woman may experience reproduction through a pervasive feeling of failure (Bartky, 1997:149).

The framing of women’s bodies as necessarily deficient also increases the potential for them to be regarded as the cause of congenital health problems. The dominance of this construction increases the willingness of women to engage with disciplinary power and to impose self-surveillance on their bodies and behaviours in order to mediate the impact that their perceived deficiencies may have on the health of their future children. In this context alcohol becomes an effective mobiliser for such understandings because, through its construction as necessarily dangerous, all women who consume alcohol are linked with the representation of ‘evil’ that surrounds it. Subsequently, some women’s ‘inability’ to abstain reinforces the understanding of them as deficient and as potentially dangerous to the health of their foetus. In the context of such an attribution of risk women may not only suffer social stigma but they may also find themselves voluntarily, or involuntarily, under the gaze of the medical profession and subject to the various forms of surveillance and treatments that are
rendered legitimate and necessary through the operation of medical and public health authority in the name of prevention (Novas & Rose, 2000:486). As highlighted in Chapter 1, in some countries this extends to legal intervention, such as imprisonment, to force pregnant women to curb behaviours that may cause harm to their foetus, such as consuming alcohol and other recreational drugs.

**Supposed moral neutrality**

Another important way that the fields of medical and public health become constructed as the ultimate sources of legitimate and authoritative information is through their representation as morally neutral. Scientific disciplines are based in the presumptions that permeate modernism. These involve the presumed existence of external realities the can be examined and understood through rational thought processes and scientific study (Carlisle, 2001:267). This provides the value of ‘science’ in that it is linked to a neutral status and presentation of observable facts rather than through acts of faith or ‘superstitution’ (Carlisle, 2001:268). The objective representation of medical knowledge as science also means that it is predominately understood as beyond the influence of a political agenda (Carlisle, 2001:268).

Through their positioning within the realm of science, medicine and public health are represented as providing objective information that is free from moral judgements and values. However, according to Peter Conrad and Joseph Schneider (1993) this representation is not accurate. Instead, medical and public health information is both reflective of and reinforcing of value judgements that support the moral order of society. In particular, the labelling of particular behaviours as dangerous or problematic to health through public health and medical information provides a clear example of how these fields apply negative judgements to particular behaviours by rendering them undesirable and, in some cases, irresponsible. Yet the medical language that is used to label disease and to describe treatments is assumed to be morally neutral, and this representation is further reinforced through the technical and scientific language that permeates medical and public health discourses. This means that the perceived ‘neutrality’ of these discourses obscures the political and moral nature of medical and public health information by representing them in the guise of scientific and, therefore, value neutral, ‘fact’ (Conrad & Schneider, 1993:249). Importantly, the methods used to ‘uncover’ and describe the ‘facts’ within supposedly objective and value free medical and public health research has directed research pursuits along certain avenues, which has left others both unexplored and unnoticed (Fausto-Sterling, 1987:69). This invests considerable power in professionals working in these fields to shape understandings about congenital health problems and also creates opportunity for the representation of certainty through a lack of alternative explanations. John McKnight (2010:85) explains this clearly by
stating that “there is no greater power than the right to define the question.” In particular, this shows how scientific ideas are used to reinforce the ‘naturalness’ of social norms and, concurrently, that scientific theory has a role in defining social realities (Fausto-Sterling, 1987:61-62).

Conrad and Schneider (1993) also implicate public health as a central field through which medical control is exercised. However, it is important to highlight that Conrad and Schneider apply a somewhat ‘top-down’ model of power through evoking a discourse of professional dominance. This is at odds, to some extent, with the model of power that Foucault offers and which I draw upon in my analysis of several aspects of my findings which argues that power is composed of both imposed mechanisms of social control and active self-regulation and that together these are involved in the construction women’s greater responsibility for congenital health problems. As Conrad and Schneider (1993) suggest, however, public health operates as an agent of control by defining and enforcing certain health related standards—either directly through policy or more indirectly through the transmission of health advice at a population level. In addition public health is presented as having the power to prevent and treat particular health problems, particularly through achieving the compliance of individuals to preventative health messages, such as those contained with health education resources. This is particularly relevant in the context of the findings presented in this Chapter because while there is evidence to suggest negative health impact from the exposure of a foetus to alcohol, the evidence on the health impacts of this tends to be overstated, particularly since considerable contestation and uncertainty exists within the existing body of evidence (Armstrong, 2003). This suggests that the health promotion message which prescribes abstinence from alcohol may be as much part of an ideological project as it is part of an empirically driven project.

The morally charged nature of discourse surrounding congenital health problems became apparent during the interviews that I undertook. For example, it was inferred in the following response from Robert, an obstetrician, when I suggested that current research indicates that low levels of alcohol consumption may not be implicated in the cause of congenital health problems:

Yeah that’s right … I think, you know, [pregnant women] have to recognise that our bodies have got a very great degree of built in defence mechanisms and filter systems which actually enable us to survive in a pretty hostile environment. It’s only when you bombard it with either high, you know, excessive, doses of things or with chronic, long term exposure that you may overwhelm those sort of primary defences.
On the basis of this response, and the theory that I have presented so far, it is clear that health has become positioned within a moral discourse where it has become aligned with, and reflective of, self-control, self-denial and willpower (Bell, McNaughton & Salmon, 2009; Foucault, 1975; Lupton, 1995). However, a lack of health has become representative of moral insufficiency, and as highlighted in the previous quote, a lack of self-control and a personal inability to refrain from excess and gluttony.

Finally, I consider how the reduction of medical information and dominant health promotion messages to the level of biology operates to reinforce the authority of medicine and public health in defining understanding about responsibility for congenital health problems.

Reductionism: The reinforcement of biological linearity

According to Rose (2000a:6) we live in an inescapably "biologized" culture. Within this culture the personalities, capacities and identities of individuals become explained in biological terms (Rose, 2000a:6). The findings of my research suggest that information about reproductive health and the factors that influence it are reduced to the level of biology. Reductionism operates within the medical and public health discourses to reduce knowledge about causation to simplistic and lineal links between the biology and behaviours of women and congenital health problems. Reducing the cause of congenital health problems to biological factors, when these may be merely one set of causal factors among others, creates a need for therapy as well as control (Rose, 2000a:7). This is based on the identification and management of ‘risky individuals’ and demands interventions upon individuals to prevent their ‘risky potential’ harming others (Rose, 2000a:7).

Thoughts about the origin of congenital health problems have become entangled with understandings about how women should (ethically and responsibly) conduct their lives, formulate objectives and plan for their future in relation to managing risk (Novas & Rose, 2000:507). Forms of personhood and identity based on knowledge about risk and congenital health problems have also become intertwined with dominant neo-liberal social ideologies that construct women as self-responsible and self-actualising (Novas & Rose, 2000:507). Within this context, a new relation between women and experts has developed in which biomedical expertise is increasingly being constructed and interpreted as a resource that can (and should) be drawn upon in life planning (Novas & Rose, 2000:507-508). Alongside this, biomedical expertise operates within other forms of communities, such as support groups, which, for the most part, although unintentionally, contribute to dominant discourses which encourage individuals to organise their lives around their risky, improvable and changeable bodily existence (Novas & Rose, 2000:508).
The emphasis on individual responsibility denies broader, social determinants of health and disease. As I argued in Chapter 5, the limited, individualised focus also obscures the environmental and structural factors that impact on the lives of individuals and impact on their ability to make choices that will promote their reproductive health. This is consistent with feminist critiques of public health which suggest that health education campaigns give women, particularly mothers, responsibility without also providing them with the necessary social power (Bell, McNaughton & Salmon, 2009:163). From this it is possible to critique the adequacy of health promotion messages which prescribe abstinence from alcohol, and then operate to blame women if they do not achieve this. This is particularly evident since many women who drink alcohol heavily during pregnancy may do so in a long established attempt to escape social realities over which they have limited individual control. Current understanding about the reasons that women continue to consume alcohol during pregnancy is limited, particularly since most research is focused on exploring the effects of women’s drinking and on foetal development and on measures to detect and prevent women’s drinking during pregnancy. In addition, the majority of the research in this field remains quantitative, which may be useful in documenting the epidemiology of women’s drinking but is not able to provide information about the complexities which underlie why some women continue to drink alcohol during pregnancy while others do not.

More recently there has been an international focus on exploring the links between gender and women’s consumption of alcohol during all life stages (Wilsnack & Wilsnack, 2003), but this remains in its formative stages and the qualitative aspects of this work are still being developed. One study (Kost, Landry & Darroch, 1998) does provide limited insight into factors that may present barriers to women abstaining from alcohol during pregnancy. The study was undertaken in the US which means that the findings may not be appropriately transferrable to the Australian context because of the differing socio-cultural circumstances. However, the findings suggest that the age at which a woman becomes pregnant may have an influence, with women older than 30 years less likely to abstain, possibly because the habit has been in place for a longer time (Kost, Landry & Darroch, 1998:85). Women who have low levels of education are also less likely to abstain than women who have undertaken tertiary level studies (Kost, Landry & Darroch, 1998:85). The study also revealed that women who had already given birth were less likely to abstain than women who were pregnant for the first time (Kost, Landry & Darroch, 1998:85). Furthermore, research in the field of domestic violence has also revealed that women in domestic violence situations are also less likely to abstain, which means that they are not simply engaging in risk taking behaviour voluntarily but instead their social circumstances mean that they live, in general, at risk (Bell, McNaughton & Salmon, 2009:163). Such complexities are ignored in reductive health
promotion messages, however. The content of these messages highlights clear acknowledgement of the risky, damaging potential of women’s behaviours yet the pressures that may lead to those behaviours in the first instance are not highlighted (Bell, McNaughton & Salmon, 2009:164). The reductive framing of these messages also ignores factors which are beyond individual women’s control, factors which result from structural inequality (Rogers, 2004) including the structure of workforce with women holding lower paid and lower skilled employment, violence against women in relationships, sexualisation, coercion, rape and so on.

The analysis that I have presented in this Chapter suggests that the elimination of alternative interpretations of scientific data and the rendering of these alternatives as less plausible is a central characteristic of scientific activity (Latour & Woolgar, 1986:36). Rather than representing moral and political neutrality, medicine and public health are inevitably entangled within social structural networks of authority and surveillance which result in their role being legitimised and reinforced as agents of bodily regulation. Within this entanglement, disease becomes a metaphor for social disorder in the collective social body and medicine and public health provide the expert knowledge that will be effective in re-establishing order (Davis & George, 1988:123).

**Conclusion**

Throughout this Chapter I have shown that the erasure of uncertainty within public health and medical information reinforces women’s relationship to the cause of congenital health problems. While uncertainty within public health and medical knowledge could operate to weaken the links between women’s behaviours and perceptions of risk, the current framing of health promotion messages does not convey the underlying uncertainty. I have also shown that the widespread distribution of health promotion messages, legitimised particularly through standardisation and representations of objectivity, convey authority to medical and public health discourses in ways that legitimise the understandings of responsibility that emerge from them. Therefore, consideration of the information that I have presented in this Chapter makes clear that despite the inconclusive state of the available evidence, the discourses surrounding reproductive health call for strong controls on the freedoms of women in order to reduce the potential risks that they are perceived to pose to foetal development. In constructing women as primarily responsible for congenital health problems, medical and public health discourses obscure the structural and contextual factors which may influence the cause and prevention of these problems. While it is difficult for public health professionals to decide at what point particular behaviours become risky, especially on the basis of uncertain evidence, making such judgments is a necessary part of
preventative practices. However, as this thesis reveals, critical reflection on the secondary effects of designating what is (and what is not) risky is important because this practice can produce detrimental implications.

It is also apparent that the discourses that I have examined reinforce dominant understandings of women as blameworthy and lacking while reinforcing representations of health professionals as competent and knowledgeable. This legitimises women’s engagement with medical professionals throughout their reproductive experiences and provides the potential for them to be considered irresponsible if they resist medical intervention (Malacrida, 2002:381). Yet it is through their engagement with medical and public health discourses that women gain even greater exposure to information which renders them potentially responsible for their child’s health problems. This represents the empowering yet entrapping nature of current systems of medical power, which I explore further throughout the next Chapter as I examine the fourth theme that shapes this thesis.
CHAPTER 8

Congenital health problems as an extension of the maternal self

Throughout Part 3 of this thesis I have explained several processes through which responsibility for congenital health problems becomes extracted from social context, and as a result, reduced to a naturalised and individualised maternal responsibility. By applying a Foucauldian approach I have demonstrated that public health and medical discourses form a complex web of technologies of power and technologies of self. The regulatory capacity of technologies of power emerges from the ways that public health and medical discourses construct particular norms of behaviour and understanding about the cause and prevention of congenital health problems. Technologies of self result in women’s active engagement with these discourses, which encourages them to closely monitor and control their bodies. Therefore, the analysis that I have presented so far makes clear that public health and medical discourses provide a powerful framework of understandings that construct and perpetuate maternal responsibility. If I were to conclude at the level of such a direct and linear relationship, however, I would replicate the reductionism and over-simplification, which I argue, restricts current understandings about the origins of child health, and perpetuates women’s exclusive responsibilities in relation to it. Instead, in this, the final findings Chapter, I extend the central argument of my thesis to consider in more depth the way that women embody a relationship to congenital health problems. I argue that women’s embodiment of a relationship to congenital health problems, and their subsequent expression of this relationship as part of their identities, provides another, more complex and socially embedded basis through which maternal responsibility becomes constructed and legitimised. I show that women’s embodiment of a relationship to congenital health problems is encouraged through public health and medical discourses but that women do not passively accept the messages promoted through these fields. Instead the process is an active and interactive one, involving women’s expression of agency as they negotiate, oscillate between and, in some cases, resist, the ideas that are perpetuated through medical and public health discourses. In order to establish this argument I draw upon Judith Butler’s (1990) theory of performativity which embraces the power of agency.

Performing maternal responsibility: Butler

Whereas feminist writers Susan Bordo (1992) and Bartky (1997) focus on Foucault’s notion of disciplinary power, another feminist writer, Butler, draws upon, and critiques, Foucault’s theory of subjection. In her book Gender Trouble (1990) Butler explains that for Foucault “systems of power produce the subjects they subsequently come to represent” (Butler,
Therefore, as Foucault understands it, and as I have elaborated in previous chapters, individuals become subjected to power relations and they actively reinforce these through their engagement with them. Such a process of subjection results in the governance of individuals, both through their self-regulation and through the regulatory function of broader institutions of social power (Foucault, 1988). This renders the body as having limited capacity for expression outside of the power relations through which it exists (Foucault, 1976).

Based on a critique of Foucault’s understandings, Butler introduces the term gender *performativity* to analyse how the self is formed and performed within the context of power relations. Butler (1990, 1993) suggests that to understand how individuals engage in social processes, and how the self is formed through this engagement, it is important to consider how the materiality of the body operates as part of the discourses through which it exists. In developing her argument Butler (1990, 1993) challenges Foucault’s assertion that the human body is constituted only by and within the discourses that permeate society. Butler (1990, 1993) contends that the meaning and use of bodies is broader than this. For Butler (1990, 1993), bodies do in fact have a meaning outside of their inscription with dominant relations of power and individuals’ bodily expressions come to form part of these relations. In mounting this argument she attempts to reconcile an understanding of the influence of social and cultural norms, and their role in constructing the body, with an active notion of performativity. This means that for Butler (1990, 1993), the way that our identity is constructed is neither a manifestation of our biological characteristics nor simply an extension of prevailing cultural norms. Instead it is a combination of these, and the construction of self emerges most powerfully from our bodily performance—that is, the way we think about and perform our sense of self within relations of power and culture.

Based on this understanding Butler outlines the significance of the body as a medium through which discourses are given social significance and through which these discourses are negotiated and performed. The discourses that emanate from powerful social institutions interact with the expressions made by individuals as they negotiate, participate in and give meaning to these discourses (Butler, 1993). Therefore, Butler (1997) contends that understanding how discourse operates in the lives of individuals requires an analysis of the psychic and experiential forms in which they engage with these discourses. It is only through such an analysis that the role of power in shaping the self become apparent.

In the context of my research Butler’s theory of performativity offers a way of viewing maternal responsibility as a dynamic enactment that is produced by and through women’s
engagement with the discourses that emanate from medicine and public health. As part of this, Butler’s theories extend beyond those of Foucault to provide greater scope for understanding and highlighting the agency that women express as they engage with the ideas about reproduction, mothering, responsibility and causation that permeate medical and public health discourses. I now begin to explore the ways that women’s engagement with, and performance of, maternal responsibility mediates the understandings that are made available through medical and public health discourses. In doing so I show how women rationalise their situation through a unique and entangled relationship between self and other.

**Congenital health problems as identity: Blurring the boundaries between the self and other**

Several of the women I interviewed internalised their child’s health problems to the extent that the problems became a central part of their own identities. This first became apparent during my interview with Melanie. Many times throughout the interview Melanie referred to her child’s spina bifida as if she herself had the health problem. This confused me in the early stages of the interview because Melanie’s use of statements such as “compared to what I have” when referring to the spina bifida made me wonder if she too had spina bifida or whether she was referring to her daughter’s experiences. As the interview progressed, I realised that, for Melanie, there was no distinction between her daughters’ experiences and her own. Melanie had come to understand spina bifida as something that was centrally related to, and entangled with, her own identity. It was something she spoke of as if it was part of her body, something she had responsibility for and something that she thought a lot about. Melanie’s internalisation of spina bifida, and the resultant blurring of the boundaries between her daughter and her sense of self, became particularly apparent when Melanie recounted the following experiences:

They told me they were going to cut her open, like, you know, she needed the operation, and they made clear that if they nicked [her daughter’s spinal cord] just slightly she’d stop crawling. But then I kept thinking she’s young enough not to understand because looking back at my age now I wouldn’t have remembered crawling at four months old if I had of lost function in my legs. It would be like this is how I’ve always been. But then oh God when the surgery day came that was awful … On that morning they took her in and they said she won’t be out for about six hours. So I made myself physically sick like literally physically sick. For about two hours I couldn’t stop throwing up and I’m thinking what’s happening have I got gastro and then I thought; no it’s just how sick I feel about what she might be feeling now. It was like I got sick because she’d be feeling hurt in there too and so that was pretty hard and then … I kept remembering … like I didn’t care what [daughter’s father] was feeling, it was about me. Like this has happened to me and not him. Then when I saw him crying I thought oh God, that was worse than thinking about her being in there, I thought I’ve never even thought to ask how you were feeling or anything. It just seemed to all be happening to me...
because she’s mine. (Melanie, 28 years old, 5 year old daughter with spina bifida)

Melanie’s comments suggest that she internalised the effects of her daughter’s treatment to the extent that she understood her own nausea to be an extension of her daughter’s pain. This blurring of bodily boundaries led to the development of new and direct relations between the body of her daughter and Melanie’s sense of self, which intensified her bodily relationship to the congenital health problem (Novas & Rose, 2000:487). In addition Melanie’s interpretation of her child’s pain as extending only to herself and not to her child’s father further reinforced her central position in relation to the health problem while marginalising her partner to the extent that he appeared largely unrelated to the experience.

Some similarities between Melanie’s narrative and those of other women became apparent during the analysis. While the other women did not internalise congenital health problems to the same extent as Melanie, it was clear that many devoted considerable energy to thinking about their child’s health problems. In doing so, it appeared that the women developed multifaceted identities as mothers. One aspect of their identities was based upon traditional mothering practices whereas a second aspect was based upon efforts to understand and manage the health problems of their children. In this sense, the women became constructed as mothers both to their children and to the congenital health problem itself. The distinction between mothering their child and mothering the health problem is important because it was a stated desire of several of the women to raise their children in a way that deflected attention away from their health problems. Therefore, many of the women actively constructed a division between their traditional mothering practices and the things they did in order to manage their child’s health problem, things which were often done in isolation from the child if possible. The effect of this division, however, is that it led women to understand themselves as not just having responsibility for their children but also as having a particular and separate responsibility and personal relation with the congenital health problem. So in creating a division between the health problem and their child they dissolved the boundary between themselves and the health problems which existed as part of the bodily identity of another. In doing so the women ‘took on’ the health problem as part of their own identities.

**Embodiment**

The findings that I have explored to this point in the Chapter reflect women’s embodiment of maternal responsibility. Theory on embodiment is related to Butler’s notion of performativity and it is a useful concept for illuminating the relationships between biology, society and selfhood. Embodiment refers to the way that we come to understand our bodies through our
social experiences and exposure to social discourses (Gabe, Bury & Elston, 2006:73). Embodiment also allows for consideration of the way that our understandings about our bodies and our sense of self, shape our interactions with the social discourses that we are exposed to and are an active part of. This means that an individual's embodied existence is carried out within a particular social context that is shaped by culture, power relations, history and interpersonal relationships with the self and others (Doucet, 2009:82; Turner, 1992). In their elaboration of embodiment theory, sociologists have increasingly taken up the theory of phenomenologist Maurice Merleau-Ponty, particularly in relation to his idea that human perception is influenced by an individuals' social position. According to Merleau-Ponty (1962:206) “We are in the world through our body, and ... we perceive that world within our body.” However, a more useful sociological connection, particularly in relation to gendered embodiment, may be with the work of Alice Rossi. Rossi (1984) views embodiment as an integration of social and biological constructs and, as such, she regards self-identity as being both embodied and socially embedded.

A focus on embodiment in the context of reproductive health provides an important means of understanding the links between the social discourses and personal experiences that are central to my thesis. For example, consideration of the way that women embody and express their identities as mothers provides insight into the potential influence of broader discourses in shaping their personal experiences as reproductive beings. In addition, a focus on embodiment can assist in clarifying the relationships between structure and agency in the women’s lived experiences. This is particularly useful in illuminating how different understandings of the reproductive self influence and are influenced by an individuals’ embodied sense of empowerment or disempowerment or of being worthy or unworthy in the ‘eyes’ of the broader society (Gabe, Bury & Elston, 2006:75). I now continue to explore how women embody a relationship to congenital health problems, but in doing so I also reveal a tension between the ways of knowing thrust upon women by medical and public discourses and their own embodied ways of knowing by exploring the concept of maternal intuition.

**Maternal intuition as mothering ability and maternal devotion**

While analysing the interview data I found that discourses of maternal intuition emerged within eight of the interviews. In four of these interviews maternal intuition was the dominant focus of the women’s narratives and something which framed the way they interpreted their overall experiences of mothering. Therefore, unlike the general focus applied in the other

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44 Some of the information that is presented in this section is an extract from a paper that I published during my candidature. The full citation of the paper is: Delany, T. (2009) ‘To Entrap and Empower: Understanding the Social Implications of Maternal Intuition within Heterosexual Family Relationships’, *GLIP Review*, vol. 5, no. 2, pp. 110-120.
sections of this Chapter, the following analysis draws in detail upon the accounts of those eight women who discussed the issue of maternal intuition throughout their interview. While these findings are, therefore, based on a small number of participants’ narratives, the analysis is useful in exploring the meanings that may be applied to intuition and also useful for examining how these may illuminate further the ways in which women embody a relationship to congenital health problems.

The prominence of intuitive knowledge in several of the interviews prompted me to undertake a search of the existing academic literature about intuition. I found that the existing literature on intuition can be loosely grouped into five main categories. First, there is a wide body of literature about the importance of the intuition expressed by professionals, such as nurses, surgeons and lawyers, within their work contexts. In this literature intuition seems to refer to an informal way of assembling clinical evidence or observations (Smith, 2007; Wright, 1987). A second body of literature relates to religious beliefs, in which intuition is associated with a connection to spiritual beings. Third, there is relatively extensive and diverse literature about the psychological origins of intuition within which intuition is generally regarded as a form of thought that involves unconsciously accessing information previously stored in the brain. Due to the unconscious nature of this process, intuitive knowledge becomes interpreted as being based on a ‘feeling’ rather than an explainable thought processes (Hodgkinson, Langan-Fox & Sadler-Smith, 2008). A fourth body of work originates from philosophical theory. Within this field intuition is generally regarded as the ability to know something without relying on previously developed knowledge. For this reason intuition is regarded as a kind of higher order knowledge that is developed through a superior human faculty which serves to complement knowledge gained from experience or reasoning. Such philosophical understandings seem most similar to the intuition that the participants expressed during the interviews.

The fifth body of literature relates specifically to maternal intuition. Given its relevance I now focus only on this literature. Existing literature on maternal intuition makes up a relatively small body of work. There appears to be two main themes that underpin the existing theory. First is the idea that maternal intuition arises from women’s biology. Authors Robbie Davis-Floyd and Carolyn Fishel Sargent (1997) support this assertion and explain that maternal intuition arises from a maternal instinct that women are born with. This innate instinct is thought to make women ‘natural nurturers’. Theorist Harry Wright (1987) and others such as Arnold Lohaus et al. (1997) apply a slightly different perspective to argue that while women are not born with intuitive abilities they do develop these through the biological processes involved in pregnancy. In particular, they refer to changes that occur within the brain of a
woman during pregnancy as giving rise to maternal intuition. The reduction of maternal intuition to the biological capacities of women renders it as something that women have little control over. For this reason these theorists define maternal intuition using terms such as *unconscious communication* (Wright, 1987). Other theorists, including Peter Callery (1997) and Jean Mercer (2006) take a different approach by arguing that maternal intuition is not natural but rather that it is learned by women. However, within this literature such learning remains linked to women’s biological capacities. In particular, it is thought that women learn how to develop intuitive knowledge about their child during the time they spend with them during pregnancy.

This brief review makes clear that different understandings about the origins of maternal intuition have emerged within the existing literature. Most authors who write about this topic assert that women develop intuition about their children and their needs through biological process, whether that be through women’s ‘natural’ abilities or through the way that they learn to connect intuitively with their child during the time that they spend with it in pregnancy. Underlying these various theories is a common essentialism which asserts that maternal intuition is achievable by all women who give birth to a child. In this thesis I apply a different approach. In particular, I explore intuition as an embodied and political construct within the lives of women which operates to produce particular social outcomes in women’s lives. This approach fits with the focus on agency and performativity in Butler’s work.

It is important to make clear before presenting an analysis of maternal intuition that my aim is not to question the authenticity of the intuitive feelings that the women expressed. For some of the women I interviewed this form of knowledge is real and important. For several it appeared to shape their overall understandings about their reality as a mother. Therefore, what seems more theoretically important than questioning whether intuition is ‘real’ or not, is to explore the ways it manifests for the women concerned and to explore the productive and political effects of this form of embodied knowledge.

**The type and timing of maternal intuition**

The eight women who experienced intuition expressed intuitive beliefs about their children’s needs and about their children’s health status. For some participants, such as Laura, intuition arose early in pregnancy:

> During the pregnancy I had the regular scans and processes done but nothing actually showed up that there was anything wrong with the baby. However, I had a feeling that there was something wrong with his heart even though they kept saying no there’s nothing, he’s fine ... I don’t know
why, it was just one of those things. I just had a sense … (Laura, 37 years old, 17 month old son with congenital heart disease)

Another participant, Chloe, also developed intuition about her child’s health status during pregnancy:

When I was about 5 months pregnant with Cameron, for quite a few weeks I had this feeling … I’ve only told my husband and another person this but I had this feeling that the baby was OK but there was something different, and obviously I didn’t know what it was and I sort of dismissed it because I didn’t believe in that sort of … well my upbringing isn’t sort of … you know the universe and other powers of being and things like that … But there was something … I can think back now in hindsight and say well that was my intuition saying that he has a birth mark [congenital naevus] but the baby was fine … I just sort of had these funny feelings every now and then. (Chloe, 29 years old, 2 year old son with congenital naevus)

More commonly than these premonitions, the participants explained that they developed maternal intuition after their child’s birth. Such beliefs were expressed frequently by Kate who held a strong faith in the power of her intuition to alert her to her son’s impending illnesses. As I demonstrate later, this knowledge appears to have had a strong influence on Kate’s experience of mothering her son Chris, who has congenital heart disease:

That instinct⁴⁵ twice has been what’s saved Chris. The first time it was just me being completely paranoid because there were no symptoms. I’d been to the GP and she said “There’s no signs [of any impending health crisis] but if you’re still worried at the end of the day take him up to the hospital.” So I rung the hospital and they said “Why don’t you bring him in now, don’t wait until it’s too late, just let us check him out.” And I brought him in and found out it was a serious problem. And it was pure instinct that I did what I did both times, taking him into the hospital on that feeling saved him both times. (Kate, 40 years old, 5 year old son with congenital heart disease)

Reflecting back on the essentialist or biologically determinist ideas that dominate much of the existing literature about maternal intuition, these ideas appear to be supported, to a limited extent, by the comments of some participants. For example when Natasha was talking about her husband’s difficulties in caring for their one year old child she said:

He’s a fantastic father but there’s some things where the penny doesn’t drop … like there’s just … I guess mothers’ natural intuition comes through and it just doesn’t happen with the bloke … especially when your baby’s so young your mothers’ brain is tuned into that kind of thing … you just know what babies need. (Natasha, 32 years old, 1 year old daughter with congenital heart disease)

It is important to highlight at this point that Kate and some of the other participants used the words intuition and instinct interchangeably. An analysis of the context in which they use these words shows that what they are referring to relates more to the concept of intuition than instinct—that is, an ability to anticipate or know certain things about their children rather than an innate, ‘natural’ ‘instinct’ that allows a woman to care for her child.
Essentialist ideas about intuition were also expressed by Catherine in support of her overall understandings about appropriate parenting roles:

I think, without being sexist, intrinsically women know their kids really well and so you know when something’s wrong. And so ... I think intuition does come into it, you just know your child and what’s going on with them.

(Catherine, 33 years old, 2 year old daughter with congenital heart disease)

An essentialised belief in the ability of women to intuitively know certain things about their child on the basis of their biological sex and/or gender socialisation, naturalises, and therefore reinforces, their embodied relationship to their children and to their health care. This is because, through their gender-specific capacities, the mother of a child becomes viewed as being able to provide a higher standard of care for the child than any other person. The naturalisation of women as primary, and more able, carers ultimately has the effect of legitimising women’s greater responsibility for caring for children within the family (Everingham, 1994; Hays, 1996).

The naturalisation of women’s role as primary caregivers also has the effect of excusing and excluding men from an active or equal role in the parenting relationship, which supports the arguments that I presented in Chapter 6. This is because men’s biology appears to be distinct from women’s and therefore to automatically preclude them from developing the embodied knowledge on which intuitive abilities are seen to be based and which women are said to acquire through their biological sex or during their pregnancy. The effect of intuition in excluding and excusing men from equal parenting responsibility is demonstrated in the next quote from Kate.

As highlighted earlier, Kate feels a strong sense of intuition about her son’s health status particularly in identifying when his condition is going to worsen. As a result of these beliefs she feels able to act as an advocate for her son Chris in order to ensure he gets the medical treatments that he believes he requires. When I asked Kate whether her husband also assumes an advocacy role she responded with the following comment:

He’ll be there but he has a greater respect for that maternal instinct I think ... if ever Chris is sick, even now, he’ll say “Put him in your bed, I’ll sleep in Chris’s bed because you can keep an eye on him during the night. You’ll wake up if he’s not well ... if he’s next to you, you’ll wake up, and you’ll pick something up.” (Kate, 40 years old, 5 year old son with congenital heart disease)

It is also clear from this quote that a shared belief in maternal intuition and, from this, women’s closer embodiment of a relationship to their children can operate to increase and legitimise the level of responsibility that women have for their children’s health. This is...
because Kate, as did some of the other participants, felt as though she had extraordinary abilities in relation to her son, abilities that allowed her to extend her mothering duties to predict and protect her child from illness. However, this sense of heightened maternal ability and, hence, heightened maternal responsibility also has the effect of creating a further potential for women to experience blame if something negative happened to their child (Thurer, 1995). For example in the case of Kate it was clear that she would be likely to blame herself if she did not wake up when her son became ill and she may also, potentially, be blamed by her partner given their strong reliance on Kate’s intuition, and her embodied relationship with the congenital health problem that Chris experienced.

This analysis has indicated that theories which link women’s intuitive abilities to their biological sex do provide some assistance in understanding the implications of the intuition that the participants expressed. If I maintain the essentialist, or gender determinist, focus that permeates much of the existing literature and apply this kind of thinking to the analysis of the interview data we can gain some insight into the power intuition plays in the lives of women and how they use it. However, I want to foreshadow that essentialism is not the only construct operating within the women’s narratives in relation to intuition and I now want to move on from the biologically determinist understandings that dominate the existing literature. I believe that there are several problems associated with relying only on essentialist theory to understand the women’s experience of intuition, particularly in terms of illuminating the social implications of women’s expression of intuition as part of their embodiment of a relationship with their children’s congenital health problems.

Maternal intuition as committed mothering

Further analysis of the participant’s narratives indicates that all of those who reported a sense of maternal intuition also engaged in forms of intensive mothering. As explained by Hays (1996) for intensive mothers the needs of the child become paramount and the development of appropriate child rearing practices involves the unlimited expression of physical, moral, mental and emotional energy by the mother. Although Hays (1996) alludes to potential links between intensive mothering practices and intuition she does not develop these ideas or explore what effects these linkages may have. I now go on to explain the relationships I observed between intensive mothering and maternal intuition.

First, it appears that a sense of maternal intuition as part of women’s embodied relationship to congenital health problems can encourage women to actively and purposively engage with the culturally approved model of intensive mothering. This is because, as explained earlier, a
belief in intuition can operate to increase the level of responsibility that women accept for
protecting their children's health. Therefore, women who believe in their intuitive abilities are
more likely to feel responsible for maintaining close physical and emotional connections with
their child. Such close physical contact and emotional engagement allows them to monitor
their child’s health and seek appropriate assistance if required. A quote from Renee
highlights the strong link between intuition and intensive mothering and the potential role of
intuition in encouraging maternal sacrifice as a means of satisfying cultural expectations
about maternal responsibility:

I’m a teacher and you can get sent to any school to work depending on
what’s available. I’m not prepared to be working on the other side of town, to
be that far away. I’ve ended up working part-time where my son goes to
school. I get paid heaps less because I'm working one-on-one but it’s OK
because I can be at the school where he is. But anyway that’s how you
think. You don’t want to be far. And I get other teachers saying to me “How
can you take on that position, the pay’s so much lower and it’s stepping
down?” But it’s nothing to me because I'm not prepared to put him in after-
school care or have other people looking after him. They just don’t know him
like I do, they just can’t keep that extra special eye on him like I can
because I can usually tell when something will go wrong … you know, I
watch everything, what he does, how he plays, certainly when he was little
in the playground. Every minute longer he would sleep I was questioning …
you know, that’s how it is for me. (Renee, 39 years old, 6 year old son with
congenital heart disease)

As inferred in this quote, the intensity of the relationships that emerge from a belief in
maternal intuition can be burdensome; however, as I explain next, maternal intuition can also
have empowering effects.

Maternal intuition as a potential form of empowerment
The second relationship between cultural expectations surrounding intensive mothering and
maternal intuition is based on an apparent willingness of the participants to engage in
intensive mothering practices in order to demonstrate themselves to be ‘good’ mothers. For
these women, expressing intuitive knowledge about their child demonstrates a closeness
and an attentiveness that is characteristic of the devotion and receptiveness that is
associated culturally with ‘good’, intensive and committed mothering (Badinter, 1981; Hays,
1996). Expressing maternal intuition provided a way for the women to prove that they are
connected with and actively committed to their child. It also demonstrated a closeness in
their bond with their child that would be impossible to develop if they were more distanced,
less caring or less protective mothers. Therefore, for these women, expressing a ‘special’
kind of knowledge that emerges from a ‘special’ embodied bond between mother and child is
empowering in that it provides evidence of their ability to conform to social expectations
surrounding ‘good’ mothering. As such, the expression of intuition, as a form of close, embodied knowledge, becomes a political process that allows women who may be otherwise positioned outside the boundaries of social acceptance to regain some degree of recognition by reasserting themselves as legitimate, caring and compliant social beings. Within this broader understanding of intuition, women who display intuitive abilities become positioned as operating within a higher order than those who have only ‘normal’ maternal capacities and cannot anticipate their children’s needs, wellbeing or desires. Therefore, it is these intuitive women’s ‘good’ mothering practices, and not just their biology, that becomes interpreted socially as providing the basis for a closer maternal-child bond or, rather, a bodily fusing where they feel as their child does. While this can be empowering, in an important entanglement of experience, the women’s embodiment of this knowledge also has the potential to disempower them. Such disempowerment stems from their engagement with discourses of intuition which reinforce their greater responsibility for child health by legitimising this and rendering their close relationship with the health problems as largely inescapable. This represents the power of intuition to both entrap and empower the women in relation to maternal responsibility.

Adding further to the complexities surrounding maternal intuition is its tenuous relationship to authoritative discourses of medicine and public health. Maternal intuition is not considered ‘rational’ and instead can only be sensed rather than explained, as such; it cannot be seen, measured or recognised within clinical parameters. This leads to its devaluing and dismissal within authoritative systems of knowing. However, if understood differently maternal intuition could be understood as a parallel of ‘professional intuition’ which is based on intense knowledge and immersion in the doctor-patient relationship. Re-conceptualising these women’s intuition as intense knowledge rather than intense mothering could, therefore, add to the empowering aspects of maternal intuition in the lives of women and add to its legitimacy in a way that does not compound the problematic effects of assuming that maternal knowledge is attained through female biology. This consideration adds a further layer of complexity to the possibilities that can emerge from women’s embodied enactment of particular discourses as part of their acceptance of, or resistance to, the dominant constructions of maternal responsibility and authoritative ways of knowing. I now move on from maternal intuition to continue to explore women’s engagement with and embodiment of discourses of maternal responsibility by examining further how the interview participants understood the causes of their children’s health problems.
Congenital health problems as evidence of women’s failure

During their interviews the women identified several potential causes of their children’s health problems. Consistent with medical and public health discourses most discussion about cause was focused on factors related to the women’s own bodies and behaviours. However, discourses of maternal failure emerged more strongly and explicitly from the interviews than from my analysis of the medical literature and health education resources. Importantly, the women linked their failures to their children’s health problems regardless of whether they knew what the cause was and regardless of whether they knew what they had failed to do. Furthermore, it was clear that many of the women began thinking about their personal failures immediately after learning of their child’s health problems. Nikki’s comments demonstrate this:

Straight after he was born I constantly thought ‘What did I do wrong? What did I do during my pregnancy that I shouldn’t have done?’ You know I did have a couple of drinks during my pregnancy, maybe that was it. But you talk to other parents and they drank during their pregnancy … But I was thinking ‘Oh my gosh I just really shouldn’t have done it!’ And I think in the last fortnight or something before he was born I’d had salami and I was thinking ‘That was it, I shouldn’t have had salami, I should have just waited until after he was born’ and it was just all of those things … You’re just constantly second guessing what you did and if you could have prevented any of it. But I guess knowing now that I probably couldn’t, it’s something you can’t change. But every now and then I still go through—now what did I do that has caused all of this? Was it something I did? Was it something I said? Have I been a bad person all of my life? Yes I was a terrible teenager but does that mean … you know, all of that. (Nikki, 29 years old, 5 year old son with congenital heart disease)

While it is clear that Nikki felt generally anxious about the ways she may have contributed to the health problems, several of the women identified specific behaviours or personal characteristics that they believed had an influence. When discussing these factors the women expressed feelings of guilt about their role in causing the problems, a role which they regarded as being certain. One participant, Cassandra, possessed particularly intense feelings of guilt. This was demonstrated by her unprompted disclosure early in the interview about smoking during her second pregnancy:

I guess one of the worst things I should mention in your study is … I did smoke during my pregnancy with her, I didn’t with my twins, but I did with her. And you can imagine obviously when we found out there was something wrong with her heart, the guilt, my god! I thought ‘Oh my God look what I’ve done!’ And you know it was just the … I felt like I’d got my just deserts basically. (Cassandra, 33 years old, 2 year old daughter with congenital heart disease)

Cassandra’s comments highlight her certainty about the perceived link between her child’s health problems and her own ‘failure’ to refrain from smoking cigarettes. Importantly, such
feelings persisted for Cassandra despite being told by a cardiologist that it was unlikely that her smoking caused her daughter’s heart problems. The findings of my analysis suggest that this disparity may result from the power of broader discourses which construct women and their bodies as linked, almost inevitably, to the causes of congenital health problems. I introduced this idea in Chapter 4 where I examined the hierarchy of causation that is present in the medical literature and I explained that existing knowledge about cause is linked predominantly to the behaviours and biology of women. I also extended this idea in Chapters 5 and 6 where I argued that individualisation and the exclusion of men from reproductive responsibility detract attention from potential causes that exist outside the bodies and control of women. Therefore, the dominant focus on women in relation to causation, combined with the abundance of public health information that links smoking to reproductive problems, may account for Cassandra’s strong commitment to the belief that her smoking was the definite cause of her child’s health problems.

Further than this though, it is evident that Cassandra understands the congenital heart disease to be an extension of her personal character since she ‘failed’ to demonstrate adequate self-control. This is important because it leads to a discursive shift in how the health problem can be interpreted. On the basis of such an understanding the congenital heart disease shifts again from its location within the body of the child to the body of the mother (particularly when she said “I’d got my just deserts”), in this case, to reinforce a negative impression about Cassandra’s moral character. Such an understanding also strengthens links between the body of the woman and the production of the health problem since it appears that it emerged as a form of punishment for her ‘deficient’ behaviour. Similar discursive constructions are evident in Nikki’s comments, which I presented earlier, since she reflected upon aspects of her character (potentially being a “bad person” or a “terrible teenager”) as possible causes of her child’s health problems. Overall, this suggests that not only are congenital health problems understood as being caused by women’s bodies or behaviours but they can also be regarded as an extension, and reflection, of the character of a woman. The power of women’s characters to harm their foetus has been used throughout history as a basis for explaining congenital health problems.

In the book *Altered Conditions: Disease, medicine and storytelling* (1995) Julia Epstein explains that, historically, the mental activity and character of a woman has been implicated in the creation of an ‘imperfect’ womb. Epstein’s work examines a debate that extended throughout the eighteenth century in Europe about whether it was possible for the thoughts and imagination of a pregnant woman to produce malformations in her foetus (Epstein, 1995:127). During this debate, physiologists, philosophers and medical professionals
labelled particular aspects of women’s mental activity as sources of foetal damage (Epstein, 1995:127). In particular, women’s fears, anxieties and their frequent expression of strong emotions, such as anger and passion, were explained as potential causes of miscarriage and child deformity. Women’s uncontrolled desires, particularly sexual desires, were also understood to have the capacity to mark or ‘stain’ a foetus by producing birthmarks. In addition, aspects of women’s characters were problematised through beliefs about the power of particular characteristics, such as vanity and a lack of self control, to cause foetal malformations (Epstein, 1995:130-131). Importantly, responsibility for controlling the dangerous potential that emerged from the thoughts and characters of women was placed on women themselves. As a result, in the midst of the debate, women were encouraged to suppress strong emotions, to avoid engaging in thoughts that were too serious or negative and to avoid developing desires that were immoral or unable to be satisfied (Epstein, 1995:130). On the basis of these ideas, blame for congenital problems was directed to the feelings and experiences of the mother (Epstein, 1995:131). Therefore, the birth of an infant with a congenital problem was thought to provide evidence of a woman’s moral and personal deficiencies.

Epstein (1995) explains that these understandings have clear parallels with those that exist in contemporary society. For example, the birth of a drug addicted baby in today’s society becomes interpreted as a reflection of the deficient moral character and the negatively expressed choices of its mother (Epstein, 1995:132). In addition, the criminalisation of certain conduct (such as drinking alcohol and taking illicit drugs) by pregnant women in some countries of the world, and the sporadic debate about whether this should occur in Australia, highlights the persistence of strong beliefs about women’s responsibility to suppress desires and behaviours that may result in foetal harm (Epstein, 1995:125-127). Similarly, in relation to my findings, it is clear that Cassandra’s self-blame stemmed from her feeling of moral deficiency in that she ‘failed’ to ‘control’ her desires or addiction and, as such, she believes her child now carries a mark of those failures. On the basis of similar contemporary examples, Epstein concludes that it is not surprising that the birth of a child with congenital health problems, did, and still does, call into question the moral legitimacy of its parentage (Epstein, 1995:132), or as I argue, the moral legitimacy of its mother. In important ways this means that the woman comes to embody her child’s health problems both through the expression of her agency and through the operation of the other discourses which create links between her moral character and the problems she is believed to have produced.
Chapter 8

**Congenital health problems as evidence of maternal insufficiency**

The interviews reveal that the women's feelings of personal failure were not confined to their understandings about the *origins* of the health problems. Instead such feelings also emerged in relation to other aspects of their children's health and health care. A clear example of this was provided by Nikki.

Nikki's son, Luke, has congenital heart disease and also experiences several other congenital health problems. During her interview Nikki reflected on an instance in which Luke became ill and displayed symptoms including fever and lethargy. Upon noticing the symptoms Nikki took Luke to see a doctor who diagnosed him with a minor cold. Not content with this explanation, especially after Luke's condition continued to worsen, Nikki returned to the same doctor the following day who reiterated his original diagnosis. Nikki's continued concern prompted her to seek the advice of five other doctors over the period of the next week, all of whom provided similar diagnoses. At the end of the first week of Luke's illness a relative visited Nikki and advised her to again seek medical attention because Luke's condition appeared serious. Nikki dismissed this advice on the basis that all six doctors she consulted had told her Luke was suffering from only a minor viral infection. Furthermore, Nikki said that she did not feel comfortable seeking additional medical opinions since she found it humiliating and hurtful to have her concerns constantly dismissed by doctors, particularly since their dismissal reflected stereotypical assumptions about women being emotionally excessive. However, later the same day Nikki visited a pharmacy and after she explained Luke's symptoms the pharmacist instructed Nikki to take Luke to a hospital. After consulting briefly with her husband, Nikki followed this advice. Upon arriving at the hospital Luke was diagnosed with a severe bacterial lung infection for which he required ten days of treatment in an intensive care unit.

When explaining her experience to me Nikki said that she “felt like the worst mother in the world” because she “put her child in a critical condition through not acting sooner.” In making this statement it was clear that Nikki felt personally responsible for the severity of Luke's condition, a severity that, for Nikki, only emerged out of *her failure* to act in a way that was consistent with her responsibilities as a mother. Nikki possessed these feelings despite having sought advice from six medical doctors and one pharmacist over the period of a week. This suggests that part of Nikki's understanding of what maternal responsibility entails is a form of inherent knowing, that is, the ability to *know* that her child required medical attention and to trust this knowledge even despite medical authorities repeatedly dismissing it. The fact that Nikki didn't trust her beliefs provided further impetus for self-blame because, as she rationalised her situation through multiple discourses, her mistrust represented her failure to
uphold the naturalistic discourses that link ‘good’ mothering to an ability to know how to protect your child through maternal intuition:

I felt I had done this to my child. I should have known. I should have taken him back to the doctor, I should have trusted myself! What kind of mother does this make me I kept thinking. (Nikki, 29 years old, 5 year old son with congenital heart disease)

Nikki’s comments demonstrate that she had internalised several of the ideas that permeate broader medical and public health discourses. In particular Nikki shared the belief that women have considerable power to control their children’s health status (even in the context where this power is undermined through medical authority). Nikki also interpreted her ability to control her child’s health as located outside the influence of broader factors, such as the strong power relations that shaped her consultations with the medical professionals and which reinforced the negative sense of self that she was trying to escape. Further than this though, Nikki’s comments reflect an embodiment of her relationship to her child’s health problems. This is demonstrated by the way that she, seemingly unquestionably, understood responsibility for her child’s health as located exclusively with herself and not with her husband or even with the medical doctors she consulted. Nikki’s strong commitment to beliefs about her ability and responsibility to control her child’s health provided a central basis from which she interpreted his condition as emanating from her personal failures. In addition, the tendency for Nikki to avoid considering the potential influence of factors that were outside of her control both legitimised and intensified her self-blame for Luke’s illness. This is particularly evident since Nikki’s embodiment of total responsibility rendered her child’s illness to be contingent on the choices that she made, choices which she interpreted as revealing and extending her inadequacy and deficiency as a mother.

As the interview with Nikki progressed it became clear that her feelings of failure formed part of a broader context in which she had learnt to interpret her mothering abilities as potentially compromising to the wellbeing of her child. It also became clear that Nikki’s experiences within the medical system had contributed to this self-perception. This was demonstrated by Nikki’s experiences of breastfeeding her son:

After he had his surgery we came home and I think he was nearly eight weeks old. He was delayed in coming home because he couldn’t feed. In hospital I had so many lactation consultants and everything else coming around and shoving the baby onto me and there was me balling my eyes out going “I can’t, he doesn’t want me.” But they just kept going “No you just need to persist, you need to keep trying, you need to do this!” and blah blah blah ... I guess too it was made harder because all that expectation in the hospital of—“This is best for your child. You will do this. This is what mothers do.” And you feel like you fail in a sense, and that feeling is very upsetting. (Nikki, 29 years old, 5 year old son with congenital heart disease)
Nikki’s experience of external pressure to breastfeed, and her feelings of failure for not being able to do so, contributed to her embodiment of a deficient relationship to her child’s health care. For Nikki her difficulties with breastfeeding provided further evidence of the relationship between her dysfunctional body and her child’s health problems because biologically, she had again ‘failed’ to fulfil the role of a ‘natural’, ‘competent’ mother. Her child’s ‘rejection’ of her, like the existence of the congenital health problem, served to reinforce Nikki’s failures and to reinforce the idea that she could not mother her child naturally, effectively or responsibly. Consistent with this, my analysis of the health education resources and medical literature showed that breastfeeding is not presented as a choice for women, and especially not a ‘lifestyle’ choice but instead it is constructed as a health mandate which women have the ‘natural’ responsibility to adhere to (O’Mara, 2007:10). This idea is supported by the numerous references made to the importance of breastfeeding for the health of infants throughout the health education resources and the medical literature. The number and content of these references make clear that women need to breastfeed their child in order to fulfil their natural mothering role responsibly. The high level of importance that is associated with breastfeeding\(^{46}\), and the related inference of responsibility, is conveyed in the following quote from a health education resource:

> Exclusively breastfeeding your child to the age of about 6 months gives the infant the best nutritional start in life … Studies have also shown that breastfeeding improves the infants’ cognitive development … The considerable benefits makes breastfeeding a great choice for mothers and babies. (Lyell McEwin Hospital, 2005:9)

**Embodied responsibility and an inability to “move on”**

Reflecting back on the Introduction to this thesis, I introduced Louise’s narrative and explained that she too experienced considerable guilt about her child’s health problems. A central theme in Louise’s narrative, however, was her desire to “move on” from her feelings of guilt. Yet it was clear that in conjunction with this desire, Louise maintained an unquestioned commitment to understanding her child’s health problems as emerging from her actions or failures. Similarly, in Chapter 6 I identified a tension in Jane’s narrative in which she believed that she “did everything right” during her pregnancy yet she remained committed to a belief in the exclusive ability of women to determine the outcome of their pregnancies. I now explore some of the underlying factors that contribute to this tension.

The willingness of the women in this study to ‘take up’ and reinforce beliefs which implicate them as the primary causes of congenital health problems is an important consideration in

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\(^{46}\) By using this example I am not arguing against the evidence that breastfeeding is beneficial to the health of infants. Instead my aim is to problematise the framing of this advice and to explore the implications of it for women who find breastfeeding difficult.
the context of this thesis. Embodying an identity which constructs them as the cause of their child’s health problems renders women as legitimately to blame despite it being the stated desire of several of the women to escape such blame because they found it to be hurtful and, generally, misplaced. Such disjuncture between the women’s stated desires and their active role in replicating these discourses makes clear that they reinforce dominant medical and public health discourses that blame them for their children’s health problems. Women reproduce these discourses through the self-regulation and self-monitoring (technologies of the self) that they engage in and, through this; they learn that they are forever deficient, even if they try to escape such a feeling of deficiency.

The findings of my research also suggest that engaging with processes of regulatory power, of which, I argue, medical and public health discourses form an important part, women learn to understand their bodies as being more than just ‘lacking’ or insufficient. Women are also educated about the dangerous and risky potentialities that they embody. This is established through many of the discourses that I have already identified and explored throughout the thesis, such as the strong links between women’s behaviours and teratogens (refer to Chapters 4 and 6).

The education of women about the risky potential of their bodies has particularly important implications for the ways in which women embody their reproductive identities because it infers that they have the potential to impose harm on unborn children. Through their embodiment of risk, women come to understand themselves not as at risk in the context of neo-liberalism and unequal power relations, but instead as a risk to their children’s health and wellbeing (Kavanagh & Broom, 1998). This idea, combined with pervasive social understandings about the inherently ‘lacking’ nature of the female body as explained by Bordo (1997), makes clear that women’s bodies are in need of life-long management and surveillance in order to achieve healthy reproductive outcomes. The widespread availability of such management to women through their engagement with medical and public health advice creates a situation in which women become imbued with responsibility for seeking and complying with such advice in order to improve themselves and their behaviours and to, therefore, reduce the risks that they pose to the ‘unborn’. However, in their engagement with such advice, as I have argued throughout the thesis, women are exposed to discourses which further reinforce the potential risks that they pose to the health of their future children. Women’s continuous exposure to discourses which posit them as a risk, particularly in a context where little attention is directed to risks that may emerge from factors outside the bodies and control of women, reinforces the centrality of the female body and female behaviour as origins from which child health, and the threats to it, emerge. Consideration of
this process offers some additional insight into why women may remain committed to self-blame about the origin of their child health problems even when the cause is unknown and even when they want desperately to escape the feelings of guilt associated with such beliefs. The findings of my analysis suggest that such feelings can be particularly enduring within the lives of women. This idea is demonstrated by the comments of Celia, a geneticist who I interviewed:

One time I saw a woman of about 35 and her mother was then 70 and someone realised [the daughter] had Rett syndrome and we tested her for that and she did have it. And the mother was so overjoyed really because she’d always blamed herself. So it was quite sad really, she was sort of overcome to find that it wasn’t … she’d always thought that she must have done something wrong in pregnancy and things like that. So it was really sad because she’d been blaming herself for so many years.

Interestingly, this quote also adds another layer of complexity since Celia posits medical intervention (a diagnosis of Retts) as empowering to the mother. This is dissimilar to most of the other effects of medical intervention that I have discussed so far in the thesis. Therefore, this again highlights the duality of effects as medical discourses operate to both entrap and empower women in relation to maternal responsibility.

Personal responsibility for making up for prior ‘wrongs’

Related to women’s enduring sense of responsibility is their active engagement in activities to improve their children’s current and future lives as a way of compensating them for the pain and negativity associated with their health problems. Importantly, even women who did not express feelings of self-blame for causing their children’s health problems still felt compelled to act in ways that would compensate their child. The findings of my analysis suggest that one reason for this is that the women felt a need to amend the ‘damage’ or ‘harm’ that their child had suffered even if they did not feel personally at fault for causing that harm. This is associated with understandings that are perpetuated by medical and public health discourses which position women as having the strongest influence on the health of their children, and from this, the highest level of responsibility to protect them from illness. The ability of, and need for, women to protect their children is reinforced discursively through the abundance of advice that is directed to women about behaviours they should and should not engage in before, during and after pregnancy. Implicitly, such advice and the broader discourses that circulate around reproductive health, reinforce the idea that one of the important roles of a responsible woman and mother is to protect her foetus or child from

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47 Rett syndrome is a severe genetic condition that affects speech and movement (Victorian Government Department of Health, 2009:1).

48 Celia’s statement could also be read as a strategy to dismiss anxiety about medical practice being a reinforcer of maternal guilt by offering a story where a doctor is seen to alleviate guilt rather than impose it.
harm. This strong link between responsible mothering and protection meant that even in instances where women did not feel that they had personally caused the health problems, and they actively rejected this idea, they experienced a sense of failure and irresponsibility in not having protected the foetus from congenital health problems during its development. For many of the participants this manifested in a desire to improve their children’s lives in ways that could protect them from further pain and difficulties. This idea was expressed clearly by Emma.

Throughout her interview Emma frequently reiterated her desire for her daughter to have access to as many opportunities as possible in the future. In particular Emma explained that she did not want her child to be prevented from doing anything because she believed she could not or because others treated her as ‘disabled’:

I’ve always wanted for her to learn as much as she can. No matter how much trouble it is for me. You know, I want her to experience life and I want her to become independent. And she’s shown very much that she is … She doesn’t limp, she’s fine, she’s happy. And even if she did have problems I really think we would have dealt with it, it would have been fine. (Emma, 30 years old, 16 month old daughter with spina bifida)

Emma’s comments suggest that she intended to do anything she could to create a positive future for her child regardless of the personal costs involved. Emma’s expression of her desire and willingness to shape her daughter’s future in a positive, empowering way makes it clear that she is determined to protect her children from suffering the negative consequences that may arise from her spina bifida, such as discrimination and loss of independence.

Similar intentions were also expressed by women who did blame themselves for their child’s health problems, and for these women, such intentions manifest in particularly intensive ways. For Cassandra her feelings of self-blame resulted mainly from smoking during pregnancy but she also felt particularly negligent for not being present at the medical appointment at which her child was diagnosed because she had demanding work commitments at the time and her partner had taken their daughter to the appointment. Cassandra’s guilt motivated her to engage in many activities in order to ensure that her child experienced as much pleasure in her life as possible. In the short term, this involved making sure that her daughter had “anything that she asked for”. This was difficult to achieve in some instances and Cassandra expressed further guilt about, unintentionally, creating a difference between how she treated her daughter compared to how she treated her other children. Cassandra also made major life sacrifices in order to ensure that she maintained a

49 Cassandra’s child was diagnosed when she was one year old.
high level of devotion to her child. One of these sacrifices was a decision not to have any more children before her daughter’s cardiac problems had been treated effectively and were able to be managed in a way that did not impact significantly on her health. Cassandra made this decision despite her husband’s desire to begin trying to conceive another child and also despite her own desire to have more children. Cassandra rationalised her decision by explaining that it was important that she could devote her full attention to her daughter and to the management of her health problems. For Cassandra, making her full attention available was a way of compensating her daughter for the difficulties she had to endure as well as a way of ensuring that she could remain as attentive as possible during the management of her child’s health problems to prevent the any further or unnecessary harm.

Another participant, Kayla, provided an example of a different way that she embodied a sense of responsibility to compensate for the harms that were inflicted upon her child. During her interview Kayla stated adamantly that she did not feel personal responsibility for her child’s congenital naevus. Yet Kayla also expressed the belief that it is vital that all women act responsibly while they are in their child bearing years to prevent congenital health problems developing. Kayla understood the cause of her child’s condition to be the result of bad luck or pure chance, particularly since she had knowledge of situations where pregnant women had acted in ways that Kayla believes were irresponsible and had still given birth to a healthy child. Therefore, as a way of compensating for the wrongs that she understands to have been inflicted on her child Kayla assumed the responsibility of educating her pregnant friends about how to act responsibly in relation to their reproductive health:

... with my friends I freak out, I get real nasty with them, I'll say “Put down the [alcohol], you know, stop it!” And then I hear them say “I didn’t take my folic acid” or that they found out they were pregnant and oops they accidently took the [contraceptive] pill and I’m like “What are you doing!”

(Kayla, 27 years old, 4 year old daughter with congenital naevus)

Kayla’s comments make clear that her embodiment of responsibility for congenital health problems does not only extend to her own child but it also manifests in a perceived obligation to prevent harm to the ‘unborn’ more broadly.

Kayla’s experiences are theoretically important. Through her particular embodiment of a relationship to congenital health problems, Kayla imposes judgement on other women and, in doing so, reinforces the discourses which she refuses to apply to herself. These are discourses that render women ultimately responsible for their children’s health problems. This reflects a complex situation in which Kayla resisted some of the dominant discourses surrounding maternal responsibility, while at the same time, policing the boundaries that lead...
to their reinforcement as truths (Foucault, 1979). Given the complexity, active negotiation and performativity of discourse that underlies Kayla’s experiences, Butlers’ theory is relevant.

Applying Butler’s (1990, 1993) theory of performativity assists in highlighting the implications of the way that Kayla embodied responsibility for protecting the ‘unborn’. It is clear that Kayla understood her body in a way that was separate from the public health and medical discourses that she was exposed to. For Kayla, her child’s congenital health problems did not emerge from her own body, but from other random forces, expressed as bad luck. However, during her exposure to these discourses Kayla came to embody them in a way that rendered her as responsible for ensuring that she prevented foetal damage emerging from the bodies of other women. In one sense, through her active performance of this identity Kayla behaved in ways that reinforced and legitimised the discourses that she aimed to escape. Therefore, through her active reinforcement of these discourses Kayla served to increase the power of these discourses by replicating them and blaming other women. In this sense, it is clear that through her embodiment of a relationship to congenital health problems Kayla became complicit in reinforcing the potentially damaging and oppressive structures that had the potential to define how she was interpreted in society on the basis of her particular mothering identity. However, in an interesting contradiction, which reinforces the importance of considering Butler’s theories as an extension of Foucault’s, Kayla’s zealous instruction to other pregnant women can also be read as a strategy that allows her to resist the implications of dominant discourse by restoring her credibility. Kayla’s child has a health problem that is marked on the body and, therefore, obvious to all, including those who might hold Kayla responsible. Her vocal presentation of herself as an aware advocate of good mothering and preventative advice could protect her from others’ assumption that she was ignorant of the ‘proper’ way to conduct herself (as a pregnant body) and had, therefore, caused her child’s health problems. This position was available to Kayla only because congenital naevus is not a condition that can be linked clearly to the behaviours of women during pregnancy. However, had Kayla’s child been born with FASD this would not have been a legitimate position for her but instead she could have advocated only from the position of warning other women not to become a victim of ‘failed’ motherhood by complying with public health and medical advice during pregnancy.

**Battling with medical staff: Women’s struggle for credibility**

Again reflecting back to the Introduction to this thesis, Louise explained that she felt a need to ensure that she and her children were dressed immaculately when attending medical appointments. Dressing in this way was an important performance because it gave Louise a means through which she could outwardly demonstrate both her credibility and her ability as
a mother. For Louise, such a performance of responsible mothering was vital because she believed that having a child with health problems was interpreted socially, and particularly within the medical system, as evidence of maternal failure. Louise was not alone in this interpretation. In Chapter 5 I presented the comments of Melanie who also attempted to escape the negative judgement of the medical profession by ensuring herself and her child were dressed “nicely” when attending medical appointments. Melanie believed that by presenting herself as a competent person and mother she could overcome the discrimination that she experienced to be a result of her lower class status and the associated interpretation of her as an irresponsible, uncaring mother. Despite the empowerment derived from such performance my analysis of Louise’s and Melanie’s narratives, as well as the narratives of other participants, also suggests that in their efforts to resist an identity that renders them responsible for their children’s health problems, the women become entrapped in embodying an even more intense relationship to their children’s health.

Cassandra’s experiences provide a clear example of the extent to which women come to embody responsibility for their children’s health problems through their attempts to escape negative judgement. During her interview Cassandra spoke as if she was in a constant battle with the medical staff who were treating her daughter. This battle was based both on Cassandra’s struggle for respect and her struggle for control.

It was clear throughout the interview that Cassandra felt that she lacked control of her daughter’s health. Cassandra expressed a strong desire to gain control, however, and this appeared to have been intensified by her beliefs about having ‘failed’ to control her own behaviours during pregnancy, which she interpreted as the cause of her child’s heart problems. Cassandra’s desire for control encouraged her to display intensive mothering by spending considerable time, energy and money learning as much about her child’s congenital heart disease as she could. As a result of her efforts Cassandra had discovered information about her child’s particular form of cardiac problems that her cardiologists had not yet heard or read about. When presenting this information to the cardiologists Cassandra became dismayed at the fact that the cardiologists were not aware of the information and also that they appeared to dismiss it on the basis that it “probably wasn’t relevant” to Cassandra’s child because “all cases are different.” The dismissive attitude of the medical professionals intensified Cassandra’s insecurities and, therefore, stimulated her further efforts to gain and maintain as much knowledge about and control over her child’s health as possible. These efforts culminated in Cassandra’s desire, and future intention, to study cardiology at university in order to allow her to manage her child’s treatment and also allow
her to provide a more credible, more authoritative, performance of responsible mothering when interacting with the medical staff.

In addition, Cassandra explained that she felt in constant battle with the medical professional to have her child recognised and respected as someone special, someone who mattered and “not just another patient”. This involved Cassandra frequently mentioning to the cardiologists that she cared so much for her child that if her daughter was to become severely ill or to die that Cassandra would be “emotionally crushed” to the point that her own life “would be erased forever.” This highlights a tension in Cassandra’s narrative whereby she embodied her child’s health problem to the extent that she knew a considerable amount about it, yet it was also clear that she also understood the importance of rendering the health problem as an object of medical knowledge by positioning the medical professionals as those in most control of her daughter’s health outcomes. For Cassandra, achieving this balance provided a sense of credibility in that she could demonstrate that she had a high level of understanding about the health problems while not asserting a corresponding level of authority because that would challenge the authority of the medical professionals. Yet this also has a contrary effect to Cassandra’s desire to become an expert and to her aim of being in control of every aspect of her child’s health.

Overall, consideration of these findings makes clear that Cassandra, as well as Melanie and Louise, demonstrated a particularly strong resistance to the negative identity that they believe to be associated with congenital health problems. This resistance involved these women engaging in intensive and all-consuming efforts to present themselves as credible, competent mothers who deserved respect because they were highly devoted to their children and actively taking care of their health. This had an empowering effect which encouraged a more positive interpretation of these women’s strength and abilities as mothers. However, through the complexities underlying women’s embodiment, the intensity of their efforts and their struggle for credibility came to dominate their contact with the medical professionals and, thereby, reinforced their identification with congenital health problems. This resulted in the expansion of their responsibility to not just caring for their child’s health but also to ensuring that they outwardly demonstrate a credible and respectable image in an attempt to make sure that they are not cast with blame for producing the health problems in the first instance.

**Conclusion**

Throughout this Chapter I extended the central argument of my thesis. I have argued that the women’s interactions with the constructions of maternal responsibility that are perpetuated through medical and public health discourses makes these constructions particularly
powerful. Therefore, the operation of public health and medical discourses is not linear or simply hegemonic—instead it gains power through the more dynamic processes of performativity and embodiment within which women negotiate, oscillate between and make meaningful constructions of maternal responsibility in their lives.

Rather than passively accepting the discourses of public health and medicine it is clear that women actively mediate between competing rationalities as they understand their experiences and their responsibilities for their children’s health. Through this negotiation women accept and resist aspects of medical and public health discourses in ways that both empower and entrap them in relation to the implications of maternal responsibility. This suggests that rather than being a linear process, the construction of maternal responsibility involves many tensions and entanglements that are played out within the social contexts in which women live. Interestingly these social contexts are rendered largely irrelevant within current medicalised understandings of maternal responsibility, which is a problem that I highlight further in Chapter 9.

My focus in this thesis now shifts away from an exploration of discourses related to the research lens of congenital health problems. Throughout the final Part of the thesis I explore the broader implications of my analysis, including an examination of how my findings extend and challenge current theory about the construction of maternal responsibility for child health.
Part 4

The Need to Broaden and Reorient our Understandings about Maternal Responsibility
CHAPTER 9

Understanding maternal responsibility in the context of neo-liberal health: Broadening the focus

In this final Chapter I explain how my research furthers understandings about the complexities underlying the construction, attribution and implications of maternal responsibility for child health. I begin by summarising the various contributions that my research makes to existing academic literature. In doing so I reiterate the value of my research while also establishing the basis for my forthcoming analysis of how the findings illuminate the micro-dynamics through which maternal responsibility for child health becomes so pervasive, entrenched and embodied. I structure my analysis using each of the research questions that I posed in the Introduction. Through this structure I explain how, and to what effect, women become positioned as responsible for child health and, potentially, broader dynamics of care within Australian society. Consistent with the critical post-structuralist feminist perspective that I utilise throughout the thesis, I also conclude this Chapter, and the thesis as a whole, with practical suggestions for initiating change.

Contributions made by this research

My research makes several contributions to existing bodies of academic literature. Rather than replicating a focus on the existence of maternal responsibility I have explored, through an examination of multiple data sources, the micro-dynamics and conditions through which maternal responsibility becomes constructed and perpetuated. I have done so with a particular focus on public health and medical discourses. This focus is an important aspect of the research because it allows critical examination of the constructed basis and multiple implications of public health and medical discourses rather than assuming their biological neutrality and unequivocal benefit in promoting health.

While examining the multiple micro-dynamics through which maternal responsibility becomes constructed and perpetuated I have also highlighted several different facets of responsibility. I have shown that our understanding of maternal responsibility emerges from, and is made possible through, the operation of various other forms, and constructions, of responsibility. These include individual responsibility, parental responsibility, (negated) paternal responsibility, personal responsibility and failed responsibility. Highlighting how these disparate forms of responsibility converge in the construction of maternal responsibility for child health is important in understanding how ideas about maternal responsibility remain so pervasive in society. Importantly, such diverse and multiple facets of responsibility have not
previously been brought together in research that examines the construction of maternal responsibility.\footnote{See the work of Rachel Colls and Bethan Evans (2008) for an example of research which demonstrates a unitary focus on one form of responsibility (embodied responsibility) to explain how parents are encouraged to accept responsibility for their child’s food consumption and health outcomes. The sole focus on embodied responsibility in this work does not allow for understanding about the multiple processes and other complexities which lead to the construction of parents, or mothers, as primarily responsible for their children’s health.}

Some of the other contributions that I make arise from having viewed maternal responsibility through the lens of congenital health problems. Through this lens I have brought discourses of supposed ‘failed’ maternal responsibility to the fore. This has allowed me to focus on a context where maternal responsibility is amplified and where it is frequently attributed to women and has been accepted and embodied by them. This has made the micro-dynamics underlying the construction of maternal responsibility more clearly visible and, as such, allowed me to explain more comprehensively the role of medical and public health discourses in establishing the conditions necessary for women to be held responsible for their children’s health. Importantly, it appears that such attributions of maternal responsibility are so pervasive that the particular characteristics of the health problem that a child is born with, or the certainty of evidence about cause, has little impact on women’s experiences of responsibility or blame. Instead, even in the absence of physically visible symptoms or established links between women’s behaviours and causation, discourses of maternal responsibility have a powerful and pervasive influence on how mothers of children with congenital health problems interpret and experience their mothering identities.

My use of this particular lens also offers insight into what happens when, for the most part, women have complied with what they understand to be the regimes of surveillance and discipline surrounding pregnancy and yet still experience a ‘less than desirable outcome’. This highlights a perceived failure of technologies of the self, which has remained previously unexamined in the literature on pregnancy and maternal responsibility. My research also reveals how women reconcile their perceived inability to prevent their child’s health problems with their neo-liberal socialisation as self-defining individuals. This contributes further to the social relevance and applications of my research.

By exploring the micro-dynamics of maternal responsibility through a focus on congenital health problems I have also differentiated my research from that which examines the implications for mothers of health problems that have been acquired by their children after birth. For example, academics JaneMaree Maher, Suzanne Fraser and Jo Lindsay (2010) have recently examined how childhood obesity is framed as a problem of motherhood, that is, it is portrayed as the result of women’s failure to manage their children and their children’s
health appropriately. These authors identify some of the ways in which discourses of responsibility become linked to women in dominant explanations of the aetiology of child obesity. While this focus reflects parts of what I argue in the thesis, my focus on congenital health problems means that the ‘problem’ under investigation here is embodied by women, and interpreted as arising from women, to a greater extent than would be the case with health problems acquired by children after birth. This extends my research focus beyond a context where women’s ‘misdirected’ agency is viewed as the primary (or in some cases only) foundation for blame. While I do focus on personal agency in various aspects of my analysis, and I highlight it as one important dynamic of maternal responsibility, I extend my analysis further to consider how the close, bodily relationships that are constructed between women and their children’s health problems are used to legitimise maternal responsibility for child health and to illuminate the micro-dynamics through which this occurs.

A final contribution that has emerged from my analysis is insight into the complexities that underlie the relationship between medicalisation and maternal responsibility. My research reveals that while public health and medical discourses provide a strong framework for shaping women’s understanding about maternal responsibility, it is through women’s engagement with medicalised ideas, and their negotiation of these ideas, that maternal responsibility becomes most meaningful and powerful in women’s lives. This suggests that the processes associated with medicalisation are not uni-directional. Instead, individual’s uptake of medicalised ideas is a central component of the processes through which maternal responsibility gains power, but at the same time becomes negotiated to suit the rationalisations and experiences of those involved. Therefore, my findings contribute to the growing critique of the idea that medicalisation is a hegemonic process. The research also extends understandings in this field by highlighting the dynamics of women’s engagement with medicalisation as part of the processes through which they construct their mothering identities and interpret their maternal responsibilities.

I now shift my focus to address each of the research questions that I posed in the Introduction to the thesis. I do so in order to explain, in greater detail, how the findings of my research illuminate the micro-dynamics of maternal responsibility for child health.
• *How is maternal responsibility constructed within public health and medical discourses?*

I address this question by drawing on, and summarising, the four main themes that I identified in the Introduction to this thesis as having arisen most prominently from the findings of the research. I examine each of these themes separately, beginning with the process of neo-liberal individualisation.

**The individualisation of responsibility for child health outcomes**

Some of the strongest dynamics through which maternal responsibility for child health becomes constructed and legitimised within medical and public health discourses arise from the dominance of ideas based on ideologies of neo-liberalism and individualism. The ways that we currently understand the origins of child health and what constitutes ‘responsible’ mothering are consistent with these broader ideologies. In a social context that is permeated by ideologies of neo-liberalism and individualism it is difficult to direct attention to the relational, social and environmental conditions that can make some behaviours and some health outcomes either possible or difficult for individuals. In this context, as a society, we employ a cultural repertoire, which is perpetuated and reinforced through medical and public health discourses, to explain the realities of individuals as based mainly upon their choices, moral character, will power and sense of responsibility (Kukla, 2008:83; Tierney, 2004).

Whilst there is some acknowledgement within medical and public health discourses that a broad range of factors influence women’s and children’s lives, this is outweighed by the dominance and power of the ideology of individual responsibility (Roe & Morris, 2004:14). Therefore, reproductive health ‘experts’ and members of society in general still expect all women to take particular actions on the basis of their individual responsibility and to express their individual agency in certain directions, even if these actions are unsupported by their social context (Roe & Morris, 2004:14). This individualistic cultural repertoire isolates individuals from the broader context in which they exist and represents them as self-defining agents who can act outside the influence of contextual forces. Such individualistic logic encourages health information and practice that has a predominant focus on the choices and behaviours of women rather than on creating social and environmental conditions that are conducive to healthy outcomes for women, men, children and families. Despite this conflicting situation, not making the ‘right’ choice to ‘protect’ the interests of the (future) child is regarded as a personal failure on behalf of a woman. This results in women continuing to experience a mismatch between their expectations, the expectations imposed on them as
reproductive beings and their lived experiences of pregnancy and mothering (Roe & Morris, 2004:14).

Furthermore, the dominance of an idealised notion of ‘free choice’ within the ideologies that permeate medical and public health discourses encourages a redistribution of risk away from structural and institutional factors to the individual. This redirects focus from systems of inequality and social determinants and concentrates it on individual behaviour within the context of a risk society. However, my research, as well as other feminist research (Forbes, 2008), indicates that women’s choices are structured and contained. Despite such feminist critique, choice and the ‘right to choose’ are still located predominately within discourses of individual empowerment in relative isolation of consideration about the social and political structures in which they are embedded (Lippman, 1999; Sherwin, 1998). Relying on explanations based on understandings of individuals’ free choice and personal agency obscures the processes through which choices become structured and made available or denied. In particular, understandings of ‘choice’ as a gender neutral concept obscure the power relations that serve to make particular choices available to women while also reaffirming existing systems of social privilege and concealing the many differences between women that enable or disable their ability to choose (Lippman, 1999:282). In addition, adequate access to particular social resources is essential to allow women adequate choice and, even when these resources are present, choice always remains bounded by social forces, particular those that operate through public health and medicine, in a way that means choice is never completely ‘free’ (Petchesky, 1993). This means that the rendering of the social as invisible within our current reliance on over-simplified discourses of choice within understandings about the origins of child health only makes the creation of supportive social conditions more difficult, leading to further, persisting social injustice for women (Lippman, 1999:282; Manning & Baruth, 1996:239; Rogers, 2004). Ironically then, in the context of the current neo-liberal social agenda, choice as empowerment, has, in part, become one of the primary mechanisms through which disproportionate maternal responsibility is legitimised through medical and public health discourses.

The gendering of responsibility

Through my research I have highlighted deeply embedded and gendered assumptions that inform understandings about who produces child health and who, therefore, has responsibility for it. Overall, medical and public health discourses operate to gender reproductive responsibility by constructing the female body as a source of pathology (Keane, 1996) and women’s behaviours as primary sources of risk. On the basis of what is, in many cases, uncertain and incomplete evidence about risks to child health, women, as a target
group, have become implicated in a regimen of surveillance (Daniels, 2001:325). This process has involved the positioning of women as potentially to blame for child health problems and the absolving of men from responsibility. Men’s absolution conveys them certain privileges, such as a relative lack of surveillance and blame (Daniels, 2001:325). Therefore, knowledge about what constitutes risks to the health of a foetus or child may well operate as prevention (as is intended) but in doing so it reproduces ‘truths’ about the nature of men’s and women’s relationship to reproduction and the responsibilities people have for this on the basis of their gender. This makes science both reflective of and reinforcing of the social and cultural context from which it emerges. This means that science, rather than being value free and objective, is constituted through its political location, and as my research shows, by the gendered politics that operate within the cultural context in which it is embedded (Imber & Tuana, 1988:140; Tuana, 1988).

Following from the cultural and political influences on knowledge about child health, dominant constructions of masculinity also have a role in legitimising maternal responsibility. As I and others (Beasley, 2008; Inhorn et al., 2009) have argued, reproduction is feminised. Within dominant discourses, especially those that I have analysed throughout this thesis, sex for women is framed within a broader desire for reproduction. While sex for pleasure has been added to this reproductive impetus, sex remains understood as having a primarily reproductive function for women. However, sex for men is constructed as pleasure rather than reproductive. It is only when men are required to re-frame sex as reproductive, and to therefore think beyond orgasm to conception, that they need to consider the ‘quality’ of their ejaculate and, potentially, assume a more active relationship to reproductive health. Pervasive norms of masculinity restrict the extent to which this occurs, as I have highlighted in one instance through an analysis of the discourses surrounding the promotion of the male vitamin supplement Menevit. While Menevit constructs the need for men to plan for reproduction and nurture the health of their sperm it is clear that these discourses frame reproductive responsibility as a temporary state for men, one which can be fulfilled relatively easily though the consumption of a pill. Within these discourses it is made clear that men are able to return to traditional masculinity once conception has occurred because fatherhood (as it is constructed in this scenario) requires no change by them in the long term and no ongoing responsibility to nurture health once the sperm leaves their body and enters that of a woman. This is because the health of the conception then becomes under her control and her responsibility (which echoes historical understandings of the seed and the soil (Delaney, 1988; Fausto-Sterling, 1987; Tuana, 1988)). Therefore, instead of encouraging men to focus on promoting their health and that of their (future) children, the discourses surrounding Menevit operate to reinforce traditional norms of masculine behaviour. Menevit, even though
it is represented as a sign of egalitarian social change in which both men and women share responsibility for healthy conception, has the effect of being a reinforcer of traditional masculinity and a maintainer of traditional gender dynamics, one aspect of which is disproportionate maternal responsibility.

Overall, my findings demonstrate that the relative absence of men and fathers in information about the cause and prevention of congenital health problems is pervasive and productive. In particular, it means that women alone carry responsibility for the origins of child health. When gendered understandings are combined with individualised and decontextualised constructions of responsibility, my findings highlight important absences in current discourse, all of which operate to construct and reinforce maternal responsibility for child health. In understanding the importance of these absences, the work of Nancy Tuana is useful.

Nancy Tuana (2004, 2006) argues that if we are to fully understand the complex practices of knowledge production and the variety of factors that account for why something is known, we must also understand the practices that account for not knowing. This means that the politics of ignorance should be a key element of social and political analyses (Tuana, 2004:195). Tuana views ignorance not just as a simple omission or gap but argues that it is constructed, actively preserved and linked to issues of authority, doubt, trust, silencing and uncertainty (Tuana, 2004:195). The silencing of particular issues is productive in the sense that it serves some political interests over others and operates to empower some groups over others. This is clearly apparent in relation to maternal responsibility since women as a social group have become isolated as risk while the potential influence of broader factors remains largely unexplored. Tuana (2006:3) argues that if we are to enrich our understandings in a particular field, such as child health, then we must also examine the ways in which not knowing is sustained and sometimes even constructed. I return to this as one of the recommendations that I make about future research in the conclusion to this Chapter.

The authority of medical and public health discourses
Throughout the thesis I have also shown that the perceived authority, assumed accuracy and unbiased reputation of public health and medical information contributes to its power in defining maternal responsibility for child health. The erasure of uncertainty within public health and medical information is a central dynamic through which links between women and child health become constructed, legitimised and rendered as ‘natural’. My research also indicates that the widespread distribution of health promotion messages, legitimised particularly through standardisation and representations of objectivity, convey authority to medical and public health discourses in ways that legitimise the understandings of
responsibility that emerge from them. Therefore, despite the inconclusive state of the available evidence, the discourses surrounding child health call for strong controls on the freedoms of women in order to reduce the potential ‘risks’ that they are perceived to pose to foetal development.

Furthermore, it is apparent that the discourses that I have examined reinforce dominant understandings of women as blameworthy and lacking while reinforcing representations of health professionals as competent and knowledgeable. This legitimises women’s engagement with and dependence upon medical professionals throughout their reproductive experiences and provides the potential for them to be considered irresponsible if they question medical knowledge or resist medical intervention (Malacrida, 2002:381).

My research has also revealed that competing constructions of risk operate simultaneously in the context of maternal responsibility and that negotiation occurs as people interpret and embody particular understandings of risk. Such negotiation is not only entered into by patients, or their parents, but it is also undertaken by medical professionals themselves. What becomes defined as risk, and from that, who becomes represented as risky, is influenced by the weight of authority and status associated with particular groups and systems. Therefore, while the women I interviewed had their own perceptions of risk and expressed these to me, they remained acutely aware of the interpretations of risk made by medical professionals. Even though the women may not have believed some of these interpretations, the origin from which they came meant that they persisted in their thoughts following the birth of their child, sometimes serving as a basis for self-doubt and blame. The same situation existed for medical professionals in situations where the weight of authority associated with the medical guidelines which they were instructed to follow overshadowed their own perceptions of risk. A conflicting situation resulted from this in which the messages that medical professionals promoted through their practice differed from both the beliefs that they applied in their own lives and the beliefs that they derived from their first-hand experience in treating patients. This highlights that even though risk is used as a strong basis for the attribution of maternal responsibility, it is a construction that is influenced by the social context of authority in which it is located as well as through knowledge about the biological body to which it is most generally applied. Therefore, those with the most authority have the most power to define what is risky and although individuals are able to negotiate these constructions, authority becomes used as a weight of evidence, making complete rejection of what is defined as risk extremely difficult.
Women’s engagement with, and negotiation of, public health and medical messages

My research reveals that women’s interactions with the constructions of maternal responsibility that are perpetuated through medical and public health discourses contributes to the power and pervasiveness of these constructions. Rather than passively accepting the discourses of public health and medicine it is clear that women actively mediate between competing rationalities as they understand their experiences and their responsibilities for their children’s health. Through this negotiation women both accept and resist aspects of medical and public health discourses in ways that strengthen the pervasiveness of ideas about maternal responsibility. For example my research shows that women actively subscribe to the rhetoric of individualism, as do health professionals, which strengthens the attributions of maternal responsibility that emerge from it by making them appear universal and ‘natural’. This leads women to place considerable pressure on themselves, furthering the individualisation of maternal responsibility and its decontextualisation from broader social forces (Warner, 2005). Therefore I conclude that the subjective experience of late modernity is not one of disembeddedness as proponents of the individualisation thesis assert. Instead it is one of complex entanglement in which the ideals that we strive for operate to both entrap and empower us as citizens, particularly when it comes time for us to reproduce. Importantly, in part, it is perceived to be in women’s interests to engage in such entanglements around the effects of individualism since doing so, through a belief in the overriding power of free choice for example, provides a personal sense of empowerment in a context where women frequently experience processes which lead to their disempowerment and subjugation. Sara Ruddick highlights further the seduction of the image of choice and control when she observes that:

A choosing person is increasingly active, less passive; her desires and reasons are increasingly integrated; she is less self-deceived or ignorant and more knowing. (Ruddick, 1991:105)

Throughout this section I have identified the main dynamics through which maternal responsibility for child health becomes constructed and legitimised. In doing so I have explained how it is that women can be made responsible for “everything” in relation to their children’s health. This clarifies the micro-dynamics of maternal responsibility beyond the common, surface level assumptions that I identified in Chapter 1. I now address my second research question.
• **What broader implications do the constructions of maternal responsibility have for women’s roles and responsibilities in relation to their children?**

The dynamics of maternal responsibility that I have identified in this research have multiple implications. One of the most apparent is that they shape ideals of motherhood in particular ways. These ideals replicate, and reinforce, stereotypes of what it means to be a ‘good’ mother and, through this, a ‘good’ woman.

**Constructions of the ‘good’ mother**

Within the discourses that I have studied the ‘good’ mother is defined as a woman who remains committed to reproduction as one of her primary roles. As such, a woman must consistently attend to her body in ways that will optimise its capacity for healthy reproduction. This reflects and reinforces the traditional belief that a ‘good’ mother is always available to her children regardless of the level of self-sacrifice involved (Wearing, 1984:72) and, presumably in this context, even before those children are conceived. In addition, the ‘good’ mother adheres to traditional expectations around femininity which involve such things as preparing meals at home during her pregnancy and, therefore, ensuring she has the time, skills and willingness to do so effectively (Johnston & Swanson, 2006:509). Implicitly, this specifies the private domestic space as the appropriate place for a pregnant woman rather than the inherently dangerous public world of the workplace or of interacting socially with others. Therefore, the discourses that emerge from public health and medicine, along with the corresponding, powerful cultural expectations around ‘appropriate’ roles for women, encourage women’s commitment to an extremely defensive, and intensive, version of mothering even before they conceive or give birth. This form of mothering involves an unrelenting commitment to ensuring the health of the (future) child through active compliance (Dixson, 1986:19).

The inherent expectations on women to conform to a traditional mothering role, which is characterised by a devotion to domestic responsibilities, demonstrates one way in which these discourses reinforce cultural hegemony and gendered stereotypes (Johnston & Swanson, 2006:510). However, as Hays (1996) recognises, it is virtually impossible to achieve the contemporary ideal of intensive mothering and approaching this standard is accessible to only a minority of women who are both socially and economically privileged. For other women, achieving ideals around mothering is prevented by the disjuncture between the expectations imposed through these discourses and the social environments in
which they live (Bartky, 1988:71; Johnston & Swanson, 2006:510). This is particularly so for women who cannot afford to remain out of the paid workforce to attend primarily to their role as reproducers and those who are not equipped with the resources, skills and support necessary to meet all expectations imposed on them in the reproductive context. Even socially privileged women, who can come closest to achieving the intensive ideal of mothering prescribed within medical and public health discourses, do so at a cost. That is, their performance of the ‘perfect’, selfless, utterly committed mother disqualifies them from the other idealised standards of citizenship that exist for individuals in contemporary society, which are characterised by independence, self-sufficiency and self-direction. On the basis of this tension, Shari Thurer (1995) argues that unrealistic expectations around maternal roles and responsibilities, and the blaming of women for not achieving these, have the effects of maintaining social order by disciplining women and penalising them in ways that encourage their efforts to conform, regardless of the level of personal sacrifice or pain that this may involve. Furthering this tension, if ‘good’ mothering, and the corresponding ability to escape blame, is constructed partly on the basis of women’s full adherence to public health and medical advice, we must question whether this is possible at all. Such full adherence is difficult, or even impossible, given the vast amount of advice that women are exposed to as well as the conflicting and confusing content of some of the advice that is offered.

**Women as social resources**

As I have argued at various points throughout this thesis, the outcomes of a woman’s pregnancy are reduced to the level of the individual despite the relational and social complexities faced by women. Through this, child health outcomes are interpreted as a representation of a woman’s moral character and the extent to which her values re-enact a particular morality of putting the welfare of ‘the other’ before her own. The pressures on women to conform with the advice that is offered through public health and medical surveillance operates to shape behaviours in ways that are also expected to uphold the standards that are valued within society—that is, the production of non-diseased, ‘normal’ offspring who will grow into ‘proper’, productive citizens (Ettorre, 2002:68). In this sense women’s bodies become both a reproductive and social resource which is central to the continuance of moral order and the current social, political and economic system (Ettorre, 2002:68). Thus risk and the attribution of maternal responsibility operate to actively reinforce particular standards of behaviour for women in ways that feed the imagined and desired future of the population. Through this, women’s maternal responsibilities become framed on the basis of a future social imperative, making their moral obligation to comply and select particular ‘right’ choices even stronger and more pervasive. When viewed in the context of such thinking, this situation imposes responsibilities on women that extend to their role within
the broader community (Pollitt, 1998:297-298). This makes the burden of blame even more possible as it positions women symbolically as responsible for a whole spectrum of issues across all aspects of society.

The construction of a broad ranging maternal responsibility

The micro-dynamics that I have identified in this thesis result in the construction and reinforcement of women’s responsibility for many more aspects of child health than just congenital health problems. In particular, these dynamics contribute to the construction of women’s responsibilities for:

- the caring role for health (this extends more broadly to legitimise women’s greater responsibility for all facets of care from child care through to elder care);
- deciding if and when to return to work after having a child;
- managing feeding practices for children and ensuring adequate, but not excessive, nutrition;
- encouraging and achieving child milestones and transitions (introducing solid foods, toilet training, establishing age appropriate sleeping regimens and negotiating contested issues such as the use of pacifiers, exposure of children to television and use of centre based child care);
- ensuring children’s socially acceptable behaviour; and
- children’s socialisation, education and success.

Furthermore, within the narrower context of child health problems, the micro-dynamics of maternal responsibility extend to render women responsible for the production of child health problems that develop after a child is born. This is especially apparent in relation to health problems that can be linked back to the uterine environment and, in particular, to the effects of women’s ‘immoral’ behaviours on this environment. The case of childhood obesity provides a poignant illustration of how discourses of ‘immorality’ are evoked to create a mechanism of maternal blame because it is a context in which current scientific research is linking women’s ‘over-eating’ before and during pregnancy with their production of damaged, ‘fat’ eggs (University of Adelaide, 2007). Such research (Drake & Reynolds, 2010; Jungheim et al., 2010) suggests that children who originate from ‘fat’ eggs will be predisposed to childhood obesity and possibly a range of other chronic health problems. But, as my research indicates, such a reductive framing of this issue also creates predispositions that extend beyond childhood obesity or the bodies of children. Instead such reductionism operates to create the conditions necessary for maternal blame, accusations of immortality, a reinforcement of the need for increased surveillance over mothering and, ultimately,
predisposes women to attributions of failed maternal responsibility and, from this, a failure to meet standards of ‘appropriate’ womanhood.

I now return to the final research question as I continue to identify the broader implications of dominant construction of maternal responsibility.

- **Do the practices and bodies of knowledge that are intended to improve maternal and child health also have the potential to compromise the wellbeing of women, men and children?**

My analysis of the research findings suggests that through the particular construction and perpetuation of ideas about maternal responsibility, medical and public health discourses detract from wellbeing in these three main ways: legitimising a distanced and reductive view of the roles of fathers, restricting understandings about the causes of child health problems and encouraging blame for women.

**Implications of a normalised exclusion of men**

Through the discourses I have examined men are rendered less important than women in the lives of their children and as almost ‘foreign bodies’ in relation to reproduction. Men become excused and excluded from responsibility on the basis of their presumed non-influence as well as through the positioning of women as more legitimate targets for medical and public health intervention. My findings suggest that the current positioning, or exclusion and excusing of men, is problematic. However, it is important to highlight that I am not advocating the inclusion of men in the same model of intensive parenting and responsibility that women are currently exposed to. While greater egalitarianism in parenting relationships could provide benefits in improving health and wellbeing, these benefits will not be realised if egalitarianism becomes reduced to a mechanism for sharing individualised blame or misplaced attributions of responsibility between mothers and fathers. Instead, what is necessary is a re-conceptualisation of parenting in a way that includes men as active, and important, partners in the promotion of health and as active contributors to the overall wellbeing of their children. Finding ways to achieve this is important because the consistent and normalised exclusion of men may have implications for the way that we think about the capabilities of men in relation to the ‘hands on’ care of children and also about the appropriateness of men taking an equal role in parenting relationships. In particular, the exclusion of men early in their experiences of becoming a parent (such as during a
pregnancy) is likely to have ongoing effects for how we as a society, and individual men, understand the possible and appropriate role of fathers. Furthermore, one of the important consequences of men’s exclusion is that they are denied the potential to help improve the health of their child through doing things before conception and during a pregnancy to promote health.

The advantages of including men as more equal partners in the context of reproduction and child health have been recognised recently on a global scale by the World Health Organisation (2002). Efforts have been made in recent years across many countries to broaden understandings about men’s responsibility for their own reproductive health as well as the reproductive health of their partners (World Health Organisation, 2002:vii). Measures have also been undertaken to improve gender relations by promoting understandings about the roles men can have in relation to family planning and sexual and reproductive health issues (World Health Organisation, 2002:vii). The reasons for this are that including men to a greater extent offers benefits for the health of women, men and families. In the context of this thesis it is also clear that re-conceptualising men as contributors to reproductive and child health has the potential to allow for greater knowledge about the causes of congenital health problems, which is important in relieving the effects of misplaced attributions of maternal responsibility and in enhancing wellbeing.

A partiality of understanding
The findings of my research indicate that the continuance of gendered and individualised understandings about the causes of congenital health problems may mean that our knowledge will only ever remain selective, unduly limited and uncomprehensive. The enduring focus on, and the intense regulation of, women’s behaviours and bodies in order to promote and protect foetal health creates the conditions for other causes to be overlooked. If women are the problem, then it is women who must be ‘fixed’ (Appell, 1998:376). As long as the focus is on ‘fixing’ individual women, adequate understanding of the full range of factors that influence child health will not be possible. Furthermore, women will continue to be positioned as a threat to child wellbeing, and potentially blamed for this, rather than being supported in ways that may allow them, their partners and other members of the community to contribute positively to the health of their children (Appell, 1998:376).

Within the current context of maternal responsibility the approach taken by public health authorities to women and to reproductive health is instructive. My analysis of the health education resources reveals complicity on behalf of public health in succumbing to a reductive, largely biological and individualistic focus. This is reflected particularly in the
narrow and overly simplistic framing of health promotion messages which operates to constrain women’s choices, sometimes on the basis of conflicting evidence about whether such strong constraint is necessary or effective. The reductive focus that is reflected in the health education resources is not consistent with the broader aims of public health in recognising and emphasising social influences on, and social responsibilities for, health and illness. An overly simplistic focus within health promotion messages may also undermine their credibility and therefore hinder women’s compliance both before conception and during pregnancy. This is because women’s social experiences teach them that there are greater complexities underlying the cause of child health problems than is reflected in overly paternalistic messages such as total abstinence from alcohol during pregnancy. The message that “There is no safe time to drink alcohol during pregnancy, there is no safe amount of alcohol.” (Government of South Australia, 2007a) [Emphasis in original] runs counter to women’s lived experience as well as to scientific evidence. Disbelief in these messages stimulated by the use of an overly reductive framing may, therefore, compromise rather than enhance the success of public health initiatives. However, public health is well placed to highlight and acknowledge the damaging effects of not recognising the relational, social and environmental influences on child health outcomes and also the negative implications that arise from a continuance of positioning individual women as having greatest responsibility for these outcomes. Therefore, a shift away from overly-simplistic reductionism and a move towards a more comprehensive and inclusive view of reproduction and child health may be useful in enhancing the relevance and effectiveness of public health initiatives in these areas.

Broader effects for women
My research has revealed that the individualistic ideologies that permeate contemporary society and that have a powerful influence within medical and public health discourses contribute significantly to the blame of women on the basis of their child’s health. The dominant belief that individuals define their own realities renders outcomes to be the result of personal actions. As women embody their child during pregnancy it is readily assumed that their child’s reality and wellbeing (as well as their own) are defined by the woman’s actions. Therefore, given the dominant understanding that women have a stronger influence over their child’s health than any other people or forces, women may be blamed for not having taken appropriate measures that are consistent with ‘good’ mothering to protect their child, despite the complexities and often inaccuracies underlying this attribution of blame.

Furthermore, what women are taught as being good for the health of others often compromises their own health. This has applications in terms of reproductive health as well
as more broadly in terms of what constitutes maternal responsibility. For example, the findings of Megan Warin, Karen Turner, Vivienne Moore and Michael Davies (2008) suggest that mothers may be discouraged from engaging in physical exercise because taking time away from their children to exercise is perceived (by themselves and others) as selfish. This perception emerges from the belief that upon becoming mothers responsible and devoted women shift the focus from themselves to their children and, therefore, being concerned about improving their own health through exercise only absorbs “precious time and energy” (Warin et al., 2008:106) that mothers could otherwise spend with the family.\(^{51}\) Therefore, even if women escape the imposition of external blame for their child’s health they live out maternal responsibility through guilt and constant efforts to improve themselves in ways that often compromise their own wellbeing.

**Conclusion and recommendations**

My research reveals that within contemporary, neo-liberal Australian society women mother within a complex relationship to medical and public health authority. Medical and public health discourses provide a strong framework for constructing, attributing and legitimising women’s maternal responsibility for child health. Women also engage with the attributions of responsibility that emerge from these discourses to interpret, negotiate, embody and, in some cases, resist a relationship of responsibility for their child’s health problems. As I have made clear through an analysis of discourses relating to congenital health problems, maternal responsibility for child health is legitimised through a focus on women’s bodies and behaviours as the main determinants of child health. This focus dominates theory and practice in relative isolation of detailed consideration about broader relational, social and environmental influences. Compounding maternal responsibility even further are expectations and experiences of disproportionate child care responsibilities within couples and society in general, despite pervasive ideals of egalitarianism. All of these factors converge to imbue women with greater responsibility for creating, managing and ensuring their children’s health. Correspondingly, this also provides the foundation for disproportionate maternal blame when child health problems develop.

The analysis that I have presented also indicates that mothering is the focus of considerable social attention and anxiety. Within this, children’s health is regarded as representative of a woman’s moral character and her ability to uphold standards of responsible citizenship. A woman’s performance of a commitment to child health, which is perceived to be

\(^{51}\) This belief was expressed by several of my interview participants. Importantly, one participant, Kate, justified her regular attendance at the gym by stating that keeping fit made her a “better, happier mother”. Therefore, in order to relieve the guilt that she experienced about leaving the home to exercise, Kate found it necessary to re-position her exercise within a discourse of responsible mothering rather than locating it in a discourse of personal fulfilment or the pursuit of personal wellbeing.
demonstrated through the health outcomes of her child, is, therefore, used as a measure to judge her personal abilities, values and her value as a person.

Women also become imbued with responsibility for reflexively internalising the medical and social gaze in order to fulfil their mothering role in a way that is deemed appropriate and in the best interests of future generations. ‘Good’ mothers are those who consistently pass a number of tests, the production of a healthy child being one such test. However, these tests are never ending and largely unattainable, making the status of ‘good’ mothering temporary, tenuous and in constant need of maintenance and attention. Passing the tests of ‘good’ motherhood require women to adhere to particular rules created, in part, through medical and public health discourses and reinforced through broader social understandings about the appropriate roles and responsibility of the individual in general and of women in particular. Such rules apply even before conception. This reductive understanding of mothering, and the reductive ways in which the origins of child health are understood within public health and medicine, produce counter-productive effects for women’s overall wellbeing. In particular, such reductionism encourages initiatives, attitudes and values that penalise mothers who do not pass the tests established for them and who do not live up to cultural norms (Kukla, 2008). In the context of such penalisation, support is a secondary focus, especially in terms of the broader social supports that are necessary to assist women, men and families in achieving healthy reproductive outcomes and in promoting child wellbeing in a more holistic sense.

The findings of my research suggest the need for an expansion and reorientation of understandings about the origins of child health. Child health emerges from a context which involves a complex web of social relationships, physical environmental influences, relations of power and biological factors. Therefore, I argue that the current dominance of a focus on the power of individual women to determine child health outcomes creates an insufficient, but overriding, emphasis on maternal responsibility and constructs the foundations for misplaced maternal blame. The emphasis on maternal responsibility and individualised blame obscures the context in which a pregnancy is undertaken and in which individual decision making and health related behaviours take place. Furthermore, the current focus instructs women to be individually responsible at a time when they are often least capable of controlling the wide variety of factors (relational, social, environmental and biological) that will influence the health of their child and, through this, influence how their own bodies, behaviours and morality become interpreted by medical professionals and members of society more generally.
Suggestions for practical strategies and future research

Consistent with the critical, post-structuralist feminist approach that I apply in this thesis, I propose several practical strategies that may provide first steps in relieving the impacts of dominant constructions of maternal responsibility. Overall, it appears that we, as researchers, policy makers and health professionals, need to challenge the myth of ‘perfect’ motherhood and, in doing so, recognise the complex, conflicting and constraining contexts in which conceptions occur and in which women undertake pregnancies. On the basis of this, it is important to reduce the level of judgement cast on individual women and actively avoid perpetuating assumptions about the simplistic link between women’s bodies and behaviours and foetal or child health outcomes. Deconstructing this link and reducing the potential for individualised blame or judgement is an important consideration in terms of future practice around reproductive and child health.

I also suggest that health professionals and policy makers focus on including men as more equal partners in the context of reproduction. There is a need to acknowledge men’s reproductive influence, both as biological contributors to a conception but also as people who have the potential to influence the environment in which a pregnancy is undertaken. A relatively simple and practical way to begin this process involves the routine provision of information to men during antenatal appointments about becoming a father, about pregnancy and about child health. While not all men attend antenatal appointments and while not all pregnancies are undertaken in a couple relationship, the routine inclusion of such information with information provided to pregnant women may still be an effective first step in offering greater opportunities for men to engage with pregnancies and recognise themselves as important and valued contributors to their health of their children. This strategy may also reinforce the shared, rather than exclusively female, context of responsibility for child health.

In addition, my findings indicate a need for a broadening of current understandings about what influences pregnancy outcomes and child health. While it is clear that women’s behaviours and exposures do have considerable influence, these are not the only factors that are important. Further exploring the impact of relational, social and environmental influences on child health outcomes may lessen the potential for the blame and guilt that is associated with the current dominant and limiting focus on the bodies and behaviours of individual women.

Importantly, public health and medical research which explores broader influences on reproductive health does exist. However, as I have demonstrated in this thesis, factors
outside the female body are rarely considered as part of mainstream medical and public health practice around reproductive health. Therefore, broadening the focus of current practice and also continuing to broaden the scope of the research questions that we ask about the origins of child health, may produce positive effects by reducing the potential for women to feel blame simply because they carry a pregnancy. An integral part of this will be exploring the potential influences of physical environmental factors on pregnancies and also exploring the potential effects of men’s exposures on reproductive health, which have been barely studied (Cordier, 2008). As part of broadening our focus it will be necessary to translate these ideas into mainstream health advice. My findings also suggest that it will be beneficial to emphasise more clearly as part of medical and public health practice that while women and men can behave in ways that are conducive to good reproductive health, medical uncertainty inevitably exists about many aspects of the origins of child health problems. Even where relative certainty exists, it is important to emphasise that adjusting individual behaviour will not ensure reproductive health in all cases.

My final recommendation is that future research in this area considers the views of both men and women to avoid replicating gendered inequalities and to provide the potential for greater understanding about the micro-dynamics of responsibility for child health and the effects of current constructions of blame. As I acknowledge in the Introduction to this thesis, the exclusion of men from my research has not allowed a full exploration of the relational nature of reproduction as it operates within social context. While it was necessary for me to design the research with a focus on eliciting the views of mothers and health professionals, I intend to pursue further research that involves eliciting the insights of men about issues that are raised in the thesis. I believe that including men as more equal participants in research and practice related to reproduction, child health and parenting is an important step in learning about the barriers that exist to a more relational, contextually appropriate understanding of how we, as individuals and a society, can contribute to improved health outcomes and enhanced social wellbeing for women, men and children. Undertaking the kinds of research that this study indicates is necessary may also contribute to a more realistic recognition of the limits of the neo-liberal belief that individual action can ensure ideal health outcomes in all cases.
APPENDICES

APPENDIX 1: Description of selected congenital health problems

Spina bifida
Spina bifida is a neural tube defect. It results from the abnormal development of the neural tube and the vertebral column, which are structures associated with the spinal cord (Saladin, 2001:495,501). The spinal cord is usually covered and protected by bones called vertebrae which form during foetal development (Saladin, 2001:277-278). However, in individuals affected by spina bifida some of the vertebrae do not form completely. This causes the spine to remain divided, hence the term spina bifida, which is Latin for the words spine and split or divided (Lewis, 2003:14; Saladin, 2001:495). The divisions within the spine leave the spinal cord and its coverings exposed and also allow these structures to protrude through the gaps created by the unfused vertebrae (Lewis, 2003:14). Such protrusion can result in damage to the spinal cord and the surrounding nerves.

Spina bifida develops during early foetal growth. The most critical period for neural tube development is from 17 to 30 days gestation (CNSDPL, 1990:412; Moore & Persaud, 2003:130). Therefore, it is likely that spina bifida develops within the first trimester of pregnancy given that this is when the tissues that form the neural tube, and the associated structures, are most vulnerable to disruption (Moore & Persaud, 2003:129).

Symptoms and complications
The symptoms of spina bifida vary and are dependent on the location at which the vertebral divisions occur and the severity of spinal damage. One form of the condition, spina bifida occulta, involves only one or a few vertebra and causes no functional problems (Lewis, 2003:14; Saladin, 2001:495). The only external sign of spina bifida occulta is usually a dimple or pigmented spot on the back of affected individuals in the region where the vertebral divisions are located (Saladin, 2001:495). However, more severe forms, such as spina bifida cystica, involve the external protrusion of a sac from the spine. The sac may be present on any part of the back from the neck down to the buttocks. It contains the fluid and structures that have escaped through the openings left by the unfused vertebra (Lewis, 2003:14). The segment of the spinal cord that protrudes into the sac is usually defective and the associated nerves are often damaged. As a consequence, individuals with the more severe forms of spina bifida may experience paralysis, muscle weakness and a lack of sensation from the damaged region of the spine downwards (Lewis, 2003:14-15). Nerve damage in the lower
region of the spinal cord may also result in incontinence because this is where the nerves that usually provide bladder and bowel control are located (Lewis, 2003:15).

Another complication that can be associated with spina bifida, particularly spina bifida cystica, is hydrocephalus. Hydrocephalus involves the excessive accumulation of cerebrospinal fluid within the brain. This accumulation may result from an obstruction in the circulation of the cerebrospinal fluid or from the overproduction of the fluid within the body. If hydrocephalus occurs, a shunt device can be surgically inserted into the brain of the affected individual to allow the excess fluid to be drained (Lewis, 2003:15). Such drainage may assist in preventing the brain damage that can occur as a result of prolonged hydrocephalus (Lewis, 2003:15).

**Frequency**

According to the most recent population based data, which is produced by the Australian Institute of Health and Welfare (AIHW) National Perinatal Statistics Unit, the overall rate of infants born with spina bifida was 2.7 per 10,000 births between 2002 and 2003 (Abeywardana & Sullivan, 2008:16). This rate has remained constant since 1998 (Abeywardana & Sullivan, 2008:16). However, spina bifida can be detected through antenatal screening and this means that many affected pregnancies are terminated before birth. Data provided by the four Australian states that report terminations of pregnancy to the AIHW (New South Wales, Victoria, Western Australia and South Australia), indicates that only 30.2% of infants from affected pregnancies were born alive between 2002 and 2003 (Abeywardana & Sullivan, 2008:16). Therefore, the actual rate of affected pregnancies would be much higher than 2.7 per 10,000 births nationally. This rate may actually more closely reflect the rate of 4.7 per 10,000 pregnancies, which was that reported by New South Wales, Victoria, Western Australia and South Australia between 2002 and 2003 (Abeywardana & Sullivan, 2008:16). In addition, the incidence of spina bifida is likely to be even higher than currently documented given that the current statistics do not include infants or terminated pregnancies that are affected by mild forms of the condition, such as spina bifida occulta (Abeywardana & Sullivan, 2008:16).

**Congenital naevus**

*Naevus*, or the plural form *Naevi*, is the scientific term used to describe pigmented lesions on the skin. The condition congenital naevus involves the formation of naevi before birth. The pigmented lesions that are associated with congenital naevus are called congenital melanocytic naevi (CMN). CMN typically display different characteristics to naevi that are
acquired after birth, such as those commonly called moles. In general, the differences between CMN and acquired naevi, or moles, relate to the larger overall size of the CMN, the greater depth of naevus cell involvement in the skin and the possibility of the CMN cells invading other structures in the body, such as the blood cells (Dave & Mahaffey, 2004:722). Most CMN are dark brown or black in colour and are formed as a result of an accumulation of melanin producing cells. CMN can form anywhere on the body and they vary significantly in terms of size.

CMN present on the skin as multi-shaded dark pigmented patches which are often oval shaped. Most CMN enlarge proportionately with the bodily growth of affected individuals, so the size of CMN is likely to increase as an infant matures into an adult (Oakley, 2001). For this reason, the classification of CMN is based on the predicted or actual size of the CMN once an individual reaches adulthood. CMN that are less than 1.5 centimetres in diameter are classified as small. CMN that are up to 10 centimetres in diameter are called medium. CMN between 10 and 20 centimetres in diameter are called large and those greater than 20 centimetres are called giant (Oakley, 2001). Infants with large or giant CMN often have many smaller lesions called satellites which surround the CMN.

The cause of congenital naevus remains unclear. Possible causes are thought to originate from random, localised genetic defects and occurrences, such as physical trauma, during a woman’s pregnancy which may affect distribution of skin pigment in the foetus (Oakley, 2001; Schwartz, 2010a).

**Symptoms and complications**

The significance of CMN relates mainly to the associated cosmetic disfigurement as well as the potential progression to melanoma (Barnhill, Piepkorn & Busam, 2004). CMN are a risk factor for melanoma and those that lie across the spine can invade the spinal cord creating increased risk for the development of cancers in the nervous system (Schwartz, 2010a). Although the risk of malignancy is only increased slightly, it means that children and adults with congenital naevus must be diligent about protecting their skin from the sun and must also engage in regular checks of their skin to detect any potentially suspect changes. In addition to the increased risk of melanoma, skin affected by CMN can also produce excess hair and lack sweat glands, making cooling and maintenance of the area difficult.

Given the cosmetic disfigurement, complications and risks associated with CMN some parents seek treatment for their child’s congenital naevus. Treatment options include surgery and laser treatments (Schwartz, 2010b). The aim of these treatments is to remove the CMN
completely or to reduce the associated pigmentation and hair growth. However, because CMN cells extend deep throughout the skin the effectiveness of the treatments is limited and does not always reduce the risk of malignancy.

Frequency
Congenital naevus is a rare condition. Internationally, 1 to 2% of infants are born with one or more CMN (Schwartz, 2010a). Congenital naevus cannot be indentified through routine screening in Australia (antenatal detection requires specialised imaging equipment) and, as a result, termination of pregnancy is not usually considered in relation to this congenital health problem.

Congenital heart disease
Congenital heart disease (CHD) is a term used to refer to a range of different problems with the structure and function of the heart that develop before birth. Some common problems that can develop prenatally include:

- narrowing of the heart valves and arteries,
- blockages within the heart or in the pathways between the heart and the lungs,
- openings or ‘holes’ in the tissues and walls of the heart; and
- undeveloped or malformed connections between the heart chambers and vessels.

These problems can occur together or alone and they produce symptoms if they are severe enough to interrupt the flow of blood through the heart (Abeywardana & Sullivan, 2008).

Like spina bifida, CHD is believed to develop a short time after conception since this is when the heart of a foetus begins to develop. The cause of approximately 80% of CHD cases are unknown, with the remaining 20% linked to factors including genetics, infections during pregnancy (such as rubella) and exposure to particular drugs and chemicals during the early stages of pregnancy (Abeywardana & Sullivan, 2008; Kurt & Schumacher, 2009).

Symptoms and complications
The particular symptoms and prognoses that are associated with CHD are determined by the type and severity of the specific heart condition. Infants can be completely asymptomatic following their birth or they can display symptoms immediately including blueness (cyanosis), breathing difficulties and non-responsiveness (Kurt & Schumacher, 2009). If symptoms appear they must be treated in order to prevent death and to increase quality of life.
Congenital heart disease is the most common congenital health problem. Currently in Australia approximately 1 in 100 infants are born with congenital heart disease, although many remain asymptomatic and, therefore, may not be diagnosed until a long period after birth (Abeywardana & Sullivan, 2008). Some cases of CHD are diagnosed during antenatal screening, especially when severe or linked to other congenital health problems, such as Down syndrome (Kurt & Schumacher, 2009).

Foetal alcohol spectrum disorder
Foetal alcohol spectrum disorder (FASD) describes the various effects on the foetus that are thought to result from women’s consumption of alcohol during pregnancy. FASD refers to several different, but related, conditions including foetal alcohol syndrome (FAS), partial foetal alcohol syndrome (PFAS), alcohol-related neurodevelopmental disorder (ARND) and alcohol-related birth defects (ARBD) (Manning & Hoyme, 2007:230; Peadon, Fremantle, Bower & Elliot, 2008:1). Considerable uncertainty exists about how much alcohol needs to be consumed and at what times during pregnancy before the foetus will be affected by these conditions, and it is likely that these factors differ on a case-by-case basis. However, like spina bifida and CHD, it is generally (although not uniformly as I highlight in Chapter 7) believed that a foetus is most susceptible to the effects of alcohol during the first trimester of pregnancy.

Throughout the medical literature on FASD numerous risk factors are identified. The majority of these are maternal risk factors, that is, characteristics of the pregnant or mothering woman that are identified as increasing the risk of her foetus developing FASD. Such factors include advanced maternal age, low education levels, untreated or poorly treated mental health problems, social isolation, reduced access to prenatal and postnatal care services and a history of victimhood and abuse, particularly sexual abuse during childhood (Chudley et al., 2005:S1-S2). The other risk factors appear to relate more directly to the characteristics of the child itself, or interestingly, those of their father. For example, paternal alcohol consumption and paternal drug use at the time of pregnancy are identified as increasing the risk to the foetus (Chudley et al., 2005:S1-S2). However, the reasons that these paternal behaviours increase the risk of FASD are not stated explicitly. Various characteristics of the child are also identified as risk factors. These include low socioeconomic status, prenatal exposure to cocaine and smoking, frequent custody changes, inadequate nutrition and living in a poor developmental environment, which may exist as a result of abuse, neglect or stress. Importantly though, the most important risk factor for FASD is consistently represented as
the high blood alcohol level of the pregnant woman. The frequency at which the woman

drinks, her pattern of drinking (binge drinking is identified as posing a particularly high risk)

and the stage of the pregnancy at which she consumes alcohol are also identified as

important considerations that are associated with this risk factor. I explore further the
dominant constructions and representations of these risk factors at various points throughout
the thesis.

**Symptoms**

FAS is the most severe of the conditions that are classified under the term FASD (Elliot *et al.*, 2008; Stratton, Howe & Battaglia, 1996:52). The main features of FAS are characteristic cranio-facial malformations, prenatal and postnatal growth problems, abnormalities in brain growth and structure and, subsequently, damage to the central nervous system (Al-Yaman, Bryant & Sargeant, 2002:79; Manning & Hoyme, 2007:235). Children born with PFAS also have the characteristic cranio-facial malformations and at least one of the other symptoms typically associated with FAS (deficiencies in growth or problems with the structure and function of the central nervous system) (Manning & Hoyme, 2007:235-236). Children with ARBD display regular growth patterns but have the characteristic cranio-facial malformations of FAS as well as other structural problems that have been linked to the effects of alcohol such as multiple minor anomalies of the limbs or major malformations of the bodily organs (Manning & Hoyme, 2007:236). Individuals with ARND display regular growth patterns and structural development however they demonstrate characteristic patterns of altered behaviour and cognition as well as abnormal brain formation (Manning & Hoyme, 2007:236-237). According to the criteria used to diagnose these conditions, the associated abnormalities must be consistent with the effects of prenatal exposure to alcohol, whether or not maternal consumption can be confirmed, and must not be able to be explained by genetic predisposition or familial traits alone (Manning & Hoyme, 2007:237).

**Frequency**

Given the issues that I document in Chapter 3, it is difficult to determine how many infants are born with FASD. Existing estimates are vague and inconsistent across sources. As argued by Iris Smith (2003) the incidence of FASD is low compared to other health issues that receive less attention in the media and by public health and medical professionals but its controversial nature makes FASD a prime topic of focus within these fields.
APPENDIX 2: List of search terms

Before and during the process of searching the databases I compiled a list of search terms that I thought may yield relevant results. These terms were:

- Congenital
- Congenital*
- Pregnancy
- Pregnan*
- Birth defect
- Birth defect*
- Prenatal
- Prenatal care
- Antenatal
- Abnormalities
- Nevus
- Foetal alcohol syndrome
- Congenital heart disease
- Spina bifida
APPENDIX 3: Details of the selected medical journal articles

<table>
<thead>
<tr>
<th>Authorship</th>
<th>Country of journal origin</th>
<th>Country where research was undertaken</th>
<th>Type of article</th>
<th>Research design</th>
</tr>
</thead>
<tbody>
<tr>
<td>Berg et al. (2006)</td>
<td>US</td>
<td>Germany</td>
<td>Research paper</td>
<td>Literature review and retrospective case review</td>
</tr>
<tr>
<td>Carvalho (2005)</td>
<td>US</td>
<td>UK</td>
<td>Opinion piece</td>
<td>Literature review</td>
</tr>
<tr>
<td>Gibbin et al. (2003)</td>
<td>US</td>
<td>US</td>
<td>Research paper</td>
<td>Case-control study</td>
</tr>
<tr>
<td>Groenen et al. (2004)</td>
<td>US</td>
<td>Netherlands</td>
<td>Research paper</td>
<td>Case-control study</td>
</tr>
<tr>
<td>Henderson, Gray &amp; Brocklehurst (2007)</td>
<td>UK</td>
<td>UK</td>
<td>Research paper</td>
<td>Systematic review</td>
</tr>
<tr>
<td>Hobbs et al. (2006)</td>
<td>US</td>
<td>US</td>
<td>Research paper</td>
<td>Case-control study</td>
</tr>
<tr>
<td>Kozer et al. (2002)</td>
<td>US</td>
<td>Canada</td>
<td>Research paper</td>
<td>Meta analysis</td>
</tr>
<tr>
<td>Platt et al. (2000)</td>
<td>US</td>
<td>US, Canada, Germany and Denmark</td>
<td>Research paper</td>
<td>Cohort study</td>
</tr>
<tr>
<td>Schaefer-Graf et al. (2001)</td>
<td>US</td>
<td>US</td>
<td>Research paper</td>
<td>Case-control study</td>
</tr>
<tr>
<td>Verkleij-Hagoort et al. (2006)</td>
<td>UK</td>
<td>Netherlands</td>
<td>Research paper</td>
<td>Case-control study</td>
</tr>
<tr>
<td>Wenstrom et al. (2001)</td>
<td>US</td>
<td>US</td>
<td>Research paper</td>
<td>Case-control study</td>
</tr>
</tbody>
</table>

Summary:
Country of journal origin: 13 US, 2 UK
Country in which research was undertaken: 8 US, 2 UK, 2 Netherlands, 1 Canada, 1 Germany, 1 US, Canada, Germany and Denmark
Type of article: 12 research papers, 1 review article, 1 opinion piece, 1 seminar paper
Research design: 6 case-control studies, 1 cohort study, 1 literature review, 1 survey, 1 meta analysis, 2 systematic reviews, 1 literature review and retrospective case review, 1 literature review and best practice report
APPENDIX 4: Information sheet for women who mother children with congenital health problems

Congenital Conditions and the Maternal Experience:
Exploring the experiences of women who have given birth to a child with congenital health problems

Information Sheet

What is the study about?
This study aims to explore the experiences of women who are the mothers of a child with congenital health problems. We are interested in talking with women about how they felt during their pregnancy, during their interactions with medical professionals and also upon finding out about their child’s condition.

We are interested in finding out more about these issues because little is currently known about the experiences of those who have given birth to a child with congenital health problems in South Australia. Furthermore, a lack of knowledge exists about the ways in which women understand the origins of their child’s health problems. The development of greater knowledge about these issues is important, especially in developing strategies that may, potentially, improve women’s experiences of pregnancy and foetal or infant diagnosis in the future.

Why are you being invited to take part in the study?
You are being invited to participate in this study because you have a child with the congenital condition (spina bifida, naevus or congenital heart disease [insert appropriate term]) who is aged six years or younger. We have chosen to interview women with children aged less than six years because they are likely to be able to recall their experiences of pregnancy more readily than those who have older children.

By being involved you will be assisting us to learn more about the factors that influence maternal health and women’s experiences of foetal or infant diagnosis. Your participation will also ensure that your views and experiences are represented in research that is being undertaken to learn more about congenital health problems.

What would taking part in this study involve?
If you agree to take part in the study you will be asked to participate in an interview with Toni Delany, who is a PhD student at the University of Adelaide. The interview will probably take about one and a half hours. You may choose the location of the interview. Toni can visit you in your home or the interview can be conducted at the University. Alternatively, you can choose another location that is convenient for you.

With your permission, Toni will tape record the interview so that she can get an accurate recording of your views. If you prefer not to be taped then Toni will take notes instead.
Confidentiality and assurances

All information that you provide will be strictly confidential. Toni will protect your privacy by using a coding system rather than your name on all research documents.

The conversations that take place during the interview will be transcribed by Toni. The transcripts will be stored in both a digital and written form. The digital audio files will be stored on a password protected personal computer and the written versions will be stored in a locked filing cabinet. After the study has concluded, all transcripts will be destroyed or deleted electronically.

The results of this study will be published, but you will not be individually identified and your name will not be used. Toni will send you a copy of the transcript of your interview. Once you receive the transcript you will have the opportunity to identify any information that you do not want quoted when the research is published. You are also free to withdraw from the study at any time and this will not have any negative repercussions for you or your relatives in the future.

This study has been approved by the University of Adelaide Human Research Ethics Committee. If you would like to speak to a person not directly involved in the study, particularly in relation to your rights as a participant or to make a confidential complaint, please refer to the attached form.

Arranging an interview

If you would like to be involved in the study please contact Toni Delany to arrange an interview. Toni can be contacted by telephone on 8303 3723 or 0402 917 549. You can also contact her via email at toni.delany@adelaide.edu.au. Alternatively you can send your contact details, using the sheet provided, to Toni at the University. A reply paid, self-addressed envelope is provided with this information sheet to assist you.

Further information

If you have queries about the study, please feel free to contact any member of the research team who is listed below.

Toni Delany, Researcher, PhD student
Discipline of Gender, Work and Social Inquiry
Phone: 8303 3723 Mobile: 0402 917 549
Email: toni.delany@adelaide.edu.au

Associate Professor Margie Ripper, Primary Supervisor
Discipline of Gender, Work and Social Inquiry
Phone: 8303 5947 Email: margie.ripper@adelaide.edu.au

Associate Professor Vivienne Moore, Co-supervisor
Discipline of Public Health
Phone: 8303 4605 Email: vivienne.moore@adelaide.edu.au
APPENDIX 5: Letter of invitation sent to medical professionals

Dear Dr xxx

We would like to invite you to contribute to a research study that is being undertaken within the Discipline of Public Health. The research is investigating how parents understand the aetiology and preventability of their children’s congenital health problems. Your experience in working with families who are affected by congenital health problems means that you have valuable insight into how parents may understand and respond to information about congenital conditions. We hope that you might be willing to share your perspectives with us during a confidential interview.

Please refer to the attached information sheet for further details about the study. The study has been approved by the University of Adelaide Human Research Ethics Committee. Professor Jeffrey Robinson has endorsed the study and encourages you to consider participation.

If you decide to take part, please contact Toni Delany via email at toni.delany@adelaide.edu.au or via telephone on 8303 3723 or 0402 917 549. If we don’t hear from you, Toni will contact you via email or telephone soon to answer any questions that you may have about the study and to ask if you are willing to have an interview. Participation in the study is voluntary and if you decide to participate we will arrange the interview at a time and location that is most convenient for you. We hope to hear from you soon, thank you for your time.

Yours sincerely

TONI DELANY
PhD Candidate

VIVIENNE MOORE
Associate Professor
Discipline of Public Health
APPENDIX 6: Information sheet for medical professionals

**Congenital Conditions and Parental Experiences**

**Information Sheet**

**What is the study about?**

This qualitative research study aims to explore how the parents of children with congenital conditions understand the aetiology and preventability of their child’s health problems. 28 parents who have children with health problems such as spina bifida and congenital heart disease have already been interviewed. The parents have spoken frequently about the influence that their contact with health professionals has had in shaping their understandings, particularly around the time of initial diagnosis. For this reason, we have decided to commence interviews with selected health professionals as part of the study.

It is hoped that as a health professional you will act as a key informant for the research. You will not be asked to divulge information about individual patients but will instead be asked to speak generally about your experience in consulting with parents. In particular, we are interested in finding out more about the processes that are used to explain diagnoses to parents, how parents respond to information about aetiology and prevention and also about any dilemmas that professionals encounter while explaining diagnoses to parents.

Your contribution will enhance the quality and depth of this research by supplementing the experiential information provided by the parents. The information gained during the interviews will also assist in the development of strategies that may, potentially, improve parent’s experiences of infant or foetal diagnosis in the future.

**Why are you being invited to take part in the study?**

You are being invited to participate because you are a health professional who has experience that is relevant to this study. We hope that you will share your views and professional insights with us to assist in the development of greater understanding about these issues.

**What would taking part in this study involve?**

If you agree to take part we will ask you to participate in an interview with Toni Delany (PhD student, University of Adelaide). The interview will take approximately 1 hour. You may choose the location of the interview. Toni can visit you at your workplace or anywhere else that is convenient for you.

With your permission, Toni will tape the interview so that she can get an accurate record of your views. If you prefer not to have a taped interview then Toni will take notes instead.
Confidentiality and assurances

All information that you provide will be strictly confidential. Toni will protect your privacy by using a coding system rather than your name on all research documents. The results of the study will be published, but your name will not be used.

Following the interview, if you choose to have the interview taped, Toni will send you an audio recording of the discussion on CD. Once you receive the CD, you will have the opportunity to identify any information that you do not want quoted when the research is published. You are also free to withdraw from the study at any time and this will not have any negative repercussions for you in the future.

Toni will maintain the confidentiality of your information. The transcripts will be stored in both a digital and written form. The digital audio files will be stored on a password protected computer and the written versions will be stored in a locked filing cabinet. After the study has concluded, all transcripts will be destroyed or deleted.

This study has been approved by the University of Adelaide Human Research Ethics Committee. If you would like to speak to a person not directly involved in the study, particularly in relation to your rights as a participant or to make a confidential complaint, please refer to the attached form.

Arranging an interview

If you would like to participate please contact Toni to arrange an interview. Toni can be contacted by email at toni.delany@adelaide.edu.au or by telephone on (08) 8303 3723 or 0402 917 549.

Further information

If you have queries about the study, please feel free to contact any member of the research team.

Ms Toni Delany, PhD student
Disciplines of Public Health and Gender, Work and Social Inquiry
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Discipline of Gender, Work and Social Inquiry
Phone: (08) 8303 5947   Email: margie.ripper@adelaide.edu.au

This study has been discussed with Professor Jeffrey Robinson who endorses it and encourages your participation

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APPENDIX 7: Interview schedule for interviews with women who mother children with congenital health problems

Interview schedule
Interviews with mothers of children who were born with a congenital health problem

Thank the participant.

Read the information sheet? Any questions?

Consent forms- Provide the participant with two copies of the consent form (one for their own records and one for my records) and ask that they read and sign the forms. State that the consent forms are a requirement of the University of Adelaide Human Research Ethics Committee but that nobody else besides me will view the details on their forms. I will then sign the consent forms in the witness section and seal my copy in an envelope with only the participant’s code number on it.

Throughout the interview I will guide you with some questions but please feel free to raise any issue that’s important to you as we go along.

Tape recording? No one else besides me will hear the recording and that the recorder can be turned off at any point during the interview if the participant wishes.

If the participant agrees, begin recording. If the participant does not agree, prepare to take notes instead.

Commence interview

So you have a child named ……. and she/he is [age], is that right?

Ok well as you know, my research is exploring the experiences of women who have a child with health problems.

For my research I’m mainly interested in hearing about your early experiences with [child’s name], such as during your pregnancy and soon after her/his birth.

So can we start with you telling me your story? So tell me about your pregnancy with [child’s name], the diagnosis and where you’re at now?

Prompts (if issues are not covered by participant):

What did you think when you found out you were pregnant?
How did your partner feel about the pregnancy? Do you think he felt included?
How did your family react?
Did you and your partner know much about pregnancy and what it involved when you first got pregnant?

When was your child diagnosed?
Who first diagnosed the health problem?
How were the health problems explained to you?
What first went through your head about what might have caused [child’s name] problems?

What kinds of things did the medical staff look for and ask you about when they were investigating the cause?
Is there anything that they didn’t ask about or look for that you think they should have?
How did those around you react to the diagnosis?
What are your thoughts now about the cause of [child’s name] health problems?

How did you feel when [child’s name] was born?

Some women have told me that they grieved after finding out about their child’s health problems. How does that fit with your experience?

Did the health problems affect how you bonded with your child? Why?

Was there a lengthy hospital stay for [child’s name]?  
If so:  
How did you find your contact with the medical staff?  
Did the stay involve you spending lots of time at the hospital?  
How did you and your partner negotiate your time in terms of things like who would go to the hospital and who would take care of other things?  
If not:  
What kinds of treatments or procedures did [child’s name] go through after the diagnosis?  
How did you find your contact with the medical staff?  
How did you and your partner negotiate your time in terms of things like who would be with [child’s name] during those times and who would take care of other things?

How do you think that parents who have a child with health problems like [child’s name] are viewed by others, are they viewed differently or the same as other parents?

Some of the information that I’ve read suggests that having a child with health problems like [child’s name] can affect women’s relationships with others, what do you think?

Some women have told me about instances in which they have felt to blame for their child’s health problems, either because they feel responsible or because others make them feel like that. How does that fit with your experience?

Did your husband/partner ever express similar feelings of blame or responsibility?

I’d just like to go back to the start of your pregnancy now, were you a public or private patient?  
Have you ever got the impression that being a [insert public or private] patient may have influenced your experiences?

If they have changed- why did you decide to change?

In information that I’ve read about reproductive health there seems to be a lot of things that people are advised to do or not to do before and during pregnancy. Can you tell me about the advice that you received?

Prompts (if issues are not covered by participant):

When did you start hearing about things that you could or should do to improve your reproductive health? (during pregnancy? before pregnancy? after giving birth?)

What were you told to do or to avoid during pregnancy?

Where did you get advice from?
What kinds of things did you read?
Pamphlets? Scientific literature? Self-help books (pregnancy manuals etc)? Magazines?

Which sources did you trust the most? Why?

Did you believe all the advice that you were given?
Did you feel like it was your free choice to follow the advice or did you feel pressure to do so?
Some people say that they feel differently about the advice that they received during pregnancy after they have had their baby. How does this fit with your experience?

Do you recall what kinds of advice your partner received about ways he could help ensure the health of the baby?

Do you think your partner was expected to be involved in helping you to follow the advice you received?

Is there anything that is not included in the current advice to parents that you think should be included?

Given that you have a child with health problems, is there anything that you would like to have been different about your experiences?

Prompts (if issues are not covered by participant):

Now thinking outside of the health system, what other things would you have liked to have been different?

Now I’d just like to ask you a bit about [insert the name of the relevant support group]. How did you come to join the group?

What has the group been like for you?

Prompts (if issues are not covered by participant):

What do you think being a member of the group does for you?

Thinking to the future now, if [child’s name] asks you about why s/he is different from other kids what will you say?

And to finish, what is the most enjoyable part of your life with [child’s name] now?

That’s been really useful, thank you. I’m just going to take a few moments to look at the topics I wanted to cover. While I’m doing that can you have a think about whether there is anything else you wanted to talk about?

Fill in answers to demographic questions

Thank you
Confidential Descriptive Questions

Please answer the following questions. If you do not want to or cannot answer any of the questions please leave them blank. All answers will remain confidential.

1. What suburb do you live in? ........................................................................................................................................

2. How old are you? ........................................................................................................................................................

3. Please describe who lives with you in your household/family and what their relationship to you is. Please include the ages of any children (write on the back of the page if you need more space)
........................................................................................................................................................................................................
........................................................................................................................................................................................................

4. Do you have private health insurance? ......................................................................................................................

5. What are the main sources of your household income at the moment?
   - Pension or benefit? (please say which and the approximate amount per fortnight)
     ......................................................................................................................................................................................
   - Wages (please say whose and the approximate amount per fortnight)
     ......................................................................................................................................................................................
   - Savings/investments (please say whose and the approximate amount per fortnight)
     ......................................................................................................................................................................................
   - Other (please describe and give the approximate amount per fortnight)
     ......................................................................................................................................................................................

6. What was your country of birth? ...............................................................................................................................

   6.a. If you were not born in Australia, how long did you live in your country of birth for before moving to Australia?
     ......................................................................................................................................................................................

Thank you for your answers, they will assist me greatly with my study.
Thank the participant.

Read the information sheet? Any questions?

Consent forms: Provide the participant with two copies of the consent form (one for their own records and one for my records) and ask that they read and sign the forms. State that the consent forms are a requirement of the University of Adelaide Human Research Ethics Committee but that nobody else besides me will view the details on their forms. I will then sign the consent forms in the witness section and seal my copy in an envelope with only the participant’s code number on it.

Before we begin, I just want to say that this is an open ended interview. So I will guide you with some questions but please feel free to raise any issue that you think is relevant as we go along. Also, I will not ask you to speak about any specific patients as I’m interested in your experiences in general. But if you would like to use specific cases I will not include their detail in my research.

Tape recording? No one else besides me will hear the recording and the recorder can be turned off at any point during the interview if you wish.

If the participant agrees, begin recording. If the participant does not agree, prepare to take notes instead.

INTRODUCTION

As you know my research is investigating the experiences of parents who have children with congenital health problems. During the interviews that I’ve done I have noticed that the participants talk a lot about the contact that they have with health professionals when their child’s condition is first diagnosed. So it seems important to me that I learn a bit more about the processes used to inform parents about a diagnosis. I am also interested in finding out about how parents usually react to a diagnosis and about the questions that they may ask.

So to begin, can you tell me about your role and what kind of contact you usually have with parents who have a child with congenital health problems?

Prompts (if issues are not covered by participant):
- When do you first have contact with the parents? (during pregnancy, post-partum, during diagnosis, after diagnosis, during treatment)
- What kinds of issues do you discuss?
- What services do you offer?
- How many times, on average, would you see each couple?
- Over what period of time do you usually consult with parents?
- What conditions do you mainly see?

What happens once a child/foetus is diagnosed with a congenital health problem? Can you explain the process to me?

Prompts (if issues are not covered by participant):
- Who speaks to the parents?
In your experience do you usually have contact with both parents when you are explaining a diagnosis?
To what extent is it important to involve both of them?
Where would the mother and father usually sit when you consult with them—can you show me?

What is the most important information for parents to be told?
What information is not important for the parents to know?

What kinds of questions do the parents usually ask?
Do mothers and fathers usually ask different kinds of questions?
Is the issue of causation raised?
Who usually speaks about possible causes first—you or the parents?

Do men and women usually react differently to the diagnosis?
Do men and women usually react differently when you explain the causes?

Some of the parents I’ve interviewed believe that they are responsible for their child’s condition and they feel guilty about it. In your experience, have you seen parents blame themselves and how do they try to deal with this?

Prompts (if issues are not covered by participant):
How is the blame or the guilt usually expressed?

Are there circumstances in which it is appropriate for the parents to blame themselves or acknowledge some responsibility for the condition?

What are some of the positive outcomes of parents acknowledging some personal responsibility for their child’s health problems?
What are some of the negative outcomes of parents acknowledging some personal responsibility for their child’s health problems?

In your experience, do men feel responsible for their children’s health problems in the same ways that women do? What is the difference? Is that difference appropriate?

Are there some conditions for which it is more appropriate for the parents to feel responsible for causing it or not preventing it? What are those conditions?

I understand that there are congenital conditions for which there are no known causes or at least considerable uncertainty about the possible causes. How do you deal with questions about causation when explaining these conditions to parents?

Prompts (if issues are not covered by participant):
In relation to conditions for which there are no known causes do you think that parents may feel more or less responsible for their child’s health problems?

What factors do you believe have the most influence in causing congenital health problems?

Prompts (if issues are not covered by participant):
What do you think about the role of factors in the physical environment, such as pollution, in causing congenital health problems?

Is the role of factors in the physical environment usually considered by you or the parents when discussing causes?
What is your best advice to couples who are keen to prevent congenital health problems?

From your experience, what are the hardest myths to dispel about how congenital conditions are caused (either in general or in relation to specific conditions)?

I have written some hypothetical scenarios to give me a practical understanding about how you might explain congenital conditions and address parents’ questions. Would you mind reading this through and then telling me how you would respond to the question at the end? [give participant a scenario card]

Scenario number 1
31 year old Michelle gave birth to a baby girl who appeared healthy immediately after birth. However, three weeks after taking her home, Michelle and the child returned to the hospital. Michelle was referred back to the hospital by her GP who suspected that the child had a heart murmur. Following investigation, Michelle’s child was diagnosed with a large atrial septal defect (hole in the heart). In your contact with Michelle following the diagnosis she admits that she smoked throughout her pregnancy but did not divulge that during her antenatal appointments or to her husband. She asks you whether her smoking has any link to her child’s condition. What do you tell her?

In general do you think that women feel pressured to report their smoking and alcohol consumption differently when speaking with medical professionals?

Scenario number 2
Steven and Kelly have a four month old son with multiple congenital heart defects. Both parents want to find out about the potential causes of his condition because they wish to have more children and want to prevent the defects developing again. They underwent genetic counselling and no genetic problems or abnormalities were detected in either parent.

Since then they have been reading medical literature about the possible causes of CHD. They have learnt that women who use the drug Roaccutane for acne have an increased risk of conceiving a child with CHD and other structural defects (e.g. craniofacial and neural tube defects). Kelly has never taken Roaccutane. However, Steven is currently using the drug and was using it when they conceived their child. Steven asks you whether his use of the drug could have caused the CHD. How would you respond?

What advice would you give them for preventing CHD in future?

Scenario number 3
Maria and Nick have a 1 week old baby with spina bifida. They were not aware of the condition until the third trimester of pregnancy when the defect was detected on an ultrasound. Maria was hospitalised twice during early pregnancy for dehydration but apart from that had no medical problems.

Maria is feeling particularly anxious, depressed and confused about her child’s condition. She believes that if she could find out what caused the condition then she would feel better because she would know if it could be prevented in future pregnancies. Maria asks you where she should start looking to find the cause of her child’s health problem. What would you suggest?

Scenario number 4
Jessica is a 30 year old pregnant woman who lives approximately 700m from a large factory where plastic products are manufactured. During one of her antenatal appointments Jessica asks you whether her exposure to pollution from the factory increases her risk of having a foetus with congenital health problems. How do you respond?

Scenario number 5
26 year old Rebecca attends her first antenatal appointment. She is a non-smoker and a non-drinker. What questions would you ask Rebecca to assess the potential for foetal health problems?
Scenario number 6
Liz and John want to conceive. However, they are concerned about conceiving a child with spina bifida since one of John’s cousins and one of his nephews have the condition. There is no known family history of spina bifida on Liz’s side. What advice would you give them?

Scenario number 7
Karen attends her first antenatal appointment. She appears to be relatively healthy, is a non-smoker and reports that she usually has one or two standard drinks each weekend. Karen conceived with a man called Garry. Garry is a smoker and usually has at least two alcoholic drinks each day and sometimes a lot more. Karen asks whether alcohol may have affected the foetus. How do you respond to Karen?

Karen then asks whether Garry’s smoking may have affected the health of the foetus. How do you respond?

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Now I’d like to ask you about foetal alcohol spectrum disorder (FASD). The reason that I’m particularly interested in that condition is because it is a condition for which there appears to be quite clear understandings about how it’s caused. However, I haven’t been able to interview anyone whose child has been diagnosed with the condition so I’m interested in learning a bit more about it and how it may be explained to parents.

Have you ever diagnosed a child with FASD? OR Have you ever had contact with parents whose child had been diagnosed with FASD?

In the case of FASD how do parents usually cope with the diagnosis and with finding out what caused their child’s health problems?

How do you explain the cause of FASD?

Do you take a different approach when explaining the cause of FASD compared to how you explain the cause of other conditions?

I understand that there is some disagreement among health professionals about the public health message that women should abstain from alcohol completely during pregnancy. What do you tell parents about alcohol consumption during pregnancy?

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Thinking generally now, has the approach that medical professionals use to explain a diagnosis changed since you began practicing?

What could improve the approach that medical professionals currently use when they consult with parents about their children’s congenital health problems?

Fill in demographic questions

Thank you
Please answer the following questions. If you do not want to or cannot answer any of the questions please leave them blank.

1. How long have you worked in your current profession? ....................................................

2. How old are you? ....................................................................................................................

3. Do you work in the public health system, the private health system or both?

   (please circle the appropriate answer)

   Public  Private  Both Public and Private

4. What country were you trained/educated in?.................................................................

5. What was your country of birth?.......................................................................................

   5.a. If you were not born in Australia, how long did you live in your country of birth for before moving to Australia?

      ........................................................................................................................................

   Thank you for your answers, they will assist me greatly with the study.
THE UNIVERSITY OF ADELAIDE HUMAN RESEARCH ETHICS COMMITTEE

Congenital Conditions and the Maternal Experience: Exploring the experiences of women who have given birth to a child with congenital health problems

Consent Form

1. I, ...........................................................................................................................(please print name) consent to take part in the research project entitled: Congenital Conditions and the Maternal Experience

2. I acknowledge that I have read the attached Information Sheet entitled:
   Congenital Conditions and the Maternal Experience: Exploring the experiences of women who have given birth to a child with congenital health problems

3. I have had the project, so far as it affects me, fully explained to my satisfaction by the research worker. My consent is given freely.

4. Although I understand that the purpose of this research project is to increase knowledge, and possibly improve medical care, it has also been explained that my involvement may not be of any benefit to me.

5. I have been given the opportunity to have a member of my family or a friend present while the project was explained to me.

6. I agree to the interview being audio taped. I understand that the tape can be turned off at any time upon my request. (If you do not agree to the interview being audio taped the interviewer can take written notes instead)

7. I have been informed that, while information gained during the study may be published, I will not be identified and my personal results will not be divulged.

8. I understand that I am free to withdraw from the project at any time and that this will not affect medical advice in the management of my health or my child’s health, now or in the future.

9. I am aware that I should retain a copy of this Consent Form, when completed, and the attached Information Sheet.

........................................................................................................................................................................
(signature)   (date)

WITNESS

I have described to ..................................................................................(name of participant) the nature of the research to be carried out. In my opinion she/he understood the explanation.

Status in Project: .................................................................................................................................

Name: .............................................................................................................................................

..........................................................................................................................................................
(signature)   (date)
REFERENCES


Carvalho, J (2005) ‘The fetal heart or the lymphatic system or...? The quest for the etiology of increased nuchal translucency’, *Ultrasound Obstetrics and Gynecology*, vol. 25, pp. 215-220.


Cordier, S (2008) 'Evidence for a Role of Paternal Exposure in Developmental Toxicity', *Basic and Clinical Pharmacology and Toxicology*, vol. 102, no. 2, pp. 176-181.


Dumit, J (2006) 'Illnesses you have to fight to get: Facts as forces in uncertain, emergent illnesses', Social Science and Medicine, vol. 62, pp. 577-590.


Government of South Australia (2007a) *Pregnancy and alcohol don't mix: Information card*, Women's and Children's Hospital, Adelaide.


Maher, JM, Fraser, S & Lindsay, J (2010) 'Between provisioning and consuming?: Children, mothers and 'childhood obesity'', *Health Sociology Review*, vol. 19, no. 3, pp. 304-316.


Smith, I (2003) FAE/FAS: Prevention, Intervention and Support Services Commentary on Burd and Juelson, Coles and O'Malley and Streissguth, Emory University, Atlanta.


Zola, I (1972) 'Medicine as an institution of social control', *Sociological Review*, vol. 20, no. 4, pp. 487-504.