THE UNIVERSITY OF ADELAIDE AUSTRALIA

Congenital Conditions and Maternal Experiences

RESEARCH STUDY UPDATE

Written by Toni Delany, PhD Candidate, University of Adelaide

The following information provides an overview of the research study *Congenital Conditions and Maternal Experiences* as well as a brief summary of some of the findings that have emerged so far. I am still analysing the research data; therefore, further findings will emerge over the next few months.

OVERVIEW OF THE STUDY

The main aim of the study is to find out more about the experiences of women who have given birth to a child with a congenital health problem.[1] This is important because much of the current knowledge about these health problems is medically orientated and is focussed largely on understanding the experiences of children who are directly affected. However, parents share the experience of these health problems with their children. Furthermore, women's role in carrying their children during pregnancy means that the diagnosis, assessment and treatment of congenital health problems may influence women's experiences of pregnancy, birth and parenting. Therefore, understanding women's experiences, from their own perspectives, is an important way of gaining further knowledge about issues associated with both congenital health problems and mothering in Australia.

In order to learn more about women's experiences I undertook 28 detailed interviews. These interviews were with women contacted through support groups for three different congenital health problems. All of the women were mothers of children aged six years and younger who were affected by one of the following health problems:

- congenital heart disease (CHD). CHD is a term used to refer to a variety of different problems that can develop in the heart of an infant before birth.
- naevus, which involves the formation of pigmented (dark coloured) growths on the skin before birth.
- spina bifida, which occurs when the spine does not form completely. Spina bifida can cause problems with walking or continence.

These three particular health problems were chosen because they have different characteristics which may influence the experiences of mothers. For example, CHD is an internal health problem, whereas naevus is usually clearly visible on the skin. Furthermore, CHD can often be life threatening whereas spina bifida and naevus are usually not. Another difference is that there is quite a lot of information about the cause of spina bifida, however, there is less knowledge about the potential causes of CHD and virtually no understanding about the cause of naevus.

The selection of specific health problems was also practical because it allowed me to work with relevant support groups to invite women to participate in the interviews. Interviewing women who already had access to established networks of support or information through their groups was valuable because some of the issues that we discussed during the interviews were sensitive and emotional.

I undertook the majority of the interviews in person; however, I also interviewed some women by telephone because they lived outside of South Australia (which is where I am located). The study included women from Queensland, New South Wales, Victoria and South Australia (both metropolitan Adelaide and rural South Australia).

[1] For the purposes of this study I am defining a *congenital health problem* as any condition that develops before birth, which produces some illness, disability or disfigurement.

PDF created with FinePrint pdfFactory Pro trial version www.pdffactory.com

During the interviews I asked some broad questions; however, for the most part, the women shared their experiences in an unrestricted way by raising issues that were relevant to them. I will now provide a brief overview of some of the main findings that have emerged from my analysis of the interview discussions so far.

SUMMARY OF PRELIMINARY FINDINGS

ISOLATION

One theme that emerged powerfully and frequently during the interviews was *isolation*. Almost all of the women expressed feelings of isolation. For some, their sense of isolation emerged from a feeling of difference, that is, of not being like other mothers and, therefore, of not being able to relate to other mothers. In addition, several women felt they had become isolated from friends and relatives after the birth of their child. This was particularly evident in circumstances where friends and relatives had difficulty understanding or coping with the child's health problems. Such difficulties sometimes resulted in friends and relatives choosing to reduce their contact with the child and, consequently, with the parents. In several cases, the child's health care needs also placed additional demands on the women's time which reduced the time available to them for socialising with others and for seeking social contact outside of their homes.

Several women explained that they felt a need to *deliberately* isolate themselves after finding out about their child's health problems. The creation of social distance was used by some women as a coping mechanism in the sense that it gave them 'space' to think about the health problems without interference from others. Several women also expressed a need to distance themselves from other people because they felt guilty about their child's health problems. For these women it appeared that isolation provided a sense of protection. It allowed them to escape the negative judgements that they felt were being made by other people as well as to avoid situations where they had to interact with others while feeling inadequate and anxious about their mothering abilities.

Throughout the interviews it became clear that feelings of isolation had affected women's relationships with others and, for some, even affected the way they thought about themselves. For example, the feeling of being judged by others, and the social isolation that was associated with this, resulted in some women losing self confidence. Furthermore, feelings of difference and an inability to relate to others resulted in some women feeling like they were 'alone' in their situation because they felt that no one else understood what mothering was like for them. For several women, feelings of being 'alone' and misunderstood also increased the anxiety and self doubt that they experienced throughout the early years of their children's lives.

Interestingly it was in relation to the theme of isolation that women expressed both the most positive and most negative aspects of their experiences within their support groups. For some, having contact with other parents, and particularly other mothers, in the support groups assisted in reducing their sense of isolation. The opportunity to engage with others in similar parenting situations allowed women to feel like they belonged to a group in which people understood them and in which the special dilemmas associated with parenting a child with health problems were appreciated.

However, for other women the opposite effect occurred. Interacting with other parents who had a child with a health problem was difficult for several of the women because it worsened their feelings of isolation, difference and inadequacy. This was particularly evident for women whose child had a particularly severe form of health problem. The severity of health problems made interacting with others as part of the group unhelpful for these women because it allowed them to compare their child to others and, in doing so, realise how severely developmentally delayed, disabled or ill their child was. Furthermore, some women explained that they believed that their child's poorer health status was viewed as a reflection of their parenting skills. This caused embarrassment and feelings of inadequacy for some because they believed that they were viewed as 'worse' mothers than others in the group whose children appeared healthier or happier.

PDF created with FinePrint pdfFactory Pro trial version www.pdffactory.com

Another reason that contact with other parents had a potentially negative and isolating effect for some women was because it reinforced their status as a 'parent of a child with health problems'. This status was undesirable for some women, especially those who felt uncomfortable about their child's heath problems or for those who felt that their child's health problems reflected something negative about their own character, such as that they were a 'bad' or 'unhealthy' person. Such feelings made some women feel further isolated during their contact with parents in the groups because they believed that although their child's health problems made them similar to the other parents, at the same time, they felt a strong desire to be unlike them in the sense that they didn't want to be the parent of a child with health problems and they didn't want to feel negatively about themselves because of their child's health status. Conversely, other women expressed that their feelings of isolation were relieved because the diverse composition of the groups, which included young parents, older parents, people from lower class backgrounds, those from upper classes etc, made them realise that congenital health problems can affect any family regardless of personal background.

RESPONSIBILITY

Feelings of responsibility were expressed by almost all of the women during the interviews. Some women felt responsible for *causing* their child's health problems. They blamed themselves for doing certain things before or during their pregnancy which they believed had caused the problems. Examples of the things that women blamed themselves for included not taking particular vitamins, not eating certain foods, smoking, drinking alcohol, having negative thoughts about their pregnancy or working in industries where they were exposed to particular chemicals. None of the women had intended to cause a congenital health problem, yet they still blamed themselves. Almost *all* of the women also explained that at some time they had thought about whether they had done something to cause the health problems. Most had asked health professionals about this. While some were told that their behaviours *may* have had some influence, the majority were told that their behaviour did not cause the problems or that the specific cause was unknown. Despite this, several women continued to believe that their behaviour *must* have had some link to their child's health problems and these beliefs produced considerable emotional pain and anxiety.

Even women who did not blame themselves for *causing* their child's health problems still expressed feelings of heightened responsibility in various forms. For example, some women felt responsible for making sure that they did everything they could to improve the life of their child as a way of 'making up for' the pain or disadvantage that their child experienced. Some women even said that if they could swap places with their child by giving themselves the health problems they would do so. This level of self sacrifice was expressed frequently throughout the interviews with some women inferring that it was their duty as mothers to treat their own needs as secondary to those of their child by devoting all of their time, energy and other resources to making their child's life as positive as possible. This high level of devotion produced negative effects for some women, however, as it resulted in them missing out on things such as employment opportunities and also in them neglecting their own health in order to fulfil the demands of their mothering responsibilities.

The tendency for women to consider themselves as responsible for and/or as to blame for the health problems is associated with a consistent theme that is emerging from the research. Apart from interviewing women during this study I have also undertaken interviews with medical professionals and analysed medical information that explains the causes of congenital health problems. An underlying theme that has emerged from all aspects of the study is that, most commonly, it is factors related to the bodies and behaviours of *women* that are considered when we search for or attempt to explain the causes of congenital health problems. Far less attention is directed to considering the influence of other factors that may, potentially, be associated with the cause. Other such factors include the health of men who father these children, and factors that exist within our environment, such as pollution or pesticides. There *is* medical evidence which suggests that men's health and factors in the environment may influence the health and development of a foetus yet these factors are rarely considered as part of our usual thinking about causation. Furthermore, it appears that it is regarded as 'usual' or 'normal' for women to take on the majority of the childcare and health care within families. According to the beliefs that were expressed by some women and medical practitioners during the interviews, this situation is not only 'usual' but it is the way things 'should be' or the way things are 'naturally supposed to be'. The existence of these kinds of understandings about the responsibilities that women have for their children, and also about the causes of congenital health problems,

PDF created with FinePrint pdfFactory Pro trial version www.pdffactory.com

puts women under considerable pressure. Such beliefs may also influence how women who mother children with health problems think about themselves and how they are treated during their contact with health professionals and others in society. Therefore, during the next stages of the research I will continue to explore the potential effects of these kinds of ideas in influencing the experiences of families affected by congenital health problems. I will also consider how the current dominant focus on women may influence, and limit, our understanding about the possible causes of congenital health problems.

THE VALUE OF TIME FOR REFLECTION

Another finding that is partly linked to the themes of isolation and responsibility relates to the importance of women sharing their experiences of mothering a child with health problems. The importance of this was demonstrated by the comments of several women about how valuable they found it to be able to share their story during the interview. Having someone to talk to about their experiences allowed women an opportunity to discuss and think about their feelings, some of which they had not shared before. My role in the interview as a researcher and as someone otherwise not involved in the lives of the women seems to have helped some women to feel more able to share sensitive information because they didn't feel that I would judge them or challenge their views. This lack of judgement is important because, as indicated before, a sense of being judged by others appears to be a quite common, and negative, part of mothering a child with health problems.

For some women the lack of opportunity to reflect on their experiences resulted from the busy nature of their lives in that they rarely had time to think about what impact their experiences had had on them. However, several women indicated that although they felt like talking and thinking about the personal impact of their experiences they couldn't do so. There were two main reasons for this. First, some women felt that they didn't have anyone to talk to. The partners of these women were either absent or uncomfortable about talking about the health problems. Due to a sense of isolation, and a fear of being judged, these women also found it difficult to share feelings with relatives or friends. Second, some women indicated that they felt guilty about spending time thinking about the personal impact of their childs' health problems. Their feelings of guilt developed from a belief that it was selfish to dwell on personal feelings because the 'proper' role of a mother is to devote attention to her child and to put their needs first. Therefore, for women who felt this way, spending time reflecting on the personal impact of their experiences was of less importance than assisting their child and they believed it could be viewed, potentially, a sign of irresponsible mothering. However, the positive comments made by women following the interviews suggests that being allowed time to think about and share (if they wish) their experiences could assist some women in working through their feelings and in beginning the process of emotional healing. Therefore, as an outcome of the research I will suggest that it is important that women be provided an opportunity to share feelings in non-judgemental and non-pressuring environments following the diagnosis of their child. I will also attempt to suggest some practical strategies for making this possible.

A NEED TO DISPLAY 'GOOD MOTHERING'

During the interviews several of the women spoke about their need to demonstrate that they were a 'good' mother. This need commonly arose out of a belief that other people, especially medical professionals, judged them and their mothering abilities negatively as a result of their child's health problems. Some of the ways in which women attempted to demonstrate 'good' mothering included dressing themselves and their children in nice clothing when they attended medical appointments or social events, learning medical terms so that they could demonstrate their knowledge to medical staff and also by frequently expressing their willingness to perform any task necessary to improve their child's health regardless of what personal sacrifice this involved. It appears that by behaving in these ways women were able to regain some power in their interactions with medical staff. Presenting themselves as credible people and as 'good mothers' allowed the women to feel that they were interacting on a more equal, rather than lower, level with medical professionals. Behaving as 'good mothers' also helped some women to reduce the negative judgements that they experienced when interacting with others. Escaping such judgement and developing their identity as a 'good mother' appeared to allow some of the women to develop greater confidence when interacting with others and also to reduce some of the guilt and anxiety that they experienced both about their child's health problems and about their mothering abilities.

PDF created with FinePrint pdfFactory Pro trial version www.pdffactory.com

MATERNAL INTUITION

Interestingly, the issue of *maternal intuition* arose during eight of the interviews. Intuition means to 'know from within'. During the interviews some women explained that they knew things about their children's health that were not easily observed or known by other people. For example, one woman said that she knew about the health problems before her child was diagnosed and others indicated that they suspected that something was wrong with the health of their child during pregnancy despite having no medical evidence to suggest this. Other women explained that they were able to detect when their child was about to become ill before any symptoms were evident. It is important to acknowledge that some women admitted that they probably wouldn't have remembered feeling like something was wrong with their baby during pregnancy had their child been born without health problems. However, several other women believed strongly in their ability to intuitively know things about their children and they explained this as being the result of the strong bond between them.

My analysis of the interview data indicates that maternal intuition has multiple, and sometimes conflicting, effects within family relationships. In one sense, a belief in the power of maternal intuition serves to reinforce a woman's role as the 'naturally' better and more suited caregiver in the family because she has the ability to know things about her child that are unknowable to others. This may have the effect, however, of both *excluding* and *excusing* fathers from equal responsibility for child care. At the same time, maternal intuition may also work in more positive ways for women who mother children with health problems. This is because the ability to know a child so intimately may provide evidence of their close mothering bond and, therefore, assist women to demonstrate that they are 'good' and 'devoted' mothers. Such an ability to demonstrate 'good mothering', as I explained before, appears to be particularly important for women who mother children with health problems as they strive to escape the negative judgements that can be made of them.

IMPORTANCE OF EARLY EXPERIENCES

Many of the women in the study spoke about the importance of their early experiences with their child in influencing their feelings about the health problems and about themselves as mothers. Of particular importance appears to be the early contact that women have with medical staff around the time of their child's birth. For some, this contact was particularly negative with women left feeling like the medical staff were judging them and/or their child and also like they didn't receive adequate support or information from medical staff. Several women indicated that their negative early experiences formed the basis for less than satisfying relationships with their child's heath care providers. Other women also expressed that negative early experiences around the time of their child's birth resulted in them feeling like they could not cope with their child's health problems or like they weren't going to be able to provide the care that their child needed. This wasn't the case for all women however with some indicating that they and their child received excellent care around the time of the birth. These positive experiences provided an opportunity for the women to learn about their child's health problems and also to feel comfortable about their future contact with health providers.

Understanding more about these findings is important because they suggest that experiences around the time of birth may have a particularly strong influence on the way that women feel about their child, the health problems and about their ability to cope in the future. This indicates a need for further examination of the role of birth experiences in influencing later outcomes for families affected by congenital health problems. Furthermore, it may be appropriate that one of the recommendations that I make at the conclusion of the study is for additional information to be given to health professionals about the sensitivities that are associated with the birth of a child with congenital health problems and about how the needs of families may be better addressed around the time of birth.

Thank you for your interest in this study. If you would like further information about the findings please contact me via email at toni.delany@adelaide.edu.au or by phone on (08) 8303 3723. I would like to again thank all of the women who participated in the interviews. Without your time and openness this research would not have been possible. I would also like to thank the support groups who generously supported this research.

PDF created with FinePrint pdfFactory Pro trial version www.pdffactory.com