

School of Nursing Midwifery and Paramedicine

**The formative evaluation of a psychosocial assessment framework
for families of children who are seriously or chronically ill**

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of
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Declaration

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgment has been made.

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

A rectangular box containing a handwritten signature in black ink. The signature reads "Mary Margaret Tallon" in a cursive script.

Mary Tallon

Candidate

January, 2017

Abstract

The formative evaluation of a psychosocial assessment framework for the families of children who are seriously or chronically ill

Background

Seriously and chronically ill children frequently experience diminished health and developmental outcomes across the life course. Effective diagnosis and treatment are essential; however, long-term outcomes are greatly influenced by the care these children receive, mostly from their primary caregiver. The care children receive varies widely depending on a range of family sociodemographic and psychosocial characteristics. Children who live in families with abundant financial, physical, human and social capital resources are likely to have better health and developmental outcomes.

Furthermore, the level of care provided is frequently compromised if the primary caregiver (PCG) is experiencing significant distress associated with their child's prognosis and managing the child's complex care needs along with the needs of other family members. The prevalence of anxiety and depression is increased in the families of seriously and chronically ill children. Relationship problems and family dysfunction are also increasingly likely as life-stresses that result from child's illness proliferate. The majority of seriously and chronically ill children spend very little time in hospital, however, this time is important for their future health and wellbeing. In addition to essential clinical care, it provides an opportunity for families to obtain professional support to enable them to cope successfully. Paediatric nurses contribute a great deal to this process when they apply effective assessment and communication skills.

In Australia, the family-centred approach is accepted as the preferred model of care in the paediatric setting. However, it has not been clearly defined and is not uniformly practised. Consequently, there is little evidence supporting the effectiveness of Family-Centred Care in improving outcomes for children and their families. Anecdotal evidence suggests that the care of children in hospital remains clinically focused where the needs of the child and family are expressed through the child's principle health condition. While nurses regularly spend a considerable amount of time providing hands-on care for seriously and chronically ill children, and have opportunities to assess and manage family psychological and social issues, this is seldom routine practice. It is not altogether clear why many nurses and other healthcare professionals

are hesitant to engage with families about the personal issues that concern them. One reason may be that, in Australia, there is no psychosocial assessment framework available that focuses specifically on the family.

Psychosocial assessment in the healthcare context is difficult for both patients and healthcare providers (HCPs). In the paediatric context, PCGs almost always put the needs of their seriously or chronically ill child above their own and any attention given to them and their family is frequently perceived as a distraction that could impact negatively on their child. For HCPs, identified barriers to the conduct of psychosocial assessment include a perceived lack of time, resources, and methods to evaluate and respond effectively to psychosocial issues.

Despite these potential barriers, there are approaches to psychosocial assessment that have been found to be helpful in drawing attention to specific family issues. For example, interventions based on Family Systems Nursing which have been implemented in the US and Canada, draw attention to psychosocial factors through relationship building and therapeutic communication. While Family Systems Nursing approaches have many advantages, they tend to be utilised by advanced practice nurses, rather than nurses who provide care for seriously and chronically ill children, more generally. One model that has been adopted in Australia to identify levels of psychosocial risk in the families of children newly diagnosed with cancer is the Psychosocial Assessment Tool (PAT.2). However, the PAT.2 is focused on the developmental needs of the child and while it does include an assessment of the family, the needs of the family can be overlooked.

In an effort to understand more about family psychosocial assessment in the Australian context, and develop an appropriate model to guide paediatric nursing practice, this study sought engage with key stakeholders to undertake the formative evaluation of a psychosocial assessment framework for the families of children who are seriously and chronically ill.

The following objectives were addressed:

1. To identify the attitudes and beliefs of participating primary caregivers (PCGs) and healthcare providers (HCPs) regarding sharing of information about family psychosocial issues in hospital.

2. To estimate the levels of importance assigned to the psychosocial components included in the proposed framework by participating PCGs and HCPs.
3. To examine and interpret the expressed feelings and experiences of PCGs and HCPs regarding the sharing of information about family psychosocial issues in hospital.
4. To recognise and name emerging themes from thematic analysis and construct an emergent conceptual model to illustrate the final proposed family psychosocial assessment framework.

Methodology

Formative evaluation was chosen as the methodology for the study because it is based on the understanding that a health intervention that is feasible and acceptable to those who use it is more likely to be successfully implemented. In the first stage of formative evaluation, the researcher proposes an intervention they believe to be appropriate for addressing the issue of concern. In this case, it was envisaged that a family specific psychosocial assessment instrument would be helpful for nurses and other healthcare professionals to collect data and direct their attention to family psychosocial issues.

Based on current knowledge and understanding about family characteristics and children's health and development, ten aspects of sociodemographic and psychosocial functioning were identified for inclusion: maternal education; parental occupation; maternal emotional health; maternal self-confidence; family structure; family functioning; family life-stress; social support; financial strain; and community engagement. The formative evaluation was undertaken using a concurrent mixed methodology design of triangulation whereby quantitative and qualitative data were collected and analysed separately. The findings were then integrated to explore similarities, inconsistencies, and new understandings. Participants were drawn from major tertiary paediatric healthcare facilities in two Australian state capitals.

Survey data were obtained from 141 PCGs and 350 HCPs. Surveys contained sociodemographic information and validated instruments that measured attitudes toward psychosocial assessment. The PCG survey included a modified version of the "Parent Attitudes towards Psychological Support Index" (PATPSI), by Turner (2012), while the survey completed by HCPs contained the "*Physician's Belief Scale*" (Ashworth, 1984). Both surveys included a section asking participants to assign levels

of importance to each of 10 psychosocial components, from evidenced based research which were ultimately included in the proposed framework.

To gain deeper insight from participants' experiences related to talking about psychosocial issues, an inductive approach was applied to the analysis of interview and focus group transcripts using Braun and Clarke's six phases of thematic analysis. Data saturation was achieved when all categories were well defined and no new data were emerging. Ten one-on-one interviews were conducted with PCGs, as well as eight face to face interviews and four focus groups with HCPs. Through the process of examination and re-examination, data were grouped and emerging themes suggested a final conceptual model.

Results

A total of 491 surveys were collected with a combined response rate of 65 per cent. The sample of PCGs and HCPs primarily comprised females (91% and 92% respectively). Over 60 per cent of the HCP sample reported more than five years of clinical experience in paediatrics. All participants agreed that most of the psychological components were important and acceptable to talk about in hospital. However, levels of maternal education, and parental occupation were not considered important or appropriate issues for discussion by both PCGs and HCPs. Positive attitudes to talking about psychosocial issues expressed in the surveys were found to be congruent with the experiences and feelings shared in the interviews and focus groups. Three themes emerged from analysis of the transcripts.

The first theme named "building relationships" contained expressed willingness by PCGs and empathy by HCPs to talk about family issues that was constrained by reluctance to broach issues considered to be sensitive. This theme was found to be intrinsically connected to two emergent process themes named "listening with curiosity and openness" and "building trust and safety". Tensions between the experiences of PCGs and HCPs surfaced during examination and re-examination of the data. PCGs expressed the desire to feel heard by HCPs while the need to build trust and safety before talking about psychosocial issues was the source of hesitancy among HCPs.

The second theme named "the whole family" emerged from an overwhelming consensus that caring for the child in hospital involved every member of the family.

The final theme; “the hospital and services” contained a sub-theme “the hospital people and culture”. Here, further tensions were identified between PCGs and HCPs about giving and receiving information, and clarity of roles. A balance in power was also revealed within this theme and sub-theme.

Discussion

The study findings were synthesised and the finalised emergent conceptual model was discussed in detail in relation to the existent literature. Initially it was thought that the family psychosocial assessment framework would include an instrument to identify specific psychosocial issues experienced by families in hospital in a similar way to the PAT 2.0 developed by Kazak (2006). However, the findings showed that rather than identifying specific psychosocial issues, the framework should be more about creating a receptive and responsive environment in which meaningful conversations about family life could be conducted.

Some psychosocial issues were considered unhelpful by PCGs and HCPs for inclusion in conversations altogether, while others were considered important and easy to talk about. Rather than targeting specific psychosocial issues, the emergent conceptual model revealed that it was more appropriate for HCPs to engage in gentle enquiry about how PCGs were feeling, before guiding conversation about aspects of family structure, functioning, and access to support. The findings also showed that HCPs who had more experience in their roles were more comfortable and confident talking about psychosocial issues. These findings indicated that the promotion of family psychosocial assessment could be achieved more successfully through skills-based educational and mentorship programmes.

A key recommendation from this study is that an inter-professional learning package be created in collaboration with stakeholders to enhance healthcare provider skills in family psychosocial assessment and support. The learning materials will need to be designed to be presented flexibly to healthcare providers working with the families of seriously and chronically ill children. It is envisaged that the learning package will consist of learning modules covering the following themes: underpinning evidence-based knowledge of family issues associated with caring for a seriously ill child; relationship building; assessment and identifying families experiencing distress; strategies to enhance coping and adaptation; and leadership and mentorship of skills in psychosocial assessment and support.

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Additional publications and presentations

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http://link.library.curtin.edu.au/p?cur_digitool_dc230136
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List of abbreviations

ABS	Australian Bureau of Statistics
ACSQHC	Australian Commission of Safety and Quality in Healthcare
CAHS HREC	Child and Adolescent Health Service Human Research Ethics Committee
CFAM	Calgary Family Assessment Model
CFIM	Calgary Family Intervention Model
FaMM	Family Management Measure
FCC	Family-Centred Care
FSN	Family Systems Nursing
HCP	Healthcare provider
HPA	Hypothalamo-pituitary-adrenal
HREC	Human Research Ethics Committee
IBM	Illness Belief Model
PAT	Psychosocial Assessment Tool
PAT 2.0	Psychosocial Assessment Tool 2.0
PATPSI	Parents' Attitudes Towards Psychological Services Index
PCG	Primary care giver
PMH	Princess Margaret Hospital, Perth
RCH	Royal Children's Hospital, Melbourne
RCH HREC	Royal Children's Hospital Human Research Ethics Committee
SEIFA	Socioeconomic Index for Advantage
UK	United Kingdom
USA	United States of America
VIC	Victoria
WA	Western Australia
WHO	World Health Organisation

1. Introduction

“We had this beautiful baby, with an illness we never heard of. We didn’t imagine it would be possible, and no one could imagine what we were going through. They need to focus more on that because it is the whole family affair...”

(Annie, a primary caregiver)

1.1 Chapter outline

In Chapter One, the formative evaluation of a family psychosocial assessment framework on which this thesis is based, is introduced. The impact of serious or chronic illness in childhood and the importance of family are briefly outlined. The current approach to caring for children and families in hospital in relation to psychosocial assessment and support is summarised. Justification for this formative evaluation of a family psychosocial assessment framework is provided, and the aims and objectives of the study are presented. This chapter concludes with a summary of the structure of this thesis and the research components contained within each chapter.

1.2 The impact of a child’s serious or chronic illness on the family

As the mother expressed above, the diagnosis of her child’s life-long illness came as a shock, overturned her expectations, and was immensely distressing. When a child is diagnosed with a serious or chronic illness the primary caregiver (PCG) is obliged to rely on the expertise of healthcare providers (HCPs), and adapt to an unfamiliar clinical environment where investigative procedures are undertaken and complex words are spoken. While it is essential that emphasis is placed on effective diagnosis and treatment by the healthcare team, the long term health and developmental outcomes for these children will greatly depend on the care they receive from their family especially their PCG.

The anxiety experienced by a PCG when a child is seriously or chronically ill can be considerable (Zebrack et al., 2014). High levels of distress can interrupt how PCGs respond to their child’s needs and may result in the child having diminished health and developmental outcomes (McFarlane et al., 2013). The stress and anxiety associated with understanding new and often complex information, managing special care needs at home, attending numerous appointments, and accessing medications, for

example, can further impact parental caregiving activities (Malik, Wells, & Wittkowski, 2015).

The stress, fatigue, and burnout experienced by primary caregivers and the subsequent impact on family relationships can take their toll (Lavelle, Wittenberg, Lamarand, & Prosser, 2014; Zubrick, 2000). The experience of parental worry and fatigue related to continuously managing their children's health needs can be further amplified when there is little access to social support (Lai & Oei, 2014). For some primary caregivers their relationships with extended family members provides a means of emotional and practical support while also instilling confidence and fostering their capacity to cope (Surjadi, Lorenz, Wickrama, & Conger, 2011). For others, the experience of extreme stress, when their child is seriously ill, may result in non-adaptive responses such as taking out their anger and frustration on those to whom they have the closest emotional attachment (Wiener et al., 2014). As a consequence, the serious illness of a child can place a great strain on the parental relationship. There is some evidence that a high proportion of or intimate partner relationships fail as a consequence of the strain associated with parenting a child who is seriously or chronically ill. (Loucas et al., 2014).

Within the family, exposure to additional life-stresses can heighten the impact of parental caregiving on child health and developmental outcomes (Barrera et al., 2014). Maintaining the parental work routine and professional work responsibilities, or pursuing promotional aspirations, for example, can be difficult or even unattainable for the parents of children who are seriously or chronically ill, and may result in considerable financial burden (George, Vickers, Wilkes, & Barton, 2008). Depending on their level of personal and social resources, some parents are better able to manage their child's healthcare needs and access professional care to assist them to cope in the longer term (Kendall & Tallon, 2011).

1.3 The importance of the family for children's health and developmental outcomes

The care given by PCGs is important because children who are seriously or chronically ill are at increased risk of poor physical, emotional, and cognitive developmental outcomes (Bell, 2016). A seminal research project conducted in Canada, the Ontario Child Health Study (Cadman, Boyle, Szatmari, and Offord, 1987), was instrumental in drawing attention to the psychological and emotional wellbeing of children with a

chronic illness or disability. Following epidemiologic examination of over 3,200 children it was found that those with a chronic illness and disability were almost three times more likely to have an emotional or behavioural problem than those who had a chronic illness without disability (Cadman et al., 1987). Additionally, the risk of emotional and behavioural problems in children with chronic illness were significantly increased in comparison to their healthy peers. It was also found that the few supportive healthcare services that were available, were under used. The authors suggested that these services may have been helpful had they been implemented (Cadman et al., 1987).

This study became a platform for further global enquiry where the original epidemiological survey has been adapted elsewhere and opportunities for earlier developmental intervention have been identified and pursued (Bradford & Rickwood, 2014; Sawyer & Spurrier, 1996). More recent studies have shown that children with congenital heart disease, diabetes, and asthma, for example, are also at increased risk of poor cognitive, as well as emotional and behavioural health outcomes (Beacham & Deatrack, 2015; Bernier, 2010; Schwartz, Wasserman, Powell, & Axelrad, 2014). To minimise the impact of the illness on subsequent health and development, these children require considerable on-going individualised care. Unfortunately, for many families the distress they experience affects their capacity to care for their children appropriately. Furthermore, even when caregiving activities are appropriate, if children witness constant conflict associated with the high levels of stress experienced by their parents and they receive little emotional support, their development may be compromised through biological embedding (Shonkoff et al, 2000).

Biological embedding is the process whereby the early physical and psychosocial environments that children are exposed to may influence gene expression, brain development, and the development of psycho-neuro-endocrine-immune pathways that impact long term health and wellbeing (Hertzman, 2013). The concept of biological embedding evolved as a plausible explanation for the consistent finding of social gradients in children's health and developmental outcomes (Hertzman, 2009; Shonkoff & Phillips, 2000). For example, living in a dysfunctional family in the early years of life has been associated with depressive symptoms in adolescence (St Clair et al., 2015). Furthermore, through epigenetic mechanisms, altered DNA can be passed

on to successive generations so the impact can be intergenerational (Danese & McEwen, 2012; Demetriou et al., 2015).

Children who are seriously or chronically ill are especially vulnerable to poor health and developmental outcomes when the care they receive is not appropriate or they experience high levels of stress at home. This is why PCGs require a great deal of support to enable them to develop adaptive coping strategies to optimise their child's health and wellbeing.

1.4 The need to recognise and respond to family psychosocial issues

Despite the development of Family Systems Nursing (FSN), the Family Measurement Model (FaMM), and the Psychosocial Assessment Tool (PAT 2.0) in the US and their use internationally, paediatric nurses in Australia do not routinely assess the psychosocial needs of the parents of children who are seriously or chronically ill (Kazak, 2008; Knafl, Deatrick, & Havill, 2012; Priest, 2006). The PAT is becoming more widely used in a variety of acute care settings (Kazak, Schneider, Didonato, & Pai, 2015). It has drawn attention to the psychosocial issues many families experience. It is useful for identifying the escalating levels of distress experienced by some PCGs (Haugli, 2015; Pai, Tackett, Ittenbach, & Goebel, 2012). Furthermore, it provides a mechanism for collecting evidence that may be used for triage and referral (Kazak, 2008). However, in seeking to assess psychosocial characteristics of the child along with the characteristics of their family, the questions contain partial detail about both. It is argued here that it would be preferable to assess the child's health and development using valid and reliable screening instruments, such as the Child Behaviour Checklist (CBCL), and the psychosocial characteristics of the parents using a suite of validated instruments designed for this purpose. This is the principal rationale for the advent of the current study.

In Australia as in other settings, such as the United Kingdom (UK), a family-centred approach continues to be promoted as the preferred philosophy of care. There is, however, considerable debate about its effectiveness (Shields, 2010; Smith, Swallow, & Coyne, 2015). FCC (FCC) has been widely operationalised as the involvement of the family in all aspects of care of the child in hospital. (Mikkelsen & Frederiksen, 2011).

The authors of a recent review of international literature examining FCC identified that parents expect to stay with their children in hospital and this is what FCC means to them (Watts et al., 2014). There is some evidence that paediatric nurses do understand that there is more to FCC than simply allowing family members to room in with their child, but they have difficulty implementing care that involves the provision of emotional support and the development of appropriate caregiving skills (Coyne, O'Neill, Murphy, Costello, & O'Shea, 2011). Many paediatric nurses in Australia lack knowledge, understanding, and the skills required to assess the complex psychological and social needs of the families of seriously and chronically ill children (Priest, 2006). Furthermore, it has been suggested that hospital cultural and organisational issues are the biggest barriers to implementing FCC (Noyes, 2011). For HCPs, barriers to effectively evaluating patients' psychosocial situations, including insufficient time, and a lack of support and resources, are recognised (Fagerlind, Kettis, Glimelius, & Ring, 2013). A lack of clarity about roles and responsibilities in relation to addressing psychosocial issues has also been identified (Gosselin, Crane-Okada, Irwin, Tringali, & Wenzel, 2011).

It is understandable that many nurses and other HCPs find it difficult to engage with families regarding personal psychological and social issues. Some families regard psychosocial assessment as an intrusion on their privacy and they believe that psychosocial care is unnecessary (Dilworth, Higgins, Parker, Kelly, & Turner, 2014). Reluctance among patients and families to ask for help even when their needs are obvious has been identified in an examination of parents' perspectives about coping with serious illness (Bradford & Rickwood, 2014). For PCGs, the need to maintain some control and to be perceived as coping have also been identified as barriers to accessing support (McFarlane et al., 2013, Zoffmann & Kirkevold, 2012). While the FCC approach continues to be promoted in Australia, there is little evidence supporting the fundamental influence parental caregiving in hospital has on children's long term health and developmental outcomes in practice (Tallon, Kendall, & Snider, 2015b).

1.5 A conceptual framework for family psychosocial assessment

There is a great deal of evidence that supports the benefits of applying a systems approach to healthcare policy, research, and practice. Firstly, the bioecological model of human development has evolved in recent years as a meta-theory that facilitates the integration of evidence-based knowledge and understanding generated by scientists in

the biological, behavioural, and social sciences (Bronfenbrenner & Ceci, 1994). This research study is guided by this model as well as the family and community resource framework, and the theories of biological embedding and systems theory that underpin FSN (Tallon, Kendall, & Snider, 2015b).

The Family and Community Resource framework developed by Jeanne Brooks-Gunn (2003) provides a useful model in which to consider the financial, physical, human and social resources of parents that influence children's health and development. Research in this area has shown improved child health outcomes as a result of early childhood intervention and home visiting programmes (Maggi, Irwin, Siddiqi, & Hertzman, 2010; Olds et al., 2013). The theory of biological embedding whereby interaction with the physical and psychosocial environment in the early years of life influences gene expression, brain development and stress physiology has already been described very briefly above and will be examined in more detail in the following chapter of this thesis. Finally, FSN by Wright and Leahey (1990), supports a biopsychosocial approach where integration of psychosocial components with clinical thinking is encouraged (Smith, 2002).

Using a systems approach, FSN guides better understanding the interpersonal dyads of the family unit, and the family structure and functioning (Friedman, 1989; Wright & Leahey, 1990). Furthermore, the models of family assessment that have emerged from FSN, such as the CFAM and the IBM, apply a strength-based approach to exploring the family unit and functioning (Wright & Leahey, 1994). Furthermore, application of a FSN approach to the care of children with chronic illness is interdisciplinary, in that it incorporates the social, health, and family sciences (Knafl et al., 2011). A growing body of evidence from FSN practice shows that bringing this systems approach to practice results in improved health and developmental outcomes for individuals and families (Chesla, 2010; Östlund & Persson, 2014). These theories and related evidenced-based findings will be presented in more detail in the review of the key literature relating to the question underpinning this thesis.

1.6 The evolution of this study

The focus on family psychosocial assessment in the current study has evolved from a Research Master's Degree undertaken by the author and many years of experience in clinical practice working with seriously ill children and their families in hospital. At

the time, research enquiry was based on a disparity between assumed levels of maternal understanding following information giving in a clinic setting, and the subsequent care giving activities reported by mothers during follow up appointments after major surgery. It was hypothesised that higher levels of maternal knowledge and understanding at the time of a child's major surgery could impact positively on maternal care giving.

A measure for maternal knowledge and understanding at the time of a child's major surgery was developed (Tallon, Kendall, & Snider, 2015a). However, rather than knowledge and understanding per se, it was found that the instrument was really measuring maternal self-confidence (Tallon, Kendall, et al., 2015a). Mothers' who scored lower in their confidence in knowledge and understanding reported higher than normal levels of anxiety and low levels of social support (Tallon, Kendall, et al., 2015a). This attention to psychosocial issues raised questions. Firstly, how do PCGs and HCPs perceive the concept of discussing family psychosocial issues during routine caregiving in hospital? Secondly, is implementation of a family psychosocial assessment approach that focuses on the family concurrently with the child, feasible and acceptable for use in paediatric hospitals? Thirdly, if so, what psychosocial components are more appropriate to discuss, and if not, what alternative approach would be preferred? These questions emerged not only from the findings of the research conducted by the candidate, but importantly are supported by the body of evidence that fosters the notion that parents have the greatest impact on their children's long-term health and developmental outcomes through the care they give. This is especially important when a child is seriously or chronically ill. The development of the proposed family psychosocial assessment framework is outlined in detail in Section 3.3 in the Methodology chapter of this thesis.

1.7 Aim

The overall aim of this research study was to undertake a formative evaluation to assess the feasibility and acceptability of a family psychosocial assessment framework that stemmed from research findings from a range of disciplines. Four objectives were developed and are outlined below. Objective one and two addressed the feasibility of the family psychosocial assessment framework in development while its acceptability by PCGs and HCPs was addressed in objective three and four.

1.8 Objectives

The following objectives were addressed:

1. To measure the psychosocial attitudes of participating primary caregivers (PCGs) and healthcare providers (HCPs) about sharing of information about family psychosocial issues in hospital.
2. To measure the levels of importance assigned to the psychosocial components included in the proposed framework by participating PCGs and HCPs.
3. To examine and interpret the expressed feelings and experiences of PCGs and HCPs regarding the sharing of information about psychosocial issues in hospital
4. To recognise and name emerging themes from thematic analysis and construct an emergent conceptual model to illustrate the proposed family psychosocial assessment framework.

1.9 The significance of the study

It is anticipated that an acceptable family psychosocial assessment framework will encourage paediatric HCPs to assess and support PCGs and other family members who experience significant levels of stress when their seriously or chronically ill child is hospitalised. By addressing the psychosocial needs of the family separately to the child, the circumstances of the family can be comprehensively examined. In doing so, the ultimate influence parental care has on child health outcomes by assessing family functioning is emphasised where the need for support can be identified and tailored to the family.

Implementation of the proposed family psychosocial assessment framework has the potential to contribute to the body of knowledge that guides paediatric healthcare practice. Through continuing research, education and mentorship programmes, findings that focus on improved health outcomes of children who are seriously or chronically ill could be incorporated into policy and curriculum. Further to this application of a family psychosocial assessment framework to practice could provide evidence for FCC that supports the care of children in the context of family. It is also anticipated that implementation of the emergent family psychosocial assessment framework will strengthen recognition of the nurse's role, as distinct from other HCPs both in practice and curriculum, in improving child health outcomes. Furthermore, the implementation of a family psychosocial assessment framework that is acceptable and

feasible could provide a platform for research that would respond to a call for evidence for National Standard Two: Partnering with Consumer which is one of ten nation standards that outline requirements for quality healthcare service in Australia set out by the Australian Commission of Safety and Quality in Healthcare (Australian Commission of Safety and Quality in Healthcare, 2011).

1.10 Structure of the thesis

In this chapter the background to, and context of, this study was introduced. An overview of a range of psychosocial stresses that can impact parental care giving and family life was provided. The impact of serious or chronic illness on children's development was briefly outlined and the need for optimal parental care highlighted. The philosophy that guides the care of children and families in hospital where this study was conducted was presented.

In Chapter Two, the findings from systems theory knowledge and research that underpin and support this study are provided. This review of the literature chapter is divided into three main sections. In the first main section the early environments of children are presented where the influence of social determinants of health and the impact of stress responsiveness are examined. The second main section begins with an examination of findings related to FCC, before examining in detail, historical and theoretical perspectives of FSN. In the third main section, research findings pertaining to the evolution of psychosocial assessment in the care of adults are examined before critically analysing findings pertaining to psychosocial assessment of children with serious or chronic illness.

In Chapter Three, the formative evaluation that guided this mixed methodology study is introduced. A health promotion approach with consumer participation is provided to give context. The aims and objectives of the study are presented. The participants, sampling approach, and setting are introduced and the procedure for recruitment, data collection, instrumentation, and analysis are described. Recruitment and analysis are presented for the quantitative sample followed by the qualitative sample. This chapter concludes by outlining the ethical considerations addressed in the conduct of this study.

To follow, Chapter Four is divided into two parts where analysis of survey data and thematic analysis of one-on-one interviews and focus groups are presented separately.

Firstly the quantitative analyses of the survey data are presented, beginning with the PCG sample. Here the response rates, frequency distributions for attitudinal scores, and levels of importance assigned to components of the psychosocial assessment framework are presented. Relationships between sociodemographic variables and components of the psychosocial assessment framework are highlighted. These findings are repeated for the HCP sample finishing with presentation of the relationships between PCG and HCP attitudinal scores and levels of importance assigned to psychosocial components of the framework. Secondly, presentation of thematic analysis of one-on-one face to face interviews with PCGs and HCPs, and focus groups with HCPs are presented. The conceptual model that emerged from the data is illustrated whereby presentation of the findings is guided by the emergent main themes, process themes and sub-themes contained within the model.

In Chapter Five a summary of the integrated findings is presented where triangulation of the findings occurs in keeping with the mixed methodology selected for this study. This is followed by more discussion of the findings in relation to the current literature. The finalised family psychosocial assessment framework is presented and implications for practice and research are considered. Strengths and limitations of the study are discussed and followed by study conclusions.

2. Review of the literature

2.1 Introduction

In this chapter, relevant published literature pertaining to psychosocial assessment and the care of individuals and families in the healthcare setting is examined. This integrative review of the literature aims to provide a greater understanding of the evidence pertaining to the theory, research, and practice of psychosocial care relevant to families of children who are seriously or chronically ill. As critical review of the findings within this chapter aimed to support and justify the formative evaluation of a family psychosocial assessment framework that is central to this research, it must be acknowledged that this review of the literature was not exhaustive.

In this review of the literature, the impact of the biological, relational, and environmental influences that impact children and families are examined. The findings of this review are discussed in the context of children who are seriously or chronically ill, and their families in the Australian context. Because the findings of this review are discussed in the context of theoretical underpinnings that relate to the psychosocial assessment and care of children who are seriously or chronically ill, and their families in the Australian context, this review of the literature is a representative review of literature rather than an exhaustive integrative review. This integrative review is guided by a systems theory approach that is almost universally used to guide research and practice in children's health and development where the application of evidenced based models of care from FSN are presented and discussed. The evolution of approaches to psychosocial assessment and screening instruments are examined with respect to their psychometric properties and function. Psychosocial assessment in the care of children in hospital that are relevant for understanding family functioning are examined more closely. The benefits of conducting psychosocial assessment of the family that is independent of the child's clinical condition are explained. The relevance of family psychosocial assessment to practice and curriculum in the Australian setting, is also briefly outlined.

An integrative review was selected for this purpose because the process allows for the inclusion of a wide range of research methodologies (Ganong, 1995). As a consequence, inclusion of a variety of research approaches was addressed by referring to the components of conducting an integrative review developed by Whitemore and Knafl (2005). These components were considered in the context of the family in

healthcare and included: maintaining a focus on issues that are central to this research project, clearly outlining the search strategies undertaken, and discussing the findings with consideration for the rigour of selected research data analysis and evaluation (Whittemore & Knafl, 2005).

2.2 Search strategy

A wide range of relevant research findings were sought by searching databases that contain health research including both peer reviewed published research ‘black’ literature and pertinent semi published ‘grey’ literature. The following databases were selected: ‘CINAHL’, ‘Medline’, ‘PubMed’, ‘ScienceDirect’ and ‘PsychINFO’. Further references were identified using the reference lists from selected published articles. In addition, relevant semi-published reports and expert opinions were sought using keywords where internet addresses were recorded to authenticate the process. Publications written in the English language that related to humans and included the search terms in first world settings were included. No time limit was set in order to allow for references that were relevant from a historical perspective. Because this representative review examined findings related to children and families in hospital in publications in languages other than English, those that did not relate to humans, or focused on third world settings were excluded. Throughout the search process a focus on psychosocial care and assessment of individuals and families in the healthcare setting was maintained. In each of the databases, terms and keywords were inserted to conduct individual searches. The search terms used during the searching process were variations of the following: Family(ies), child/ren, p(a)ediatric(s); healthcare / chronic illness /serious illness /major health problem; psychosocial / assessment / care/ psychometric testing / measures; stress /distress; and FCC, Family Nursing / Family Systems Theory Nursing. Individual searches were initially conducted using healthcare, psychosocial, psychometric testing, child, and family. These individual searches yielded a total number of 2509 articles. This number was reduced by combining the search terms healthcare, psychosocial and psychometric were combined with AND, while the terms healthcare, Family Nursing, FCC, child, family, chronic / serious illness, were also combined with ‘AND’. Following exclusion of articles outside the limitations of this search outlined above and removal of duplicates this total was reduced to 201 publications that were published between 1977 and 2016 for inclusion in this review of the literature.

2.3 Biological, relational, and environmental influences on children and families

Children who are seriously or chronically ill are at increased risk of experiencing emotional and behavioural problems as well as diminished cognitive development (Maslow, Haydon, Ford, & Halpern, 2011). A great deal of evidence has resulted from research undertaken in a range of disciplines: neuroscience, genetics, endocrinology and immunology, where the impact of factors in both the physical and psychosocial environments of children on their health and developmental outcomes is understood and examined. Understanding about why children with serious and chronic illnesses are especially vulnerable to poor outcomes is enhanced by knowledge of developmental systems theory, attachment theory, and the theories of biological embedding and allostatic load. These theories are outlined in the following two subsections.

2.3.1 Developmental systems theory and attachment theory

Children's experiences are shaped by the interplay between their physical environments and the care they receive within their families, particularly their primary caregivers. This notion was popularised by Bronfenbrenner (1977) who proposed an ecological model of early child development. This model was later extended where genetics and human development were reconceptualised and consideration for the child's environment was identified as a set of nested structures in which growth and development occurred (Bronfenbrenner & Ceci, 1994). These developmental structures started with the influences closest to the child, the primary caregiver and members of the family. The family's social network and local and wider community influences followed. The socio-political landscape that governed a family's access to healthcare, education, and recreation were included (Bronfenbrenner & Ceci, 1994).

Influences from within and outside the home that play an integral part in shaping a child's development have been the focus of considerable research examination. Physical and caregiving environments such as child care, playgroup, neighbourhood, and early school settings follow on from the intimate family environment. The emotional and cognitive development of children through attachment to their primary caregiver is of exceptional significance (Ainsworth & Bell, 1970). An understanding that children are biologically programmed to form attachments extended an understanding of attachment theory beyond a set of learnt behaviours (Bowlby, 1958).

This paved the way for further research that illustrated how early attachment and care by the primary caregiving had implications for emotional health, behaviour, and capacity to build relationships (Gumley, Taylor, Schwannauer, & Macbeth, 2014). Review of attachment literature also supports the implications for children's emotional regulation and development as a result of exposure to psychosocial stresses (Malik et al., 2015).

As well as the carers or teachers who are directly involved with a child, the impact of parental work hours, and access to activities and recreational areas made available by the local council also play a part (Bronfenbrenner & Ceci, 1994). In a succinct overview of the social determinants of early child development, Maggi et al. (2010) highlighted the impact family, neighbourhood, community, and the socio-political influences have on early life-course development across cultures. For example, the effects of early biological and environmental factors on the developing brain highlighted both maternal health and fetal development as critical determinants of long-term health and development (Maggi et al., 2010) .

The impact on health and development as a result of exposure to beneficial or damaging influences over the life-course was also emphasised by Jack Shonkoff, a former president of the American Academy of Paediatrics and co-editor of the innovative and highly influential book "*From Neurones to Neighbourhoods*". This research explains how exposure to disadvantage early in life becomes biologically embedded through complex psycho-neuro-endocrine-immune pathways, resulting in physical health problems much later in life.

Furthermore, these findings supported a call for new approaches to health policy so as to incorporate the impact of exposure to adversity (Shonkoff, Boyce, & McEwen, 2009). The key role of early child development as a determinant of health was also emphasised in the lifetime work of Clyde Hertzman whose longitudinal research across Canada focused on the early influence of psychosocial factors on children's brain functions (Hertzman, 2009). This research served as a benchmark for the impact of factors such as family income, education and parenting style; neighbourhood demographic and safety; and access to quality care on early child development (Hertzman, 2009). Findings showed that children who were exposed to adversity in kindergarten were less likely to be job ready, which drew attention to opportunities for health promotion within child welfare services and inclusion of the impact of exposure

to adversity in early childhood (Hertzman, 2013). Furthermore, Hertzman (2013) believed that by immersing these findings in health promotion policy, disease prevention programmes could be improved. Collectively these findings support the notion that children's experiences shape their physical and emotional development. These findings also illustrate the impact of exposure to both physical and psychosocial adversity and life stress on early child developmental outcomes, with implications across the life-course. Attention to the impact of adversity on child developmental outcomes also calls for further examination of the physiological processes that occur in response to stress and adversity.

2.3.2 Biological embedding and allostatic load

In addition to psychosocial factors, Bronfenbrenner's reconceptualised bioecological theory also drew attention to physical factors in both the child's external and internal environments that influence developmental outcomes (Bronfenbrenner & Ceci, 1994). Further evidence from studies examining the key processes of biological embedding show how physical and psychosocial factors influence gene expression in the study of epigenetics whereby non-genetic factors such as chronic stressful events can cause genes to express themselves differently (Erickson, Creswell, Verstynen, & Gianaros, 2014). Further to this, internal stressors such as genetic and physical factors, and external stressors such as exposure to pollutants or infection also influence neuroplasticity that can impact on health and development (McEwen & Akil, 2011; Vliagoftis, 2014). Such exposure to persistent physical and psychosocial stress impacts neuroplasticity, the process by which the malleable brains of young children are modified over time with the potential to alter their DNA (McEwen & Tucker, 2011).

Examples of external physical stressors are exposure to environmental toxins and pathogenic micro-organisms; while internal physical stressors include structural and functional abnormalities; congenital malformations; or illnesses, such as diabetes and asthma. Exposure to biological, chemical, or physical toxins in the form of infections, drugs, pollutants, and radiation can occur through the placenta in utero or during lactation in early life, with implications for health and development (Sly & Flack, 2008). For example, the association between low birth weight babies and the increased risk of development of cardiovascular disease later in life has been identified by Barker, Eriksson, Forsn, and Osmond (2002). Further to this, examination of causal pathways that explain the association between birth weight and blood pressure has

been linked to smoking in pregnancy (Blake et al., 2000). Likewise, the experience of psychological distress in childhood has consequences for physiological changes. With reference to respiratory disease, the relationship between psychological stress experienced by children and physiological exacerbation of their asthma mediated through the hypothalamo-pituitary-adrenal (HPA) pathway has become better understood (Vliagoftis, 2014). Adaptation to change from internal and external environments occurs through neuroendocrine immune pathways whereby the release of the cortisol and catecholamine hormones, mediate stress responsiveness known as allostasis (McEwen, 2013). When exposure to physical and psychosocial stressors is persistent, prolonged activation of these pathways results in damaging physiological consequences known as allostatic load (McEwen, 2000).

Further evidence supports the notion that exposure to internal and external stressors in the form of toxins and pollutants, interact with psychosocial stress and interrupt allostasis, also with implications for health and wellbeing (McEwen & Gianaros, 2010). Persistent exposure to disadvantaged environments, in comparison to environments that become more advantaged over time is associated with respiratory illness such as asthma that continues through the life-course (Kozyrskyj, Kendall, Jacoby, Sly, & Zubrick, 2010). Research enquiry focusing on the mechanisms of how internal and external stressors impact disease has resulted in increasing recognition that physiological function through the life-course, particularly in relation to lung function, can be determined very early in life (Sly & Bush, 2016).

2.3.3 Vulnerable children

Children who are seriously and chronically ill are more likely than children who are not, to experience perturbations in development associated with the mechanisms of biological embedding. Children who have survived intrauterine and neonatal insults, for example, often struggle with sequelae of learning, behavioural, and socialisation problems with long-term consequences for physical, cognitive and emotional development (Mwaniki, Atieno, Lawn, & Newton, 2012). In the examination of respiratory disease in childhood, the adverse effects of intermittent or chronic hypoxia as a result of asthma, sleep disordered breathing, or a history of respiratory instability in infancy, has been linked to a significant increase in behavioural, attentional, and learning disorders in children in a systematic review of global findings from developed countries (Bass et al., 2004). Innate adaptive immune pathways have been linked to

early atopy and exposure to viral infections through inflammatory processes in the study of childhood asthma (Holt & Sly, 2011). Such examination of respiratory disease in children has shown that lung function later in life can be determined at birth (Sly & Bush, 2016).

The physiological impact of the serious or chronic illness alone has implications for learning and attention. A number of studies have drawn attention to the risk of poor developmental outcomes for children with disabilities and major health problems (Cadman et al., 1987; Wernovsky, 2006). The impact on learning and behaviour in children as a result of congenital heart disease, for example, highlighted an increased risk of behavioural, attentional, and learning problems in affected children (Marino et al., 2012). In the same way, the impact of early onset juvenile diabetes on the developing brain has long been associated with neurocognitive deficits, especially in the early years (Schwartz et al., 2014). Similarly, children with cerebral palsy often experience communication challenges, learning difficulties and reduced executive functions which can limit participation (Morgan, Novak, & Badawi, 2013; Weierink, Vermeulen, & Boyd, 2013). Living with these physical limitations can be a source of frustration, anxiety and depression for the children and their families who often feel excluded and the presence of additional impairments such as pain, sleep problems, vision and hearing loss, or seizures, can further influence neurodevelopmental outcomes (Novak, Hines, Goldsmith, & Barclay, 2012).

The understanding that children affected by chronic illness and / or disability are at increased risk of cognitive, behavioural and social adjustment problems in comparison to their healthy peers continues to drive early intervention programmes in paediatric healthcare that support improved child health and developmental outcomes (McCormick et al., 2006). Especially notable, and with continued relevance today, was the Ontario Child Health Study where the developmental outcomes of children with chronic illness and those with disability were examined and compared (Cadman, et al., 1987). Over 3,200 children were examined, where children with chronic illness and disability were found to be almost three times more at risk for mental health problems and poor social adaptation than children with a chronic illness without disability (Cadman et al., 1987). The risks of emotional and behavioural problems in these children were also increased in comparison to their healthy peers and underuse of supportive health services, and the need for more attention on accessing services was

highlighted (Cadman et al., 1987). As indicated in the introduction to this thesis, this work was instrumental in drawing more attention to the psychological and emotional outcomes of children affected by chronic illness or disability. This study has been mentioned again because it provided a platform for further global enquiry where the original epidemiological survey included within it has been more widely adapted and opportunities for early developmental intervention have been identified and pursued (Bradford & Rickwood, 2014; Sawyer & Spurrier, 1996).

The increased risk of emotional, behavioural, and learning problems in children who are seriously or chronically ill means that children who are affected require considerable support to maximise physical and emotional health and well-being. For parents' managing and responding to their children's needs can be very difficult. Initial experiences of shock, disbelief and distress, at the time of their children's diagnoses can be replaced by hypervigilance, persistent anxiety and worry about managing the demands of family life (Cousino & Hazen, 2013). In addition the special care needs for these children can be complex, problematic, and costly (Shattuck, 2008). Feelings of stress, overwhelm, and associated sadness, can further impact the capacity of primary caregivers to cope and provide the care and reassurance their children need (Coffey, 2006). This evidenced based knowledge will be synthesised in the following paragraphs.

2.4 Caring for the child who is seriously or chronically ill

When a child is seriously or chronically ill the stress and anxiety experienced by the primary caregiver and other family members can be overpowering and even bring a family to crisis point (Zebrack et al., 2014). The secondary effects of illness on parents and family relationships is well understood (Zubrick, 2000). Research findings show that having a child with cancer, for example, is associated with considerable parental stress, fatigue, and burnout (Lavelle et al., 2014). Uncertainty, stress, and anxiety can be the source of considerable emotional tension between parents when a child is seriously ill (Da Silva, Jacob, & Nascimento, 2010). In addition to family relationships, the impact on family functioning as a result of sharing the caregiving load is also well evidenced when the rhythm of family routine is lost and usual family roles and boundaries become ambiguous (Hillegas, 2012).

The parental work schedule is often interrupted and the reduced ability to continue professional responsibilities can be a source of considerable financial strain and

additional family-life stress for parents (George et al., 2008). In a geographically large country like Australia, some children and their families live long distances away from health facilities and services. Without access to regular transport the inability to access services easily can be a further source of stress resulting in poor attendance and limited healthcare follow up (Spike, Smith, & Harris, 2011). The impact of unmet practical issues such as child care, home help, and transport have been reported where financial strain and stress are more likely to be experienced; families most affected are those from rural and remote areas in comparison to metropolitan locations (White et al., 2011). Some parents of children who are seriously ill choose to forfeit considerable income to care for their sick child. Either way, financial strain related to loss of work hours or family income can impact family harmony and functioning (Johnson, et al., 2013).

The benefits of having someone to talk to, for parents of children who are seriously or chronically ill, and the value of being able to rely on family and friends for support are well evidenced (Mills et al., 2013; Tallon, Kendall, et al., 2015a). In addition to providing support for mothers of young children, having the capacity to engage with other parents and families has also been found to provide additional social capital support with benefits to mental health well-being (Coulson & Greenwood, 2012).

When a child is admitted to hospital for short or long-term care nurses, doctors and other health professionals engage with them and their caregivers. In Australia where this research is based, FCC continues to be promoted as the ideal approach for providing healthcare for children and families. While there is consensus that FCC focuses on the child in the context of family, considerable debate continues about its effectiveness (Smith et al., 2015) . As outlined in the introduction to this thesis, research findings examining FCC have been found to be limited in their design (Shields, Pratt, & Hunter, 2006), measurement of effectiveness (Shields, 2010; Shields et al., 2012), and application of relevant theoretical components (Tallon, et al., 2015b). In order to provide the healthcare context in which this study has been conducted, it is important to explain the current position of Family-Centred Care (FCC) both internationally and nationally for the reader. The following subsection will address the evidenced based knowledge pertaining to FCC in more detail.

2.4.1 Family-Centred Care and the Australian context

Involvement of families in the care of their children in hospital evolved following increased understanding of the negative psychological effects to children from being separated from their primary caregivers (Bowlby, 1958). What followed was a gradual acceptance of parental presence in hospital and ‘rooming in’ of primary caregivers with their sick children (Shields et al., 2006 Priddis & Shields, 2011). In an concept analysis of evidenced based knowledge that examined FCC, FCC was considered a concept that was only partially mature (Mikkelsen and Frederiksen 2011). FCC was also considered a way of caring for children in hospital where care was organised around the whole family with each member recognised as recipients of healthcare (Shields et al., 2006). A systematic examination of research literature indicated that there is no solid evidence for the effectiveness of FCC as no randomised control trials have been conducted; the one study of quasi-experimental design did not allow any conclusions to be drawn (Shields, 2015).

Further to this, a systematic review limited to qualitative design of 14 international studies examining FCC, found that continuation of the parent role in hospital was positively perceived (Watts et al., 2014). The same study also identified barriers to parental involvement that centred on communication difficulties and role negotiation (Watts et al., 2014). Similar barriers were further highlighted where parents felt an expectation to contribute to their children’s care in hospital while others felt they were considered by staff to be a nuisance (Uhl, Fisher, Docherty, and Brandon, 2013). Furthermore, findings showed that FCC was mostly examined from the perspective of benefits or otherwise to parents and nurses rather than from the perspective of the child (Mikkelsen & Frederiksen, 2011). For example, a study examining nurses perspectives called for more resources and education in order for nurses to provide effective FCC (Coyne et al., 2011). This was later dismissed following a further similar study showing that nurses understood and supported FCC, however, operational barriers were identified within the healthcare system (Coyne, Murphy, Costello, O’Neill, & Donnellan, 2013).

In practice FCC has been interpreted as one or other parent “living in” with their child in hospital and taking an active role in providing routine care (Tallon, Kendall, et al., 2015b). In keeping with this, some practical implications were identified in an examination of ways nurses could promote care in hospital from the family’s

perspective (Hopia, Tomlinson, Paavilainen, and Astedt-Kurki, 2005). Looking after the child, sharing the emotional burden, and building a caring relationship were thought to strengthen the understanding of how nurses could promote care of the child and family in hospital (Hopia et al., 2005). Despite the need for rigorous research examining its effectiveness, FCC continues to be the well accepted mode of care that is promoted in the Australian paediatric healthcare setting (Shields et al., 2012; Tallon, Kendall, et al., 2015b).

Through further enquiry into the care of the family in hospital Tomlinson, Peden-McAlpine, and Sherman (2012) distinguished two important perspectives of family in healthcare. Firstly, the impact of a health condition on one or more members of the family is the focus where the family are involved in care while the focus is centred on the individual and the illness (Tomlinson & Astedt-Kurki, 2008). This is in keeping with FCC which is understood as care of the child in the context of family (Bell, 2013; Mikkelsen & Frederiksen, 2011; Shields, 2010). The second perspective, which has emerged in the last two decades, considers the family as a unit on which the illness of the family member has a systemic impact requiring the whole family to be studied in order to better understand the health phenomena (Bell & Wright, 2015; Tomlinson et al., 2012). This perspective forms the basis of Family Nursing which uses a systematic approach and is supported by a growing body of evidence and knowledge and will be examined as the underpinning theoretical perspective for this study in the following section of this review of the literature.

For healthcare providers, the provision of FCC includes attention to encouraging primary caregivers to stay in hospital with their children; supporting access for additional social support; encouraging mothers to prioritise their own physical and emotional care needs; and organising practical support such as meals and transport (Coyne et al., 2011; Fawcett, 2011). Over recent years, a shift towards involving healthcare consumers in the development and review of practices relating to evidenced based healthcare provision has been encouraged. A local example of this is the National Framework for Universal Child and Family Health Services (AHMC, 2011); made possible by the intensive input from families and healthcare providers who guided the development of the framework. This Framework has been successful in securing ongoing consumer participation in a range of healthcare, social and geographical settings across Australia (Psaila, Hesson, & Schmied, 2011). In the same

way, partnering with parents in the paediatric setting has resulted in the development of standards of care that have been implemented at a government level across Australia since 2011.

Extensive public and consumer consultation, resulted in the development of ten national standards proposing evidence based improvements to deal with gaps between current and best practice outcomes across a range of health issues by the Australian Commission of Safety and Quality in Healthcare (ACSQHC, 2011). Following a period of introduction from January 2013 all hospitals and day procedure services across Australia were required to be accredited to these national standards (Boyd & Sheen, 2014). These ten national standards represent the healthcare requirements for quality service. These standards outline requirements for levels of leadership, training, and assessment of healthcare providers; building partnerships with consumers; preventing and controlling healthcare associated infection; medication safety; patient identification; procedure matching; clinical handover; administration of blood products; preventing pressure injuries; and the prevention of falls (ACSQHC, 2011).

Reference to the national standards is important because following their introduction to healthcare provision, there has been a call for more research to address National Standard Two: Partnering with Consumers, where primary caregivers, carers and families are supported to actively participate in the improvement of patient experiences and outcomes (ACSQHC, 2011). Parental participation in the development of a family psychosocial assessment framework that is central to this project will contribute to addressing this research need.

Despite a growing body of knowledge and evidence that focuses on the effects of exposure to psychosocial strain and adversity, recognising and responding to the psychosocial circumstances of children and families is not well established in routine care by healthcare providers across hospital settings (Gardner et al., 2014). In a recent systematic review examining psychosocial care, it was revealed that many patients focus on physical aspects of their health and believe that attention to psychological and social issues is not a priority (Dilworth, Higgins, Parker, Kelly, & Turner, 2014). The following sub-section evaluates literature regarding barriers to addressing psychological and social issues within the context of healthcare delivery generally.

2.5 Barriers to addressing psychological and social issues

In an examination of barriers to providing psychosocial support following trauma, asking for help when needs were identified was also highlighted as a barrier (Bradford & Rickwood, 2014). Interestingly, the difficulties perceived by healthcare providers in the review of research findings by Dilworth et al. (2014) were found to be more complex and went beyond the healthcare providers' attitudes and qualities to include organisational and cultural features. Insufficient time, a lack of resources for taking care of potential problems, and a lack of methods to evaluate patients' psychosocial health in clinical practice were perceived by doctors as barriers to discussing psychosocial factors with patients in a European cross sectional study (Fagerlind, Kettis, Glimelius, & Ring, 2013) and similarly for nurses in a systematic review of perceived barriers to psychosocial care (Dilworth, Higgins, Parker, Kelly, and Turner (2014).

Even so, in a focused narrative review that summarised research over a 40 year span, acceptability for psychosocial screening was identified as critical in screening for emotional health problems in medical practice by Mitchell, Vahabzadeh, and Magruder (2011). Furthermore, relying on clinicians' unassisted judgements without infrastructure was identified as problematic as was the use of overly complex scales with low acceptability that should be avoided (Mitchell et al., 2011). Further to this, in a descriptive cross-sectional study of 623 nurses from the United Kingdom, a lack of time and resources were also identified as barriers to providing optimal psychosocial care in an oncology setting (Gosselin, Crane-Okada, Irwin, Tringali, & Wenzel, 2011). In the same study, over 80 per cent of participating nurses perceived that patients had a mindset that psychosocial issues were not as important as medical care, and that patients experienced stigma and did not want to address psychosocial issues (Gosselin et al., 2011). Interestingly, the same study also identified that participating nurses were divided on who was responsible for providing psychosocial care. Thirty-five per cent reported their belief that this was the responsibility of the nurse, while thirty-three per cent allocated this responsibility to social workers. For the remainder, responsibility was spread across others disciplines including physicians, pastoral care teams, and behavioural healthcare professionals (Gosselin et al., 2011).

Similar reservations were identified as a lack of confidence and skills in a study of qualitative design that used focus groups and observation records to examine the

perceptions of 53 district nurses along with one-on-one interviews with ten patients and their carers (Griffiths, Ewing, & Rogers, 2010). Thematic analysis showed that most information was shared by 'chatting' where nurses indirectly assessed the needs of their patients, however, avoidance and blocking strategies were also identified and expressed by nurses as 'moving swiftly on' when their patients' became distressed (Griffiths et al., 2010).

A deeper understanding was sought in a phenomenological nursing study that examined how 19 nurses in a palliative care setting experienced their patients' mortalities. While nurses felt 'in tune' with their patients' emotional feelings of hopelessness, they also felt a conflict between this and being part of the medically focused culture where emphasis continued to be placed on treatment (Leung et al., 2012). While end of life is not the focus of this review of the literature, reference to this study is relevant because it illustrates the complexity associated with skilfully responding to the emotional and social needs of patients in a healthcare setting that is orientated primarily towards the physical disease or health concern.

Among children and families, difficulties were identified in the process of referral and management of psychosocial issues in a large international sample of Child Behaviour Data across the US, Canada, and Puerto Rico where only 61 per cent of the 650 families in need of psychosocial support were referred for specialist support (Rushton, Bruckman, & Kelleher, 2002). Interestingly, the referrals made were for behavioural problems, poor academic performance, and mental health symptoms of the child, whereas family-life stress or a lack of emotional or social resources, were not included. Furthermore, the study showed that the issues given attention were those that were clinically relevant to the child not the family (Rushton et al., 2002). This perspective was also seen in a cross-sectional analysis of 832 practising physicians from the American Academy of Pediatrics, where the psychosocial issues identified were perceived to be behavioural problems and somatic symptoms of anxiety or depression in the child. Again, consideration was not given to other sources of psychosocial stress and strain such as family life stress or hardship. In the same study, barriers to the identification and management of psychosocial issues in children with depressed mothers were identified by the physicians as a lack of time, resources and skills (Horwitz et al., 2007).

Conversely, in a palliative care setting psychosocial issues and support were found to be more focused on the family. Here, in an integrative synthesis of 72 articles, a growth and diversity in research about psychosocial paediatric care in paediatric cancer, albeit limited to western settings, was identified. Also a lack of attention to siblings and grandparents perspectives was noted along with an absence of the children's voices. Findings suggested marginalisation in a hierarchical system or an assumed incapacity to provide meaningful insight (Weaver et al., 2016).

The literature presented in this sub-section reflects an approach to healthcare that is reductionist and dominated by attention to physical, rather than psychological and social, health outcomes and physical causal pathways to disease. The remainder of this review will focus on a systems approach to the provision of healthcare that focuses on people and their families rather than the diagnosis and treatment of specific conditions. This approach has largely been championed by the nursing profession.

2.6 A systems approach to the provision of healthcare

There is a great deal of evidence that supports the benefits of applying a range of theoretical frameworks to healthcare practice. Knowledge and understanding of the bioecological model of human development, biological embedding, the family and community resource framework, and partnership building sits well in the context of FCC (Tallon, Kendall, & Snider, 2015b). Knafl et al. (2011) identified that interest in family life in the context of childhood disease requires attention from the social, health, and family sciences where the diversity of research interests contribute to understanding how families respond to, and function in illness. It is widely accepted that review of a range of interdisciplinary research is a necessary underpinning to theoretical, research and intervention enquiry (Ganong, 2011). The many levels within the health system in Western countries include the individual patient and family, the organisation, the infrastructure that supports the healthcare teams, and the socio-political environment. These levels demand evidence from a range of contexts in order to support improved healthcare delivery and outcomes (Ferlie & Shortell, 2001).

Research has shown that systems theory knowledge and understanding provides an ideal foundation on which to identify the issues that are of concern to patients and families through therapeutic communication (Tomlinson, Peden-McAlpine, & Sherman, 2012a). For example, the use of structural counselling is used as a strategy

to identify concerns and motivate family engagement in health follow up for disadvantaged individuals where rates of adherence to follow up were low for treatment of a major health problem (Hui et al., 2014). Similarly, nurse driven programmes have achieved improved health and developmental outcomes by supporting psychosocial circumstances in vulnerable young families in the UK (Guest et al., 2013; Munday & Love, 2010; Smyth & Anderson, 2014), Australia (Fowler et al., 2012; Guest et al., 2013), and across Europe and the US (Glavin & Schaffer, 2014). Collectively these findings support the notion that bringing a strength-based approach to relationship building aids the establishment of a trusting conversation environment where psychosocial concerns and stresses can be discussed (Nieto & Day, 2009).

A growing body of research evidence supports the benefits of applying a FSN approach. In particular the work of Friedman (1989), Knafl (1996), Deatrck and Knafl (2003), Wright & Leahey (1990), and Bell & Wright (2015), all set a rich base on which to examine evidenced based findings that focus on the impact of applying a FSN approach to practice. A systematic review of the FSN literature has also shown that FSN interventions implemented in studies internationally, across the lifespan, have resulted in improved understanding, emotional well-being, and improved behavioural responses in patients and families living with chronic illness (Östlund & Persson, 2014). Further to this, emphasis on the incorporation of illness into an individual and family's daily lives rather than centring on the disease itself, is highlighted in an overview proposed by Friedman and Andrews (1990), where the conceptualisation of systems theory research informed by years of clinical practice is acknowledged.

2.7 Family Systems Nursing

FSN provides an ideal theoretical context in which to examine evidence based findings that focus on the holistic healthcare of the family. Firstly, FSN provides a wide theoretical base that invites personal choice and fluidity to draw on relevant theory (Wright, 2015). Secondly, the theoretical concepts outlined in the previous background section sit well within FSN as an overarching context where the interplay between the child and family is all-encompassing. This is because the family is viewed as a system that is therefore inclusive of both the individual and the family unit (Wright & Leahey, 1990). Thirdly, FSN integrates cybernetic theory which has its base in the science of communication and control (Wright & Leahey, 1990; Jenkins, 1985). Its application requires reflective practice, questioning, developing new ideas and turning these back

towards practice (Mason & Chandley, 1992). Bell (2009), in a re-examination of FSN, reinforced the relevance of considering cybernetics in a FSN approach so that interaction and exchange of information could be reciprocal and circular rather than simply linear. This too is in keeping with the communication skills of genuine enquiry, reflective listening and strength based approach that are also promoted in the family advisor model of partnership building in paediatric practice (Davis, Day, & Bidmead, 2002). This reflective approach to interacting with families is also supported in empowerment theory where partnerships are built using non-judgemental, non-hierarchical, and respectful sensitive enquiry based on trust and genuineness (Freire, 1999; Glavin & Schaffer, 2014; Olds et al., 2013).

In the following sub-sections the various FSN models of care are compared and contrasted. Examples of how FSN models have been applied in practice are then presented and critically reviewed. Finally, relevant models of care that are specific to children and their families are then examined in some detail.

2.7.1 Models of care

The development and application of FSN models of assessment and care have emerged from the theoretical foundation of FSN. In centres where these models have been adapted and applied, FSN education has been undertaken during clinical practice and the models applied to the assessment of patients and families in practice (Duhamel, Dupuis, Turcotte, Martinez, & Goudreau, 2015). The Calgary Family Assessment Model (CFAM) and Calgary Family Intervention Model (CFIM) (Wright & Leahey, 1994) and Illness Belief Model (IBM) (Bell & Wright, 2015) are examples of such models. These models were developed from concerns raised in practice between addressing family needs while caring for individuals (Bell, 2009).

The CFAM and CFIM were both developed by Wright and Leahey (1994) at the Family Nursing Unit, University of Calgary, Canada, where the Centre for FSN research and practice continues to be situated. A systems perspective where the family is considered as a sub-system within a larger community system is applied. Further to this, the interaction between family members are identified as subsystems within the family and community context (Wright & Leahey, 1994). In a review of FSN interventions, Duhamel and Talbot (2004) noted that the application of the CFAM provided a way to collect data about family structure and dynamics as well as theoretical data for research,

while the CFIM focused on *how* the nurse supported family members to develop their own solutions using a strength-based approach. By using the CFIM in practice exploratory questions could be asked about the family in order to assess and family health and identify any need to refer appropriately to services (Wright & Leahey, 1994). While other studies examined ways to assess the distress of patients or family members that often resulted in the development of interventions to improve understanding such as education sessions or psychological support, these remained individually rather than family focused (Duhamel and Talbot, 2004).

Importantly, the adaptation of the CFAM and CFIMs to a wide range of healthcare settings across Canada, the US, Europe, and Asia, has contributed to an emerging body of evidence for the practice of FSN (Östlund & Persson, 2014). Concurrently, the IBM, also based on FSN, was developed and published by Wright, Watson, and Bell (1996). This model is operationalised within a therapeutic conversation, but differs from the CFAM and CFIM Family Models in that it focuses on the illness beliefs of the family and the societal cultural context that can either negatively impact or improve the illness experience (Wright et al., 1996). In a review of the IBM, Feetham (1997) commended its evolution from the synthesis of nearly two decades of clinical practice based on a biopsychosocial-spiritual perspective that examined family members' beliefs about illness to facilitate more positive adaptation. At the time, Feetham (1997), also commented that the IBM was supported by practical examples which made it ideal for the clinician. On the other hand it also called for more attention to the hermeneutic approach that supported it (Feetham, 1997). Further to this the IBM has been adapted, more often for the advanced practice nurse, to a wide range of healthcare settings and circumstances within Canada, the US, Europe and Asia. In a reflection of 25 years of implementation Bell and Wright (2015) highlighted the FSN context in which the IBM is nested and suggested that nurses who brought a systems approach to practice offered the greatest possibility for health and healing (Wright, 2015). Reference to these models are relevant in the context of this research because they guide skilled evidenced based family assessment while providing a means to examine and measure care given to families in practice.

2.7.2 Models of care applied in practice

FSN models of care first developed in Canada have been applied across a range of healthcare settings internationally (Bell, 2009; Sveinbjarnardottir Svavarsdottir &

Wright., 2012; Duhamel, 2010). Application of the FSN models such as the CFAM and Intervention Models and Illness Beliefs Model (IBM), have consistently resulted in improved satisfaction, control, and adaptation among patients and families with a range of health conditions (Sveinbjarnardottir, Svavarsdottir, & Wright, 2012; Årestedt, Benzein & Persson, 2015; Mattila, Leino, Paavilainen, & Astedt-Kurki, 2009). Review findings showed the positive effects of family interventions were statistically significant for family burden where family care interventions were implemented in addition to standard compared to standard care only (Chesla, 2010). Collective examination included over 4,030 patients suggested the possibility that patients with chronic illness who received family psychosocial care could live longer than those who received the usual medical care (Chesla, 2010).

One distinction embedded in the implementation of these models guides nurses to assess the interaction between all the family members rather than assess the family through the concerns of one family member (Wright & Leahey, 1990). This way family members can gain further appreciation for the impact of the illness on the family unit as well as identify the strengths of family members within it (Wright & Leahey, 2012). Improved levels of family cognitive and emotional support have been identified following application of the CFAM and CFIM across the US and Iceland (Sveinbjarnardottir, Svavarsdottir, & Wright, 2012). In Sweden using the IBM interactions were found to be a “struggle” with healthcare providers where patients and families felt they healthcare staff were reluctant to talk when they wanted information (Årestedt, Benzein & Persson, 2015). Examination using the IBM, also illustrated that while families have their beliefs about encounters with healthcare providers, healthcare providers beliefs could also impact their relationships together (Bell, 2009).

For healthcare providers who undertook education in FSN and implemented FSN models of care the benefits of improved self-esteem and job satisfaction have been reported (Duhamel, 2010). In Canada, analysis of data before and after FSN education found that family-nurse relationships were enhanced where better attention to psychological and emotional support were reported by families while nurses focused more on their communication skills and experienced improved self-esteem (Legrow & Rossen, 2005).

Increased confidence and self-esteem have also been reported among healthcare providers with more years of experience (Desborough, Forrest, & Parker, 2012). Measurement of nurses attitudes about engaging with families conducted in Europe,

showed increased rates of openness and confidence related to interacting with families in hospital among nurses with more years of experience in practice (Benzein, Johansson, Årestedt, Berg, & Saveman, 2008). In keeping with this, nurses with the least years of experience were found to share less supportive attitudes and found communication with families to be more burdensome (Blöndal et al., 2014). However, less is understood about how nurses overcome organisational and cultural processes where constraints related to workload demands or cultural concerns such as pride and privacy related to talking about personal issues have been reported to hinder healthcare providers to talk with families about psychosocial issues (Simpson & Wah, 2006).

Despite this, application of the FSN models of care can be examined comprehensively using robust research methodologies providing an ideal platform to generate research findings about the effectiveness of family nursing care. Examination of the effectiveness of the applications of the CFAM and CFIM for example, have been found to be well suited to random controlled trials and analysis of data collected before and after implementation (Sveinbjarnardottir et al., 2012; Lee, Leung, Chan & Chung, 2010). In the same way application of a narrative design and hermeneutics have been found to effectively highlight the experiential impact of the IBM on patients and families following its application to practice with patients and families (Bell & Wright, 2015).

FSN models of care have been identified with advanced practice nursing having emerged from Scholarship of Practice with Families, based on 25 years of research and practice, that continues to offer clinical scholarship and Family Nursing Externships based on FSN models of care in Canada, the US, Denmark, Iceland, and Switzerland (Bell & Wright, 2015). Differentiation between Family Nursing and FSN has also supported advance practice where Family Nursing is conceptualised as care of the individual with family as context, while FSN focuses interactions within the family in the face of the individual's illness (Wright & Leahey, 1990).

The need to emphasise family nursing in practice more generally was identified when a lack of Family Nursing knowledge to practice was noted in Canada which motivated examination of knowledge translation to practice over 20 years (Duhamel, 2010).. Prioritising Family Nursing in nursing curricula and having the support of nursing administrators in clinical settings were identified as essential for transfer of knowledge to practice more widely, while it was acknowledged that developing strategies to bring

authors, educators, practitioners, and families in a partnership relationship were also necessary for improved family nursing outcomes (Duhamel, 2010).

While the benefits of applying FSN models of care are supported by research findings these largely come from first world countries, where the benefits of applying FSN models of care in more disadvantaged countries is less understood (Chesla, 2010; Sveinbjarnardottir et al., 2012). While FSN models of care have been applied mostly among the adult population models of care that focus on family functioning specific to children and their families have been developed and tested. These will be presented in the following sub-section.

2.7.3 Models of care specific to children

Attention to the relationships between family functioning and childhood disease have also been a focus of research in Family Nursing and in particular how family functioning is impacted when a child is seriously or chronically ill. The Family Management Measure (FaMM) by Knafl and colleagues (2011), was developed as a measure to assess family coping in the face of childhood chronic disease. The FaMM used a non-disease specific approach for assessment of family functioning and was therefore not developed in response to any particular pathophysiological condition, unlike a number of measures of psychosocial functioning which are outlined later in this review (Kazak, 2006; Pai et al., 2014; Pai et al., 2012). The FaMM is relevant to this review of the literature because it focuses on key aspects of family functioning in the context of childhood disease and illness.

Knafl and co-authors (2011) maintained that because the focus was on how families understood and responded to childhood illness, it was more focused than the Double ABCX Model by McCubbin and Patterson (1983), or the Resiliency Model of Family Stress Adjustment and Adaptation by McCubbin (1997). Furthermore, the FaMM outlined briefly in the introduction to this thesis, focused on patterns and processes that can impact families. With this in mind, the FaMM is outlined in more detail in the following paragraphs in relation to its development, validity, application, and benefits to children who are chronically ill and their families.

2.7.3.1 The Family Management Measure

The FaMM emerged from a framework named the Family Management Style Framework (FMSF) following examination of qualitative research and conceptual

reviews in Family Nursing and family research (Knafl, Deatrick, & Gallo, 2008). This research described the impact of disease on family life as a result of the ways that illness was defined, responded to, and managed by the family within their sociocultural context (Knafl, Breitmayer, Gallo, & Zoeller, 1996). Perceived vulnerabilities of the family; the child's health condition; aspects of family life in terms of the balance between illness and normal family life; future expectations; cultural beliefs about the illness; and their perspectives about managing the condition were identified as domains of the FMSF.

Earlier research influenced development of the FaMM, where normalised or disassociated patterns of family response were identified. Analysis of qualitative research data, provided more specific response categories in families that underpinned the FaMM as thriving, accommodating, enduring, struggling, or floundering (Knafl et al., 1996). In a review of 55 articles that focused on family responses to illness key cognitive and behavioural aspects in addition to the definition of the illness, family behaviours, and consequences to the family were identified that served to pinpoint areas of family strength as well as difficulty (Deatrick & Knafl, 2003). Similarly this strength based approach was central to FSN (Wright & Leahey, 1990).

Improved health and developmental outcomes as a result of identifying and accommodating aspects of family strength and / or strain are well evidenced (Kendall & Li, 2005; Maggi, 2005). Similarly, further longitudinal follow up of the FMSF found that children in families with a "thriving" management for instance, demonstrated higher social competence using a validated measure in a population sample by Foley, Barakat, Herman-Liu, Radcliffe, and Molloy (2000), in comparison to families with the "Enduring", "Struggling" or "Floundering" groups identified in a study by Knafl and Ayres (1996).

Development of the FaMM was further supported by research evidence for the mediating impact that family variables such as family cohesion, or alternatively conflict or chaos, had on child health and developmental outcomes (Brotheridge & Lee, 2006; Novick, Sadler, Knafl, Groce, & Kennedy, 2012). The merits of taking a general rather than disease-specific approach were also supported in the development of the FaMM when Knafl et al. (2011) pointed out that most non-categorical studies focused on the range of issues that impact family functioning in response to childhood

illness making the FaMM applicable to a range of conditions, families, and age groups of children.

2.7.3.2 Psychometric properties of the Family Management Measure

The psychometric properties of the FaMM was conducted to examine if the measure performed in a theoretical meaningful way (Knafl et al., 2011). Ninety seven items were identified for possible inclusion in the FaMM, each representing an aspect of one of the eight domains within the FMSF on which it was based. The relevance of each of the item was assessed by experts in Family Nursing research and parents of young people with chronic illness aged between three and twenty years (Knafl et al., 2011). Further to this, correlations with established validated measures of child and family functioning were conducted.

Overall acceptability was assessed using Cronbach's alpha coefficients and Pearson correlations to assess relationships between the FaMM and the validated measures. Acceptable internal consistency was demonstrated ranging from Cronbach alpha of .71 to .94 while correlations of limited strength provided evidence that the FaMM measured some aspects of family responses that were unique to family functioning in childhood illness in comparison to family functioning more generally (Knafl et al., 2011). The fifty three items that remained in the FaMM were found to be important patterns of family response that were either family focused or condition focused.

Further to this, the relationships between the identified patterns of family management and various family challenges were examined in a cluster analysis of 575 parents from 414 families of children who had a range of chronic conditions (Knafl et al., 2013). Post hoc analysis showed that parents who had a family focused pattern of response demonstrated significantly better family and child functioning than those who were condition focused with a *p* value of 0.05. Furthermore, parents who reported some psychosocial disadvantage were more strongly represented in the condition focused groups (Knafl et al., 2013).

Similarly, the relationships between psychosocial risk in parents and early developmental outcomes for their children were identified. For example, in a Canadian study of 382 families of well children, risk factors identified as negative parenting behaviours, parental depression, limited English, multiple moves, and those living with more than three children at home, were associated increased risk of delayed

behavioural and cognitive development (Glascoe & Leew, 2010). The impact of psychosocial issues on child health and developmental outcomes in childhood chronic illness was further emphasised in a US study where linear associations were identified between coping strategies of parents, their parenting style, dyadic relationships, and their management and adherence with their child's self-care, learning at school, and increased risk of clinical complications (Cammarata et al., 2009).

2.7.3.3 Application of the FaMM to practice: attention to family psychosocial issues

Application of the FaMM to practice in the context of chronic childhood disease has also been the focus of research that has supported its applicability across a range of chronic childhood conditions as well as cultural and geographical settings (Hutton, Munt, Aylmer, & Deatrck, 2012; Kim & Im, 2013; Novick et al., 2011). In the US where the FaMM was developed, research findings supported its application to assess how families were managing in a range of childhood illnesses including childhood genetic disorders, brain cancer, and Type 1 Diabetes (Gallo, Angst, & Knafl, 2009; Swallow et al., 2012). Research showed that attention to family functioning using the FaMM was found to have applicability in supporting families of children with chronic illness in Korea (Kim & Im, 2013). Here, aspects of the FaMM showed reasonable internal consistency with Cronbach's alpha from .69 to .89 whereby despite cultural differences, the 341 participating mothers interpreted aspects of self-efficacy, burden, stress and relationship harmony similarly (Kim & Im, 2013). This finding was mirrored in an Australian pilot study that examined use of the FaMM in the healthcare of children with cystic fibrosis, asthma and heart disease and their families (Hutton et al., 2012). In this study Hutton et al. (2012) found the FaMM had both relevance and conceptual equivalence whereby identified themes related to family management of children with chronic illness that supported the background review of literature for the study were similar to those identified in the USA. As with Kim and Im (2013) the participating mothers in the Australian study were found to interpret the items on the FaMM similarly (Hutton et al., 2012). The pilot sample was limited to six participants, where the scales generated detailed and varying accounts of family functioning. Further exploration into the emotional and social factors that affect families of children who are chronically ill is necessary in order to draw more convincing conclusions (Hutton et al., 2012).

The main focus of the FaMM is on family management and adaptation. For instance, the impact on family cohesion and functioning as a result of relationship conflict and a lack of social support was identified in a further study by Novick, Sadler, Knafl, Groce, and Kennedy (2012) that examined the healthcare of disadvantaged prenatal mothers using the FaMM (Novick, Sadler, Knafl, Groce, & Kennedy, 2012). Further to this, the issue of self-confidence was highlighted when parents reported that going home with their child who was diagnosed with Diabetes Type I was particularly confronting. In the same study, the value of having someone to talk to for support who understood the practicalities of what worked well or otherwise in relation to managing their children's special care needs was emphasised (Rearick, Sullivan-Bolyai, Bova, & Knafl, 2011). Also in this study, the FaMM was considered to be a reasonable measure of family management with Cronbach's alpha of .80 (Rearick et al., 2011).

Supporting the family to manage well is important because regardless of underlying psychosocial stress, families are required to understand specific health information and treatments that can be varied and complex. How the knowledge needs of families of children who are chronically ill are met is often a concern for healthcare providers in the paediatric setting (Tallon, Kendall, et al., 2015a). Parental capacity building has been emphasised in a UK published comparative research protocol where the positive impact of support and reassurance using an online resource for parents of children with kidney disease based on the FaMM was anticipated (Swallow et al., 2012). The importance of building confidence in parents of children with chronic illness was also highlighted in a systematic review where difficulties were identified by healthcare providers in assessing the learning needs of parents. Concern that healthcare providers misjudged or underestimated parental knowledge and confidence was emphasised and a need to carefully assess the needs of parents highlighted (Nightingale, Friedl, & Swallow, 2015).

Using a FSN approach, the application of interventional models that support a strength based relationship with the family have been found to be beneficial (Deatrick et al., 2014; Knafl, Leeman, Havill, Crandell, & Sandelowski, 2015; Leslye King, 2002; Moules, Bell, Paton, & Morck, 2012). Research findings in this sub-section support the benefits of FSN to guide and support healthcare providers to pay attention to the issues that are central to the family (Wright & Leahey, 2012). The benefits of applying

models of care such as The CFAM, the CFIM, the IBM, and the FaMM, as supportive interventions that are based on the theoretical components of FSN have been outlined. The research presented in these sub-sections has illustrated the growing body of research knowledge and evidence in family nursing that support improved health outcomes for individuals and families. The theoretical concepts and research findings came largely from FSN where practice, research, and education focus attention on the care of the whole family in healthcare (Wright & Leahey, 1990). This evidenced based knowledge supports the shift from a more traditional biomedical emphasis on the care of the individual in the context of their health condition to the care of the individual and family in the context of each other and their circumstances (Knafl, Breitmayer, Gallo, & Zoeller, 1996; Wright & Leahey, 2012). With FSN as a backdrop, the following sub-section continues with an examination of published literature related to theory, research, and practice that relates to psychosocial assessment more generally.

2.8 Psychosocial assessment in healthcare

In this sub-section, published literature about psychosocial assessment in the healthcare setting is examined. Historic perspectives and research findings with attention to the attitudes of primary caregivers and healthcare providers to psychosocial assessment and care are analysed.

Research findings pertaining to relevant theory development are then presented. More specifically research findings relating to Stress Model Theory and Adaptive Calibration Model of Stress are discussed and synthesised. To follow, available screening strategies and instruments developed specifically for conducting psychosocial assessment and providing psychosocial care are identified and synthesised. The psychometric components of the identified psychosocial screening instruments are critically analysed with attention to reliability, validity and impact on individual or family health outcomes. Finally, with an understanding of available evidence focusing on psychosocial assessment, attention is focused more specifically on the implications for psychosocial assessment for children who are seriously or chronically ill and their families in the hospital setting.

2.8.1 The evolution of approaches to psychosocial assessment

Despite acknowledgement of the complexity associated with providing psychosocial care across in healthcare, an understanding that it is important to individuals and

families is well recognised (Drake, 2008). In an integrative review of the literature focusing on the history of psychosocial screening, attention to psychosocial welfare was found to evolve from triage principles that used throughout the history of physical and mental healthcare based on the ability to survive (Zabora and MacMurray, 2012). Use of a standard questionnaire, for example, identified potential soldiers who might not be able to cope on the battlefield during the First World War (Iserson & Moskop, 2007). Similar triage systems based on survival continue to be employed in major medical or disaster circumstances today (Murray, 2012). In relation to healthcare, early findings from Weisman, Worden and Sobel (1980) in the area of cancer care, showed that patients who were considered to have lower levels of resiliency, drew attention to the levels of emotional distress experienced by individuals who were seriously ill.

Tension between behavioural and cognitive psychological perspectives at the time motivated a further enquiry (Zabora & MacMurray, 2012). While behaviourists held the view that human responses were motivated by previous learnt experiences such as that supported by operant conditioning, a theory developed by Skinner (1988), emotionally focused psychologists saw this differently. Lazarus (1990), for example, argued that how an individual assessed a situation guided how stressed they felt about it, or otherwise. The Stress Model Theory developed by Lazarus (1990) supported an understanding that internal resources such as skills in mastery and self-efficacy, aided a more positive approach to illness, while external resources such as social support could assist patients' to explore strategies to cope. This theoretical perspective served as a foundation for further research and the development of psychosocial screening practices (Lazarus, 1991). Reference to Stress Model Theory remains relevant because it considers the variation in emotional responses and the impact these responses have on stressful experiences, rather than focusing solely on the stressful event itself (Zabora & MacMurray, 2012). As a result the psychosocial and physical benefits of emotionally focused interventions in promoting improved quality of life and self-management in chronic illness, were becoming better understood (Auduly, Asplund, & Norbergh, 2012).

So too, were variations in responsivity to stress. Continued research and development of theoretical knowledge about adapting to and responding to stress have furthered understanding about how exposure to stress can impact on the health and development of individuals and families at various stages through the life-course (McEwen &

Gianaros, 2010). Research findings in the neurosciences continue to explain the brain's response to stress that extends beyond muscular responses to include the brain's function in excreting hormones (Coen, 2015).

The Adaptive Calibration Model of Stress Responsivity (Del Giudice, Ellis, and Shirtcliff, 2011), integrated empirical findings from a range of disciplines into a theoretical format that accommodated for fundamental differences in adaptation to stress such as gender, or an individual life experience, or their stage of development through life (Del Giudice et al., 2011). Within this model, the activation of stress hormones were found to be “filtered” or “amplified”, depending on relational and environmental factors such as a perceived threat, the quality of caregiving, and an individual's developmental stage. Environmental and genetic factors that influence adaptation to stress are also considered within the Adaptive Calibration Model of Stress Responsivity including an individual's development and learning, attachment and caregiving, maturation, and behaviours related to risk-taking (Del Giudice et al., 2011). Previous research knowledge is also incorporated within the model to support differences in responsivity to stress. For example, gender differences in stress responsiveness were examined by Taylor, (2012) whereby females were more likely to attend to caregiving activities and engage the support of others in comparison to males where their fight or flight response was found to be more primal. These gender differences were further supported in a more recent Australian study that examined relevant literature by (Lee & Harley, 2012), where an association was made between a gene located in the ‘Y’ chromosome that directs male development and more traditional male traits in response to stress. Research that examines the psychological and biological differences in the way females and males respond to stress has given insight to healthcare providers into how health and wellbeing is impacted by stress in relation to gender (Verma, Balhara, & Gupta, 2011).

Self-efficacy theory, proposed by Bandura in 1977, and grounded in social cognitive theory supported the notion that individuals had the capacity to exert some control over their circumstances (Bandura, 2001). In a more recent paper examining mediators for self-efficacy, further examination of the influence of physical, social, and self-evaluative motivators on an individual's confidence and capacity to exert control, further reinforced its place within social cognitive theory (Bandura, 2012). An emphasis on self-efficacy theory also sits well within Stress Model Theory outlined in

the previous subsection, where an individual's internal resources such as mastery and external resources such as access to support are well emphasised (Lazarus, 1990). Research findings from healthcare also support the notion that individuals who are more confident in general have more self-efficacy in managing their illness (Rapley, 2001). Furthermore, self-efficacy has been found to support psychosocial adjustment in serious illness more specifically in cancer care (Curtis, Groarke, & Sullivan, 2014). Traditionally, psychosocial services were only implemented on a referral basis and often only after a person had reached crisis point (Zabora & MacMurray, 2012). This approach often rendered an individual more powerless and potentially stigmatised about being viewed negatively for feeling unable to cope (Livneh & Antonak, 2005). While attention to psychosocial issues was growing in healthcare settings in Western countries, this continued to be more evident in cancer care, especially in the US (Zabora & MacMurray, 2012). An example was seen with the establishment of distress management guidelines by the US National Comprehensive Cancer Network (NCCN) in 1997 made up of a panel of experts from psychiatry, social work, psychology, nursing, and chaplaincy. These guidelines continue to be utilised internationally and are updated regularly to promote more attention to the qualities, skills, and circumstances, of patients and family (National & Medical Research, 2005). Furthermore, psychological and social influences gained greater prominence when attention to the "whole" patient was promoted by Holland and Weiss (2008) in a published report by the US Institute of Medicine that included the need for psychosocial support in their definition of holistic care.

This theoretical information is both pertinent and motivating because it provides evidence to support healthcare providers' provision of psychosocial care by informing ways that biological, psychological, and environmental factors can initiate a range of responses to stresses that many families in their care may experience. In order to better understand processes that identify and respond to psychosocial stresses and strain in healthcare, the early development of psychosocial screening interventions will be considered in the following paragraphs.

2.8.2 Psychosocial screening

A variety of early quantifiable measures were developed and tested to identify psychosocial distress particularly in clinical specialty settings mainly in the area of

cancer care (Weisman, 1979; Zabora & MacMurray, 2012). Published literature shows that early psychosocial screening in healthcare was driven mainly by medical oncologists responding to the increasing need to engage psychologists to assist their patients to cope with cancer (Sobel & Worden, 1979). This coincided with a growing understanding in behavioural psychology at the time for attention beyond psychiatric concerns and more recognition for the need to address the emotional and practical stresses associated with adaptation and coping (Monat, Averill, & Lazarus, 1972). At the time, debate between medical doctors, scientists, and behavioural psychologists about the integration of sciences and need for research was recognised. This was illustrated in records of proceedings from a Yale conference in 1977 where interdisciplinary discussion between invited medical and behavioural health specialists resulted in a proposed agreement to broaden the definition of behavioural medicine to that of behavioural science (Schwartz, 1977).

More attention to psychosocial screening followed whereby instruments already validated for assessment of psychiatric conditions were implemented to predict psychosocial adaptation to disease. In a study of 133 newly diagnosed cancer patients, Sobel and Worden (1979) administered and tested the Minnesota Multiphasic Personality Inventory (MMPI), which is still extensively used in psychiatry and psychology, as a predictor of psychosocial stress by assessing personality function. Rather than assessing its predictability for psychosomatic symptoms, application of the MMPI in this study was to differentiate between those who coped well or poorly during follow up cancer care (Sobel & Worden, 1979). While these findings showed potential utility in detecting psychosocial stress it was found to be limited in relation to psychosocial assessment. The MMPI continues to be a comprehensive lengthy psychological test containing a range of psychometric properties to measure mood disturbance (McNair, 1971), vulnerability (Weisman & Worden, 1976), with an inventory of current concerns, validated by Tinsley and Weiss (1975). Application of the MMPI was found to be additionally limited because it required administration and interpretation by a psychologist (Peek, 2011). In a further review of psychological approaches for enhancing coping among cancer patients, Telch and Telch (1985) concluded that focusing on self-efficacy theory was likely to be more useful in developing more effective psychosocial screening strategies.

Psychosocial screening instruments developed and used in the care of chronic or serious illness varied in their psychometric properties, however, all those identified for discussion targeted both psychological and social aspects related to coping and adaptation. While screening interventions have examined a range of psychosocial issues, this was undertaken mostly by targeting individuals affected by a specific disease or condition (Bogaarts et al., 2014; Braeken, Lechner, et al., 2013; Grassi et al., 2014; Hoekstra-Weebers, Coyne, & Van de Wiel, 2012; Lee Chen, Hsing-Hsia; Yeh, Li, & Chou, 2013; Ryan, Gallagher, Wright, & Cassidy, 2012). Interventions that have been written-up and published in the academic literature are described and critiqued in the following section.

The Dutch Screening Inventory of Psychological Problems (SIPP), for example, was developed recently specifically targeting patients with cancer. This instrument contained 24 items that measured physical, psychological, social or financial, and sexual problems, where respondents indicated “yes” “sometimes” or “no” (Braeken, Lechner, et al., 2013, p. 291). A cluster randomised controlled trial followed and showed reasonable internal consistency for physical issues (Cronbach’s alpha, 0.76), and psychological issues (Cronbach’s alpha, 0.89), but less so for social aspects (Cronbach’s alpha, 0.56) and sexual issues (Cronbach’s alpha, 0.51) (Braeken, Kempen, et al., 2013). While it was efficient to use, reportedly taking just three minutes to complete, it was administered by radiotherapists only, who solely decided referral options based on the scores and their judgement. Perhaps not surprisingly, further evaluative results suggested that use of psychosocial screening in this way did not in itself improve patient health related outcomes (Braeken, Lechner, et al., 2013).

In a less limited cross-sectional study, a breast cancer scale for newly diagnosed women developed in Taiwan, was found to have overall acceptable reliability and validity (Cronbach’s alpha, 0.84). The psychometric properties within it focused on physical and psychological issues rather than social aspects. However, despite this, three main social aspects were identified among the 138 participating women as patient worries about the progression of the disease, worries about their families, and worries about the impact of their diagnosis on their work and their lives (Lee Chen et al., 2013).

In a study from The Netherlands also targeting breast cancer the psychometric properties of the Psychosocial Distress Questionnaire-Breast Cancer (PDQ-BC) in a sample of 164 women was examined (Bogaarts, et al., 2014). The PDQ-BC consisted

of 35 questions that assessed psychological, physical, social, and sexual concerns as well as clinical symptoms and were found to be time efficient. The Cronbach alphas for these subscales ranged from 0.69 to 0.88 except for social issues which had limited internal consistency with Cronbach alpha of 0.44 supporting further examination of its effectiveness (Bogaarts et al., 2014).

A wide range of psychosocial variables that make individuals more vulnerable were considered important in a review of psychosocial screening and assessment interventions (Grassi et al (2014). Here emphasis was placed on life events, exposure to persistent stress, a sense of well-being and individuals' health attitudes (Grassi et al., 2014). Interestingly, in this review the application of specific screening instruments in particular the Distress Thermometer (DT), that measured levels of distress in physical, emotional, spiritual, and practical domains, was highlighted. In an international study where the validated DT was used in combination with the Dutch Screening Inventory of Psychological Problems (SIPP) the emotional impact of everyday life issues among 302 participants with cancer across the Netherlands and the USA was highlighted (Hoekstra-Weebers et al., 2012). Another study examined the sensitivity and specificity of the DT in combination with the Patient Health Questionnaire (PHQ-2) among 205 patients with advanced cancer in Ireland, where the DT was found to have 100 per cent sensitivity in detecting distress, anxiety, or adjustment disorders, but low specificity (49 to 60 per cent) where a number of false positives were identified (Ryan et al., 2012). This was amended with the inclusion of a question about participants' willingness to receive help for their feelings of distress increasing specificity and helped to identify not only those who were distressed, but also those who were willing to accept professional support (Ryan et al., 2012).

While a range of psychosocial screening interventions were applied to the care of individuals with cancer, research findings that focused on psychosocial adaptation specific to other chronic or serious illnesses were also emerging (Bogosian, Moss-Morris, & Hadwin, 2010; Livneh & Antonak, 2005; Song, Deatrick, Feetham, & Levin, 2013; Zebrack et al., 2014). The Diabetic Adjustment Scale by O'Sullivan (1979) is an example of this, which during initial testing, assessed key areas on a sample of 105 adolescent girls. These key areas assessed health and body image attitudes, family and peer relationships, school adjustment, dependency concerns

which were found to be well correlated (Pearson's correlations ranging from 0.77 to 0.95). Despite this, more recent findings examining risk indicators for young people with diabetes in Australia, highlighted continued adversity reporting low rates of follow up and poor self-care practices among adolescents calling for more widespread inclusion of psychosocial measures to efficiently identify those at risk (Kaye, Rapley, Babel, & Brown, 2013).

The impact of psychosocial burden on patients with Type I and Type II Diabetes was also emphasised in a worldwide cross sectional study of 5104 patients and 3827 healthcare providers across 13 countries across Asia, Australia, Europe, and North America (Peyrot et al., 2004). Here, application of the five item World Health Organisation Well-Being Index (WHO-5) previously validated in the elderly population by Bonsignore, Barkow, Jessen, and Heun (2001), was adapted. The five item scale measured attitudes about the impact, identification, and accessing support for psychosocial issues (Peyrot et al., 2004). Findings showed acceptable reliability in the patient and healthcare provider samples with Cronbach's alpha, 0.72 and 0.74 respectively. While this large study accommodated many differences in culture and healthcare systems, the burden of psychosocial issues remained consistent where less than optimal self-care practices were commonly reported (Peyrot et al., 2004). Also, because the survey used was restricted to participants who were able to read and speak the local language, excluding those more disadvantaged, it was likely that these findings did not represent the full extent of psychosocial burden (Peyrot et al., 2004).

The benefits of using psychometric measures to plan appropriate intervention have also been reported. For example, the importance of a healthy dyadic relationship for individuals living with Diabetes used a range of psychometric measures including the dyadic adjustment scale, a personal assessment of relationships, a depression and anxiety score, and a quality of life scale were applied in this study in a sample of 88 participants in the UK (Dempster, McCarthy, & Davies, 2011). However, despite the complexity of the psychometric measurement used other aspects of psychosocial strain such as exposure to additional life stress, financial concerns, or access to social support, were not included.

While consideration for the family in healthcare is essential across the life-course, it is especially so in the care of a child who is seriously or chronically ill. These children

depend on the care they receive from their primary caregivers and other family and friends, who often need considerable support.

In the following subsection growing attention to psychosocial assessment in paediatric healthcare is discussed with a focus on the development and revision of the widely used Psychosocial Assessment Tool (PAT) and PAT 2.0 developed by Kazak (2003, 2008) for the paediatric oncology setting. Adaptation of the PAT 2.0 to other specialty areas is outlined with a view to the psychometric properties and the tool's reliability and validity in comparison to other disease specific psychosocial assessment tools introduced in the paediatric setting.

2.8.3 Psychosocial assessment applied to children

The first published application of psychosocial assessment in the paediatric setting focused on children with cancer and involved the use of the Personality Inventory for Children (PIC) which is an adaptation of the MSPPI described previously (Sanger, Copeland, & Davidson, 1991). In the first application of the PIC children with cancer were found to have a higher incidence of somatic complaints and lower levels of school achievement where boys were more affected than girls in comparison to children who did not have cancer. However, there was no assessment of family psychosocial functioning as this psychosocial assessment focused on aspects of child development rather than family functioning (Sanger et al., 1991). The "Pediatric Symptom Checklist" (PSC) that followed, used a clinical individualised approach that also featured predictors of developmental achievement rather than psychosocial function in a later study of 21,065 children between the ages of four and fifteen years attending a primary care setting across 44 States in North America (Jellinek et al., 1999). Here the 35 item PSC measured demographic information, previous utilisation of mental health services, and number of health visits and included concentration and attendance at school, and emotional feelings as measures (Jellinek et al., 1999). The PSC (Jellinek et al., 1999). Application of the PSC was useful in drawing attention to the prevalence of learning and attentional issues in children where one in eight were found to have major concerns, however, assessment of the family was not included (Jellinek et al., 1999).

The Psychosocial Assessment Tool by Kazak (2003), was the first published instrument to include measures of family psychosocial functioning. Since its introduction it has become the most popular published psychosocial assessment tool

in paediatric healthcare internationally (Kazak et al., 2015; Pai et al., 2008). A description and analysis of the PAT is presented in more detail in the following subsection.

2.8.3.1 Development and adaptation of the Psychosocial Assessment Tool (PAT 2.0)

Development of a brief screening tool by Kazak, Prusak, McSherry, Simms, and co-authors (2001) at the Children's Hospital in Philadelphia where levels of psychosocial distress in families of children newly diagnosed with cancer were measured, was initially named the Psychosocial Assessment Tool (PAT). The initial pilot study of 109 parents of children with cancer supported the underpinning public health model illustrating resiliency among the majority of parents, whereby almost 45 per cent of parents were assessed as resilient (Kazak et al., 2001). Less than six per cent of participating parents were identified as having escalated distress in need of clinical referral, while up to 30 per cent were targeted as "at risk" (Kazak et al., 2001).

Kazak (2006) further developed the public health model named Pediatric Psychosocial Preventative Health Model (PPPHM) further supporting the distribution of psychosocial risk. Findings based on the PPPHM showed that despite the intense and complex demands on the family when a child was seriously ill, over 50 per cent were able to cope well (Kazak, 2006). Also according to the PPPHM, up to 30 per cent of families identified as "at risk" could be targeted for early preventative support while clinical referral for those experiencing escalated distress could be conducted (Kazak, 2006). The PPPHM is notable because it emerged from socio-ecological theory that drew attention to the psychosocial functioning of families (Kazak, 2003). Furthermore, adaptation of the PAT in the paediatric oncology setting has brought with it more widespread attention to the psychosocial burden families of children with life threatening health problems may experience. This was highlighted in a meta-analysis conducted on 29 research studies where parents of newly diagnosed children experienced significantly more psychosocial distress than parents of healthy children (maternal distress p value 0.03; family adaptation p value 0.01) (Pai et al., 2007).

The PAT 2.0 was also adapted to a Dutch sample of 90 parents of children with cancer where a Cronbach's alpha of 0.66 was reported and while these findings called for further examination, the tool was rated appropriate and understandable by the healthcare providers who used it (Nicolaas, Schepers, Grootenhuis, & Verhaak, 2013). Further to

this, a randomised control study from Canada of 67 parents of children undergoing treatment for cancer found that targeted risk was reduced in the intervention group in comparison to the control group with a p value less than 0.001 (Barrera et al., 2014). To follow, the original PAT was modified to a briefer Psychosocial Assessment Tool 2.0 (PAT 2.0) following a data-driven revision that was adapted to other clinical specialties of childhood serious or chronic illness (Kazak, 2015).

The psychosocial assessment of children and families affected by sickle cell disease, a chronic hereditary condition was conducted using the PAT 2.0 (Karlson et al., 2012), also in the USA where the risk classifications were found to be similar to the families of children with cancer (Pai et al. 2008). In a further US adaptation, the PAT 2.0 was identified as a suitable screening tool to measure psychosocial risk in a sample of 25 primary caregivers whose children had undergone kidney transplantation (Pai et al., 2012). Here internal consistency of the psychometric properties was found to be strong with overall Cronbach's alpha of 0.82. Despite a small sample and limited power to conduct confirmatory factor analysis, results suggested that application of the PAT 2.0 for screening at transplantation clinics was useful (Pai et al., 2012).

These findings support the use of a brief tool based on a preventative health model to identify psychosocial risk and escalating distress in children and families where psychosocial risk was measured through the child's clinical condition. Using the PPPHM, the need for referral for further support could be identified and families who were assessed as resilient would be more likely to seek support when needed. How attention was targeted for the group of parents at risk of escalating stress, or how often their circumstances were reassessed, and by whom, were less clear. Examination of parent perspectives about psychosocial interventions using mixed methods found a preference for psychosocial support in the first six months after diagnosis of their children's cancer, while over 50 per cent favoured support within two months (Hocking et al., 2014). Tension between attending to the child who was sick and addressing family needs emerged from thematic analysis of focus group data in the sample of 25 parent participants in the same study (Hocking et al., 2014). A comparative study by Di Battista et al. (2015) suggested that nurses were more likely to favour psychosocial screening compared to other healthcare providers in examination of the perspectives of healthcare providers in a sample of 15 oncologists, 14 nurses, and 8 social workers (Di Battista et al., 2015).

2.8.3.2 Limitations of the Psychosocial Assessment Tool

Findings related to the PAT 2.0 focused largely on children and families dealing with a specific serious childhood illness (Kazak et al., 2001; Pai et al., 2012, Pai et al., 2014). Concerns that the sensitivity of disease specific measurements may exclude family issues and alternatively that non-disease specific instruments may not allow for salient family issues in the context of the disease to be identified in a review of international literature on psychosocial assessment in the context of Diabetes Mellitus (Song et al., 2013). Here, family assessment instruments were examined for their validity and usefulness in response to the growing recognition for the impact on family relationships and functioning that also focused on diabetes healthcare. While this review remained specific to a single chronic health condition, both disease specific and non-disease specific instruments were included in order to compare the strengths and limitations of both (Song et al., 2013). Just four of the eight instruments assessed were found to be based on specific theoretical frameworks while those that were, were found to be poorly explained (Song et al., 2013). Disease-specific measures were found to be more useful for targeting specific issues such as assessing levels of family conflict and behaviours of family members. On the other hand the non-disease specific measures were considered more helpful to clinicians and authors who used a more holistic approach (Song et al., 2013).

A more holistic perspective to psychosocial assessment was emphasised in a further review of the published literature that examined psychosocial stress, crisis, and grief and loss in the face of chronic illness (Livneh and Antonak, 2005). Here, the overview of measures of psychosocial adaptation by distinguishing from those that were theory driven, reaction specific, or targeting a specific clinical condition (Livneh & Antonak, 2005). For example, responding to a patient's expressed defensiveness or reduced self-esteem as a result of their illness with an understanding of grief and loss could be exemplified as a theory driven response. Further to this, strategies known to be supportive and patient focused such as adaptation of a partnership approach were more useful in the early stages of psychosocial adaptation, while goal orientated strategies were identified to be more useful in later stages (Livneh & Antonak, 2005).

There is a great deal of evidence that supports the benefits of assessing the levels of psychosocial distress and specific stresses and strains experienced by the families of children who are seriously or chronically ill (Kazak et al., 2001; Kazak, 2006; Deatrick

et al., 2014; Knafl et al., 2013; Li, Mattes, Stanley, McMurray, & Hertzman, 2009). There is no doubt that interventions from FSN Theory outlined earlier such as the CFAM, the Calgary Family Intervention Model, the IBM, and the FaMM, provide evidenced based guidance for the provision of strength-based care and psychosocial support to families (Bell & Wright, 2015; Duhamel, Dupuis, Turcotte, Martinez, & Johanne Goudreau, 2015; Knafl et al., 2013; Østergaard & Wagner, 2014).

2.9 Synopsis

Evidence presented in this chapter has emphasised how considerable attention has been given to identifying and responding to the psychological and social aspects that impact the healthcare of individuals and families. The transition from a solitary to a systems approach has stimulated more attention to the physical, emotional, and care-giving environments of children in addition to their physical conditions. Adaptation of evidenced based findings using a systems approach has highlighted how early relationships, family psychosocial environments, and exposure to persistent family life-stresses shape the physical, emotional, and developmental outcomes of children with implications through the life-course. More importantly, systems based knowledge and evidence presented in this section has illustrated the additional impact serious or chronic illness has on children making them especially vulnerable.

This approach has been embraced within FSN where attention to the family unit is promoted in the nursing care of families by drawing on systems knowledge and understanding. Further to this, the provision of theoretical and practical guidance for nurses to pay attention to the psychological and social aspects of the family by using FSN models of care has been illustrated. Additionally the FSN models of care outlined, such as the CFAM, CFIM, and the IBM, have provided a means to gather evidence for the positives impacts FSN initiatives have on the health and developmental outcomes of individuals and families. Similarly, a range of psychosocial screening instruments have emerged from systems based knowledge and evidence and introduced to practice where implementation within a range of specific healthcare situations have made significant differences to families. The impact of the PAT 2.0 and the FaMM have been highlighted with reference to children who are seriously or chronically ill.

Despite this shift to a systems approach and the extensive efforts by many nurses and other health professionals, assessment of the psychosocial circumstances of families is not universal. While adaptation of FSN models of care have been rolling out to healthcare settings internationally these have been more dominantly embedded within advanced practice nursing. In a similar way, psychosocial assessment instruments identified in practice have more often been implemented in healthcare settings that specialise in the treatment and management of specific diseases rather than healthcare more generally. More specifically with attention to children who are seriously or chronically ill, examination of the PAT 2.0, and the FaMM, implemented with

significant benefits to children and families across a range of healthcare settings, have also more often occurred in specialised settings where the family is considered in the context of the child's health condition and management.

As with the shift from a medical model to a systems approach, a shift to incorporating attention to the psychological and social aspects that impact the families of children who are seriously or chronically ill could be more universally embedded in the provision of healthcare. Such an approach would invite attention to family psychosocial issues up front where conversations about family life could be anticipated by PCGs and conducted as a natural part of healthcare assessment and care by HCPs. However in order for such an approach to be a welcome or effective proposition, it must be embraced by families as well as healthcare providers.

This project seeks to engage PCGs and HCPs of children who are seriously or chronically ill to examine their attitudes, opinions, and experiences to establish if psychosocial assessment of the family is acceptable and feasible. Based on systems theory and research, a proposed framework will underpin examination. It is anticipated that this study will result in an emergent family psychosocial assessment framework shaped by the attitudes, opinions, and experiences of PCGs and HCPs that is ready for use in children's hospitals.

3. Methodology

3.1 Introduction

In this section, the health promotion context in which a formative evaluation sits is outlined and explained, together with the process of conducting a formative evaluation. The benefit of this method as a pre-planning strategy, in preparation for an implementation phase of the family psychosocial assessment that is anticipated to follow this project, is clarified. Further to this, the mixed methods design applied in this study is illustrated, and the purpose for collecting and analysing quantitative and qualitative data is explained and justified.

Within this context, the family psychosocial assessment framework which is based on valid and reliable psychosocial assessment instruments is outlined in readiness for consideration by participants of this enquiry. To follow, the aims, sampling techniques, procedures, analyses, and ethical considerations are presented for the quantitative, followed by the qualitative, research participant samples.

3.2 Formative evaluation

Over recent decades there has been an increased emphasis on preventing illness and encouraging healthier choices using health promotion models aimed at improving health outcomes and reducing mortality and morbidity (O'Connor- Fleming, Parker, Higgins, & Gould, 2006). This new paradigm was proclaimed by the World Health Organisation in the Ottawa Charter which emerged from a health summit held in Canada in 1986. The Ottawa Charter resulted in the initiation of a plethora of new health promotion programmes globally. The importance of evaluating health promotion programmes in terms of service policy, organisations, and funding, has become a priority for health promotion practitioners (Pronk, 2003).

Over time, the challenges associated with translating research to practice have become increasingly understood (Schoster, Altpeter, Meier, & Callahan, 2012; Stetler et al., 2006). Boyd and Windsor (2003), conceded that health interventions often fail to achieve behavioural change or an impact on health outcomes. Schoster et al. (2012), suggested that while evidenced based health promotion programmes are recommended in response to addressing a range of health issues, systematic evaluation of programme design remains essential in order to maximise health benefits and secure sustainability. A growing understanding among health promotion advocates that the formative

evaluation process is fundamental to the implementation of interventions in healthcare, has seen this methodology increasingly applied (Stetler et al., 2006).

A formative evaluation incorporates the analysis of data generated by the participation of the individuals and groups who interact within the context of the planned intervention. Stakeholders' perspectives are considered a necessary component of formative evaluation because they give important organisational, operational, and cultural insights (Stetler et al., 2006).

Ideally, formative evaluation of an intervention includes both a formative and summative component to allow for identification of barriers to implementation, operationalisation of an intervention as well as the effects an intervention has on various outcomes (Geonnotti et al., 2013). The process allows for exploration on how to best implement an intervention, and finally examine why some strategies would or would not work before implementation of the proposed intervention is undertaken (Geonnotti et al., 2013). Identification of barriers to implementation therefore provides a more complete approach towards successful operationalisation of a proposed intervention (Kochevar, 2006). With this in mind, it is anticipated that the formative evaluation of a family psychosocial assessment framework will allow detailed examination of potential operational strengths and limitations that will lead to a process evaluation phase where further research will address implementation by seeking stakeholders' perspectives on the operational aspects to examine and amend the proposed intervention during implementation. This formative evaluation continuum ideally leads to an impact evaluation phase where the effects on health, performance, and efficiency outcomes can be measured (Stetler et al., 2006). During each phase of enquiry, further changes can be made by systematically addressing relevant "*what*", "*how*", and "*why*" based research questions with stakeholders in relation to examining aspects of the intervention that may or may not be working well for the stakeholders using it. The formative evaluation at the centre of this research enquiry therefore focuses on the pre-implementation phase of the evidenced based family psychosocial assessment framework in readiness for an implementation phase. A formative evaluation is the selected approach because it emphasises engagement with PCGs and HCPs as main stakeholders to contribute to the finalisation of the family psychosocial assessment framework before its implementation. It is well understood that a health intervention that is feasible and acceptable to those who use

it is more likely to be successfully implemented (Geonnotti et al., 2013). Furthermore, a formative evaluation allows selection of rigorous quantitative and qualitative methodologies in order to generate reliable data to answer specific questions in order to maximise the complex process of implementation (Stetler et al., 2006).

The formative evaluation of a family psychosocial assessment framework sits very well within the National Framework for Universal Child and Family Health Services (AHMC, 2011) which encourages consumer participation across the range of healthcare, social and geographical settings in Australia (Psaila, Hesson, & Schmied, 2011). It is also congruent with the Partnering with Consumers Standard which is second in a list of National Safety and Quality Health Service Standards published by the Australian Commission on Safety and Quality in Healthcare (ACSQHC, 2011). This standard is one of nine that were developed following extensive public and stakeholder consultation to become essential components of health services across Australia at a state and national level. The development of this standard has resulted in calls to address a gap in research evidence addressing consumer participation in paediatric healthcare (Kiernan et al., 2010; Tallon, Kendall, & Newall, 2015).

3.3 Proposed family psychosocial assessment framework

The overall aim of this formative evaluation was to assess the acceptability and feasibility of a family psychosocial assessment framework to identify psychosocial issues that are experienced by families of children who are seriously or chronically ill in hospital. The proposed family psychosocial assessment framework is based on a systems approach that is commonly used to guide child health research globally which stemmed from previous research and clinical practice where associations between psychosocial issues and reduced maternal confidence in caregiving were identified. The framework borrows from a range of systems theory concepts that underpinned examination of psychosocial issues that impact on families and the ways in which HCPs recognise and respond to the psychosocial needs of families in hospital. As outlined in the background section of the review of the literature in this thesis, these concepts include the bioecological model of early child developmental by Bronfenbrenner and Ceci, (1994), the family and resource framework developed by Brooks-Gunn et al. (1995), and an understanding of biological embedding and allostatic theory (McEwen & Gianaros, 2010; Shonkoff et al., 2009). With these theoretical concepts the family advisor model partnership model of care by Davis, Day,

and Bidmead (2002), which is based on empowerment theory where self-efficacy and motivation is promoted by building a relationship that is genuine and respectful through reflective listening, was considered the ideal conduit to bring this understanding to practice.

Ten evidenced based psychosocial components were identified for inclusion in the proposed original framework. These were identified from research that stemmed from evidenced based knowledge and the theoretical concepts found to be relevant to families that are presented in the Background Section of the Review of the Literature in this Thesis.

These evidenced based psychosocial components are maternal education attainment and parental occupation; maternal self-confidence and emotional health; family structure and relationships; exposure to family life stress; financial strain; social support and engagement in community activities. The attitudes, perspectives and experiences of PCGs of children who are seriously or chronically ill and the HCPs who care for them were collected and analysed to assess if all or any of the psychosocial components were considered acceptable for inclusion in the finalised family psychosocial assessment. Further to this, thematic analysis of participants’ perspectives and experiences about talking about these issues with HCPs and seeking support in hospital aimed to provide insight into how participants’ felt such a framework could be implemented if it was considered acceptable or if not, to identify an alternative acceptable model. Figure 3.1 outlines the basic structure for the family proposed psychosocial assessment framework prior to collection and analysis of data for this research enquiry. (See Figure 3.1).

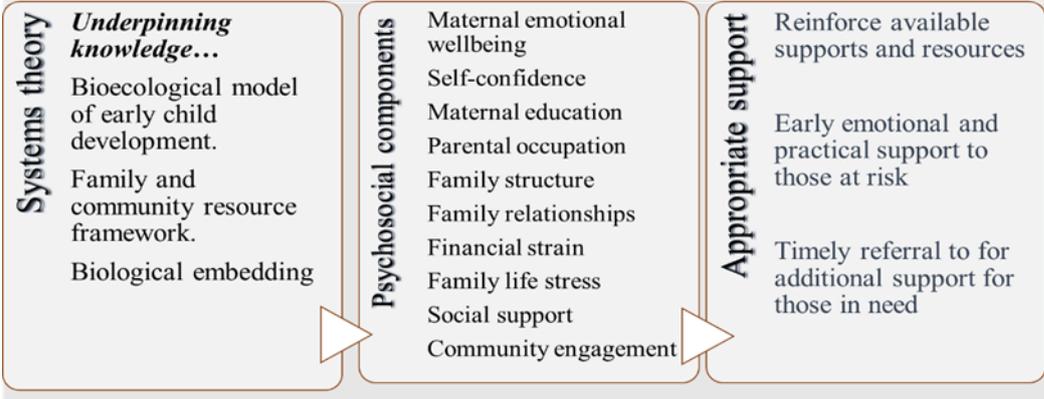


Figure 3.1

Proposed family psychosocial assessment framework in development based on research findings that motivated this formative evaluation.

3.4 Mixed methodology

A mixed methodology was selected as the appropriate approach to address the research aims of this research study. It has been suggested that mixed methods research in the social, behavioural, and health sciences potentially provides a broader understanding of the phenomena that is being examined than a qualitative or quantitative approach alone (Tashakkori & Teddlie 2010a). While many researchers believe that using a pluralistic approach to address a research aim provides the best opportunity to obtain meaningful answers (Teddlie & Tashakkori, 2012), quantitative purists who maintain that research enquiry should be objective and qualitative purists argue the benefits of relativism, hermeneutics, and constructivism in favour of positivism, have collectively advocated that their methods should not be mixed (Zhang & Creswell, 2013). However, using a mixed methods approach is based on the understanding that opposite components of purism or paradigms are not all inclusive because other alternatives may be in play (Creswell, 2007; Teddlie, & Tashakkori, 2012). While it is understood that authors' underlying philosophical perspectives guide their research questions and design, those who favour a mixed methodology encourage authors to take a logical and balanced approach to research by promoting pragmatism as the philosophical partner (Burke, Johnson & Onwuegbuzie, 2004). Furthermore, they maintain that qualitative or quantitative methods alone cannot address the complexity of research questions that are important to health authors (Tashakkori & Teddlie, 2010a). A mixed methodology was considered ideal for this study because it was anticipated that analysis of quantitative data could potentially identify the psychosocial components that were considered acceptable, or otherwise, for inclusion in the family psychosocial assessment framework that was first proposed. It was also anticipated that thematic analysis of participants' textual experiential data would provide important insights into aspects of the framework's potential implementation.

3.4.1 Concurrent mixed methods design of triangulation

A concurrent mixed methods design known as the integration approach was applied whereby quantitative and qualitative data were collected concurrently and analysed separately (Zhang & Creswell, 2013). Using Tashakkori and Teddlie's (2010a) basic mixed methods research design, the typology of the mixed methods included three components outlined in Figure 3.2.

earlier, it was anticipated that the qualitative component would also provide some insights into planning for an implementation phase. Kochevar (2006), suggests that while numerous approaches have been adopted to encourage translation of research into practice, more success is realised when the evidence for their effectiveness comes from mixed methods.

3.5 Participants

This section describes the characteristics of the participants who were recruited into the survey, one-on-one interview or focus group samples at both participating tertiary paediatric hospitals. Firstly, the sampling approach for survey data will be presented.

The survey samples were comprised of PCGs (PCGs) and HCPs (HCPs) from authorised areas where ethical approval was given at the two participating paediatric tertiary hospitals, Princess Margaret Hospital for Children in Perth, Western Australia (PMH) and the new Royal Children's Hospital in Melbourne, Victoria (RCH). Key HCPs and executive staff were approached to discuss the potential for recruitment at both PMH and RCH. The process explaining these discussions and identifying participating areas is presented in the following subsection named setting.

The PCGs targeted were those who were mostly responsible for care to their children who were seriously or chronically ill. More often than not, these PCGs were one of the parents, usually the child's mother. Serious or chronic illness was defined as an illness in childhood that lasted or was estimated to last more than six months, had a pattern of recurrence or deterioration, and produced consequences that impacted on the child's quality of life (Australian Institute of Health and Welfare, 2010). The Australian Bureau of Statistics was found to be long and complex in its categorisation of major health problems in children (ABS, 2006). Therefore, childhood illnesses were organised based on the websites of the two participating tertiary paediatric hospitals, the PMH and RCH. For further reference, the website of a third Australian tertiary hospital, the Lady Cilento Children's Hospital in Brisbane, Queensland, was included. The three hospital websites were found to be similar in their organisation and grouping of childhood health problems. On examination these categories were also found to be similar to the Children's Hospital of Philadelphia (CHOP), which is referred to internationally as a centre of excellence in children's healthcare. Please see Appendix A where the categories used for the purpose of this study are presented.

The PCGs of children of all ages who were seriously or chronically ill in hospital and attending one of the authorised areas were invited to participate. As the research was largely focused on young children, recruitment of PCGs from the adolescent wards at either hospital was not pursued. However, PCGs of teenaged children from the participating areas who expressed an interest and gave consent to participate were included. This allowed some representation of the perspectives of PCGs who were likely to have experience attending the hospital over many years for the child's specialist care to be included, while capturing a range of age groups within the sample and avoiding targeting specific age groups.

3.6 The sampling approach

Purposeful sampling was applied to obtain qualitative data from PCGs of children who were seriously or chronically ill who were attending the hospital. This meant that potential participants were identified by key staff to be approached and invited to participate. Firstly, it was considered essential to avoid any undue distress to potential participants. Therefore any PCGs who appeared anxious or distressed were not approached. As the study focused on psychosocial issues, key stakeholders in the authorised areas who were well informed about the research included their consideration for a range of situations and circumstances among those they approached. As these key hospital stakeholders were well informed about the children and families in their care, any additional hardship experienced by PCGs to support concurrent research projects that were likely to be in progress in each single state-wide tertiary hospital was avoided. Similarly, using a sensitive interpersonal approach helped to avoid any pressure or expectation that could result from encroaching on HCPs who may have felt under pressure responding to the demands of their clinical role.

The survey samples were convenience samples that were made up of PCGs of children who were seriously or chronically ill and HCPs, who were interested, available, and gave their consent to participate. Previous research investigating psychosocial issues experienced by the families of seriously ill children has almost exclusively focused on children with cancer. Given that the purpose of this study was to assess the acceptability and feasibility of a family psychosocial assessment framework for families of seriously ill children, it was necessary to choose participants from a variety of clinical settings. While a random sample is ideal, it was not feasible in this study. It was also considered neither practical nor appropriate to recruit all the parents and

healthcare providers from the participating areas. This was because it was essential to avoid being intrusive to parents who could be experiencing significant distress. It is well understood that many parents of children who are seriously or chronically ill in hospital experience significant distress and anxiety about their child's condition and care. The experience of anxiety can see PCGs significantly less confident in the care of their children and if this is the case it is likely to further add to their distress (Tallon, Kendall & Snider, 2015). With respect to avoiding any intrusion to PCGs or the HCPs caring for children and families in hospital a sensitive, interpersonal approach was favoured.

Using a non-probability sampling approach also helped to alleviate concerns that were expressed by some nurse managers at the time when data collection was proposed about the likelihood that both PCGs and HCPs could feel inundated with surveys because of concurrent research studies that were in progress in their areas. The demands to participate and support meaningful research while also managing concurrent research activities must be challenging for department and ward managers and the Human Research Ethics Committee (HREC) of both busy single state wide tertiary hospitals. The potential for feeling burdened due to numerous invitations to participate in research activities in clinical areas is well-understood (Ullrich, Wallen, Feister & Grady, 2005). With respect to the concerns raised by senior hospital staff, it was considered important to avoid any degree of hardship to potential PCG participants. It was also important to reduce any potential barriers to recruitment whereby participants could decline primarily because they had been invited to participate in too many research projects during a hospital visit.

In a similar manner, HCPs could be very busy. The demands of providing the best care and support possible along with meeting additional demands on their workload can be stressful. Often paediatric HCPs are stretched dealing with the emotional needs of patients and families who are distressed as well as fulfilling the clinical, administrative, and educational demands of their role (Sabo, 2011). For HCPs, the impact of caring for children and their families who may be feeling frightened about invasive treatments and procedures can trigger psychological distress (McGarry et al., 2013). With respect to the demands often placed on HCPs, it meant that not all who were working in the participating areas were invited to participate during the recruitment period. To avoid encroaching on staff who busy prioritising the demands of their role, it was important

to ensure that participants were recruited without pressure or imposing expectation. This was endorsed at meetings with key stakeholders where the procedure for data collection was discussed. These key stakeholders included nurse managers and staff development nurses from the participating ward and department areas, the heads' of departments for allied health, physiotherapy, and developmental paediatrics, the hospital senior registrar, and the manager for the parent advocacy team. At meetings with these key stakeholders, it was agreed that a sensitive and thoughtful interpersonal approach was best when introducing the project to both PCGs and HCPs.

A sensitive interpersonal approach was further supported by a need to capture representation of participants' from authorised areas while maintaining a quantitative sample size close to that recommended by undertaking a power analysis. The power analysis undertaken for this study indicated that a sample of 108 PCG participants and 102 HCP participants would have 80% power to detect a difference with a *p* value less than .05. The calculation for sample size is explained in more detail later in the chapter section named sample size.

While calculating sample size is important to demonstrate adequate power to identify statistically significant relationships in the sample, it is also important to avoid unnecessary over recruitment of participants. An overinflated sample can be responsible for a Type I error in clinical research (Gaskin & Happell, 2014). A selected alpha level of 0.05 could give rise to a Type I error where five times out of one hundred a finding could be reported as statistically significant when it may have been by chance. The calculated sample size for this study was not excessively large. Therefore, in addition to being the acceptable approach at planning discussions for data collection, a convenience sampling approach also supported adequate representation of participants from all authorised departments while avoiding an overinflated sample. Further to the selected sampling approach, it was also important to minimise selection bias within the sample. This was achieved by ensuring that recruitment of the convenience sample was impartial. This meant that the information sheets invited participation by completing a survey or participating in a one-on-one interview (PCGs) or one-on-one interview or focus group (HCPs). Accompanying survey packs were objectively and similarly displayed in the parent lounge areas, and staff tea rooms of the participating wards and departments. The numbers of information sheets and

survey packs were capped and recorded in each area to facilitate recording a response rate. This process is explained in more detail in the following section named setting.

It was understood that by using a convenience sampling approach, some PCGs would be excluded from participating because of their circumstances or in some cases their demographic characteristics. For instance, using a non-intrusive approach meant that PCGs who were experiencing extreme distress at the time of recruitment were not invited to participate. Also, in order to avoid any confusion or undue misunderstanding those who had no command of the English language were not approached to participate. As is often the case in health research using surveys, it was anticipated that recruitment from participants from a diverse range such as those from disadvantaged immigrant populations or those who experienced significant socioeconomic disadvantage were less likely to take an information sheet available in parent lounge areas and consent to participating in the study (Brett et al., 2012). Cultural or language barriers or simply because the need to survive had become the main priority over health has made it challenging to recruit participants from vulnerable populations into research survey studies. Likewise, it was understood that HCPs who may have been feeling under pressure responding to the clinical, administrative and educational demands of their roles were unlikely to participate.

3.7 Setting

Recruitment of participating PCGs and HCPs at Princess Margaret Hospital (PMH) in Western Australia (WA) and Royal Children's Hospital (RCH) in Victoria was proposed to address the research questions outlined earlier in this chapter. PMH is the single tertiary paediatric hospital in the State of Western Australia which had a residing population of 2.57 million in 2014 and has continued to record positive growth rate in keeping with all Australian states and territories at just over two per cent (ABS, 2014). While Western Australia does not have the highest population of residents across all Australian States it occupies the western third of the country making it Australia's largest State with over 1.90 million of the population residing in the Greater Perth area south west area of the State (ABS, 2015). With capacity for 220 inpatient beds and provision of care for approximately 250,000 inpatient, outpatient and Emergency Department visits per year, Princess Margaret Hospital provides specialist paediatric care to children and adolescents from around the state (HDWA, 2013). Participating areas within the hospital included the Department of Developmental Paediatrics and

Rehabilitation, the Children's Cardiac Centre, General Paediatric Surgical and Medical departments, and the Outpatient Department. All areas of the hospital comprise of multidisciplinary teams who are dedicated to providing state wide quality healthcare services for attending children and families. In addition to inpatient hospital care, PMH provides specialist care to children in their homes in the Perth metropolitan area and operates specialty specific services and clinics in rural and regional areas.

The RCH is the leading tertiary paediatric hospital in the State of Victoria (VIC) which had a resident population of 5.84 million people and was recorded as the second fastest growing state by the ABS for the year ended 30 June 2014 (ABS, 2014). Between 2013 and 2014 specialist paediatric care was provided for over 42,500 inpatient visits, 240,000 clinic visits, and over 83,000 presentations to the Emergency Department by children and adolescents (RCH, Quality of Care Report, 2013-2014). At RCH, participation in the research study was supported within the Department of Developmental Medicine and the Family Resource Respite Centre. The Department of Developmental Medicine is committed to the care of children living with disability and their families. Education programmes and research activities are promoted within the multidisciplinary teams within the department to optimise support and autonomy for the children and families in their care. Like PMH, the service includes inpatient, outpatient, and home support care and regional and rural specialty clinics. The Family Resource Respite Centre is situated in the hospital and offers parents support and respite from its central location that is open daily. This centre is managed by a team of staff and volunteers that are available to support families by providing; a place to take a break, seek information, access practical support, such as access to the internet, or emergency care boxes containing personal care needs. Specialist practical support is also available with the offer of appointments for legal and social services advice. While the centre is available to all families, it is visited frequently by parents of children who are in hospital for longer periods or who attend the hospital on a regular basis. It was considered likely that many of these parents had children who were caring for children who were seriously or chronically ill making it an appropriate setting to seek participation.

3.7.1 Engagement with stakeholders in Western Australia

At PMH in Western Australia, the author met with the directors and managers of all hospital departments and ward areas where seriously ill children were cared for, to

present the aims and significance of the project and discuss potential recruitment of participants from their areas. The appointments were informal and allowed time to address any questions that arose. Directors and managers who were in agreement endorsed their support with written authorisation for inclusion in the application to the hospital Human Research Ethical Committee (HREC) for approval to conduct the study. Those who agreed were notable because they voiced their understanding of the purpose of the study and a common wish to provide excellent psychosocial support for the children and families in their care. Those who did not agree were more likely to say that they already had too many surveys being undertaken in their clinical area. Of those who did not agree to participate, no one expressed the opinion that the research was not important. These HCPs included nurses, medical doctors, physiotherapists, occupational therapists, social workers and members of the parent advocacy team. Agreement by departmental and ward managers was endorsed with signatures to documents that were included in the application to the Child and Adolescent Health Service Human Research Ethics Committee (CAHS HREC) seeking ethical approval to conduct the study at PMH. These clinical departments and associated inpatient ward areas where recruitment was authorised and confirmed when ethical approval was granted were: the Department of Paediatric Medicine, Department of Paediatric Surgery, Department of Developmental Paediatrics and Rehabilitation, Paediatric Neurology Department, Children's Cardiac Centre, and the hospital's Outpatient Department. Authorisation was received from the Executive Director of Nursing and Medicine, allowing recruitment of participants to proceed within the inpatient and outpatient wards where agreement for recruitment had been expressed. These inpatient areas were the general paediatric medical ward, the infants' ward, the general paediatric surgical unit and the adjoining ward specialising in the care of children with burns. Also included were the specialty wards where children with neurological, developmental, rehabilitation, and cardiology problems and their families were cared for. The outpatient areas were the general outpatient department, and the specialist clinics for neurology, developmental paediatric medicine, rehabilitation, and cardiology that were attended by children and their families. In total there were nine departments and wards that supported recruitment of PCGs of children who were seriously or chronically ill, and which included HCPs who care for them.

3.7.2 Engagement with stakeholders in Victoria

Similarly, at the RCH authorisation to recruit participation was sought by the candidate during a visit to the hospital to attend appointments with departmental directors and managers. This was facilitated by the Professor of Nursing Research at RCH who was introduced to the aims and significance of this study during an initial collaborative teleconference in late 2013. At this teleconference an invitation to collaborate on this project by supporting data collection at RCH and contributing to the research team as an Associate Supervisor was extended and accepted.

A visit to RCH by the candidate was arranged and occurred in January 2014 before an application for ethical approval was submitted to the Royal Children's Hospital Human Research Ethics Committee (RCH HREC). During this first visit to RCH by the author, the Professor of Nursing Research facilitated meeting times with managers and directors from various wards and departments to seek their agreement and support for participation in their areas. As at PMH, agreement was also endorsed at the RCH with the inclusion of signatures from the key stakeholders who agreed to recruitment of participants in their areas in the application for ethical approval from the hospital's HREC. These key stakeholders gave written authorisation and were as follows: the Executive Directors of Nursing, Executive Director of Medicine, Executive Director of Surgery, Executive Director for Consumer Liaison, Director of Developmental Paediatrics, and the Manager of the Family Resource and Respite Centre. The participation of PCGs attending the Family Resource and Respite Centre at the RCH was also considered an ideal recruitment site as the centre is attended by families who attend the hospital regularly or for a significant length of time.

At the time of these initial meetings and similar to the process at PMH, the author invited key stakeholders from authorised areas to participate as members of a Steering Committee established to both support the data collection and contribute to the finalisation of the triage protocol that was to accompany the proposed family psychosocial framework in development. The key stakeholders who were in agreement to support data collection in their areas and also contribute to the development and finalisation of the triage protocol were: the Director, the Clinical Nurse Consultant and an Allied Health Professional from the Department of Developmental Medicine; and the Manager at the Family Resource and Respite Centre. This group was considered ideal because it represented doctors, nurses, and allied health professionals who care

for children and families in hospital, and staff members who represented the needs of children and families through advocacy and consumer support. The function of the Steering Committee is presented in more detail in a further subsection named “Establishment of a Steering Committee”.

Ethical approval from the Human Research Ethics Committees at Curtin University, Child and Adolescent Health Service (CAHS) for PMH, and RCH took some months to be granted. Therefore the author met again with the key stakeholders following ethical approval to reintroduce the project and address any questions that arose from the stakeholders. The procedure for recruitment of participants in each of the areas was specified in more detail and finalised. The procedures for recruiting participants at PMH and RCH are presented in detail in further subsections named the “Recruitment of participants from Western Australia” and “Recruitment of participants from Victoria”. Establishment of a Steering Committee at each hospital was finalised to oversee data collection in participating areas, and to contribute to the development of the triage policy to accompany the family psychosocial framework central to this study. This is outlined in detail in a further subsection in this section named “Establishment of Steering Committees”.

3.8 Establishment of Steering Committees

At PMH the author met with representatives from each healthcare professional participant group and patient advocates to inform them about the aims and significance of the project and to ask them to be a member of a stakeholder group that would oversee the study. These stakeholders: a nurse manager from one of the ward areas, two staff development nurses from participating areas, a clinical nurse consultant from a participating specialty departments, a medical consultant who was also head of department, the director of allied health services for the hospital, and the manager for the parent advocacy team. These stakeholders were allocated in both research settings to support and facilitate the data collection in their areas.

The Steering Committee established to inform the development of a triage policy to accompany the assessment framework in development consisted of: one medical representative, two allied health professionals, three nursing representatives, and the manager of the parent advocacy team. These representatives agreed to participate by attending a meeting and sharing their knowledge and experience to facilitate the

development of a triage policy to accompany the framework that is central to this research.

At RCH, following departmental authorisation and ethical approval, the relevant key HCPs who agreed to support and monitor data collection in their areas made up the Steering Committee at RCH, Melbourne. These HCPs included two nurses, one doctor, one allied health professional, and the manager for consumer support.

The Steering Committee at RCH was established by meeting with the two nurses, allied health professional, one doctor and consumer support manager, outlined above. The following aims were addressed. Firstly, to establish the defining parameters for recognition of psychosocial risk assessment; and secondly, to recommend appropriate and available interventions that were considered both effective and non-burdening to the services available at each hospital. These aims were based on the proposed framework and the anticipated likelihood of what at the time that would accompany a triage procedure.

3.9 The quantitative component

3.9.1 Recruitment of Primary Caregivers in Western Australia

At PMH, the nurse managers of the eight participating clinical areas agreed that parents who had a seriously ill child staying in the hospital at the time could be approached by nursing staff about the study. To achieve widespread participation across all participating areas and to minimise burden to nurse managers and key nursing staff, the Candidate limited the numbers of information sheets and survey packs allocated to each clinical area. Each nurse manager was given twenty survey packs containing an information sheet, consent form, and questionnaire for recruitment (See Appendices B, C and D), and a prepaid reply envelope. This number was considered appropriate in order to attain the calculated sample size and achieve representation across all the authorised participating areas. The nurse managers' agreed to contact the author if more survey packs were required.

In the inpatient areas, nurse managers were instructed to make the twenty survey packs available to parents within their specialist area. The survey packs were left on display in the parent lounge attached to each ward. In some cases senior nurses approached parents during their child's admission to the ward. This was done solely on the basis that the parent appeared available and had some experience of having a child who was

seriously or chronically ill. A parent taking an information sheet and survey pack was considered evidence that the person had some interest in participating in the survey. This approach was taken because it was considered that a parent could only make a fully informed choice about their participation in the study after they had read the detailed information sheet and seen the questionnaire.

In the outpatient areas, the information and survey packs were displayed at the reception desks for attending parents by the clinical nurse consultant, clinical nurse specialist, liaison nurse, or clinical nurse working in that area. In addition to the Steering Committee, these nurses were informed about the project by the author and agreed to facilitate data collection. These nurses also made themselves available to address any questions parents had pertaining to the survey and were able to direct any enquiries to the Candidate if required. Participants were required to place the completed survey in the prepaid reply envelope included in the pack for return to the author at the secure mailbox at the School of Nursing and Midwifery at Curtin University. Participants were informed they could leave the envelope with the nurse or at the reception desk for inclusion in the external hospital mail or they were welcome to post it independently through Australia Post. The response rate for surveys completed by participating PCGs was calculated by subtracting the number of completed surveys received in the mail from the total number of information sheets and survey packs that were made available across the authorised participating areas within the hospital.

A total of one hundred and eighty information sheets and survey packs were distributed for PCGs at PMH. This total comprised of twenty packs being left for display and distribution at each of the five ward areas by the staff development nurses who supported data collection. Twenty information sheets and survey packs were also left with nursing representatives at each of the three participating departments. During the two month recruitment period and in response to a request by the nurse representative at the general outpatient department, the author issued a further twenty information sheets and survey packs for display and distribution. At the end of the recruitment period, any remaining information sheets and survey packs were returned to the Candidate. A total of 21 survey packs were returned which left 159 that were taken by potential recruits from the participating Ward and Departmental areas. The number of

completed surveys from PCGs at PMH was subtracted from 159 to calculate the response rate for this portion of the sample.

3.9.2 Recruitment of healthcare providers in Western Australia

HCPs were informed of the study by the Candidate who presented the aims and significance of the project and recruitment processes to nurses, doctors, physiotherapists, occupational therapists and parent advocate / consumer support staff at negotiated brief time slots during scheduled ward and departmental meetings. A total of one hundred and fifty information packs and surveys were made available for HCPs at PMH. Twenty information sheets and survey packs were made available for consideration by potential recruits in the staff lounge rooms of four participating wards and two major departments while 10 surveys were made available at a smaller specialist ward; a specialist outpatient department; and the hospital doctors' lounge area. It was anticipated that the perspectives of nurses would be largely represented. This was considered appropriate as the nurses spend considerably more time with children and families in hospital providing the hour by hour care and there are more nurses employed in comparison to other health professionals. The perspectives of many nurses about applying an assessment framework that focuses on the family is also important because it is well reported that nursing perceptions of providing individualised care can differ within health organisations as work settings (Suhonen, Gustafsson, Katajisto, Valimaki & Leino-Kilpo, 2009).

Survey packs for HCPs contained the information sheet, consent form, survey and prepaid reply envelope for easy secure return to the Candidate through the hospital outgoing mail. Key staff members in each area monitored the numbers of surveys taken by staff and supported continued distribution during the data collection period. A total of one hundred and fifty information sheets and surveys were distributed to HCPs at PMH. The response rate was then recorded by deducting the number of surveys returned to the author from the number distributed. It was anticipated that as the author had previously worked at PMH for many years and was well known it was likely to reflect positively on the response rate.

3.9.3 Recruitment of primary care givers in Victoria

At RCH, Melbourne, authorisation for participation was given during a visit to the hospital to finalise an application for ethical approval as described in the earlier

subsection of this chapter named setting. Following ethical approval authorisations to collect data from the Department of Developmental Medicine, the Family Resource and Respite Centre, and Ronald McDonald House were confirmed. As at PMH, key HCPs from these areas were identified at individualised meetings arranged by the author to present the aims and significance of the project and to address any questions that arose. Two nurses, one medical doctor, one allied health professional, the manager for consumer support, and the manager at Ronald McDonald House agreed to support and facilitate data collection from PCGs in their areas.

Following ethical approval, the author visited RCH for a second time for one week. During this time the project was reintroduced, the Steering Committee confirmed and data collection was initiated. Four key HCPs were identified to support and monitor data collection and record the number of survey packs displayed in the parent lounge rooms in the participating areas. The key stakeholders consisted of two nursing staff from the Department of Developmental Medicine, the Manager for the Family Resource and Respite Centre. The Manager at Ronald McDonald House was no longer available to support the project so data were not collected at this venue. Data collection were conducted by the author with the support of members of the Steering Committee who continued to collect and monitor collection of PCG survey data for four weeks following the author's visit where contact was maintained using telephone and email.

As at PMH, the survey packs at RCH also consisted of the information sheet, consent form, the survey, and a prepaid reply paid envelope to a secure mailbox at the University addressed to the author. These stakeholders also assisted with the monitoring of the response rate by recording the numbers of hard copy survey packs distributed for the author. A total of 50 hardcopy information sheets and survey packs were displayed for PCGs in the participating areas and the total of 30 completed surveys were deducted from this total to give the response rate.

3.9.4 Recruitment of healthcare providers in Victoria

HCPs at RCH were invited to participate by completing the survey that was included in the online weekly RCH Hospital Staff Bulletin. This invitation was included in the weekly staff publication for two weeks. The invitation contained a link to the survey that was created using the Qualtrics Software Package. This package is endorsed by Curtin University as a secure and appropriate platform for the purpose of survey data

collection and is made available to staff and students for research purposes. Use of this online approach was suggested and discussed during the author's initial visit to RCH at a meeting with the Director of Nursing Research and included in the application for ethical approval. The online survey consisted of the same information sheet, consent form, and survey, as the hardcopy version distributed at PMH. Unlike the PCG survey, the online survey for HCPs at RCH was made available to all staff. Approval for this was also included in the application for application for ethical approval at RCH.

It is well understood that securing reasonable response rates may be difficult to control particularly when online or by post (Kelley, Clark, Brown & Sitzia, 2003). With this in mind every effort was made to calculate a response rate that was well explained and accurate. The response rate for hardcopy questionnaires distributed at RCH for completion by PCGs was calculated by deducting the number of completed surveys returned to the author from the total number distributed. The response rate for the online survey for HCPs was monitored differently using the "*Qualtrics Mailer*" option setting that is available within the software system. This was set up to include only those respondents who had opened the link provided in the email. The total number of surveys circulated and opened via the Qualtrics link made up the total number from which the response rate was calculated. This was calculated by subtracting the number of online surveys that were completed from the total number of links that were opened by potential participants.

The survey link was published in the weekly hospital bulletin two weeks in a row, however, the response rate was calculated using the total number of emails sent in week one. Using the "*Qualtrics Mailer*" option in the survey software programme, 580 bulletins were sent to hospital healthcare staff. The Qualtrics software survey tool indicated that a total number of 306 survey links had been opened. The number of completed surveys collected by the Qualtrics programme was deducted from this number to give the response rate for the HCPs at RCH.

It was anticipated that there would be a disparity between the response rates at PMH and RCH where the response rate at RCH would be less than that at PMH for a number of reasons. Firstly, the author was onsite for only a short period and was not able to visit outside these times to provide any additional onsite support to the key stakeholders who were supporting data collection in addition to their often demanding schedules. Secondly the author was not known at RCH unlike PMH where well

established colleague relationships may have influenced receptiveness to the project and ultimately supported a better response rate. And finally, the author was not able to control the number of HCP recipients of the online survey. This meant that the number of invitations were not capped and monitored as they had been with hardcopy information sheets and survey packs.

3.9.5 The primary caregiver survey

The PCG survey was made up of three parts, A, B, and C and is shown in Appendix D. Part A asked the PCG details about their child: age in years, gender, and to identify the category which represented their child's main health problem. Participants were asked to record their postcode in this section. Locations where participants resided ranged from the local metropolitan areas, and regional and interstate locations. Using the Socio-Economic Index for Advantage (SEIFA) made available by the Australian Bureau of Statistics (ABS, 2011) participants' postcodes were allocated to one of ten categories with one indicating a geographical location of least advantage and ten representative of a location of most advantage. The areas of advantage were further categorised with SEIFA levels one to three where one was representative of an area with the least advantage; two indicated some advantage; and three identified advantaged geographical areas.

Part B.1 contained the modified "Parents Attitudes towards Psychological Support Index" (PATPSI) to measure participating PCGs attitudes about psychosocial issues. Part B.2 asked participants to allocate one of four levels of importance to the ten evidenced based psychosocial issues contained within the proposed framework from "*not at all important*" to "*very important*". These items are outlined in detail in the following subsection of this chapter named "evidenced based psychosocial predictors".

The *PATSPI* was adapted for the purposes of this study as the attitudinal measures for "*help seeking intentions*", "*help seeking attitudes*", and "*stigma*" related to families seeking support when children have psychological problems were considered equally applicable to families seeking support for psychosocial issues. The scale was developed in response to a lack of psychometrically sound measures of attitudes towards child mental health services and it builds on previous attitudinal measures to include the issue of stigma more specifically (Turner, 2012). Included in the PATPSI

is the subscale ‘stigma’ that is a measure for the extent to which parents are concerned about how others may negatively perceive them and how this may detract them from seeking support for their child’s mental health problems. As outlined on page 12 a higher score indicates a more positive attitude, while a lower score indicates a less positive attitude towards accessing psychological services.

The original 24 item PATPSI showed reasonable internal consistency for the total scale with alpha coefficient of .90. Reasonable internal consistency was also demonstrated within the subscales; help-seeking intentions, help seeking attitudes, and stigma with a Cronbach Alpha of 0.70, 0.88, and 0.89 respectively (Turner, 2012). Outcomes from the development of the PATPSI were supported by findings from the National Stigma Study in Children by Pescosolido (2009), which recommended the need to address stigma associated with childhood psychological services through public education. As the PATPSI was modified for the purpose of this research it was also subject to reliability and validity analyses as outlined in a subsection named statistical analysis later in this chapter.

The PATPSI was modified and adapted for the purpose of measuring parental attitudes towards seeking professional support for psychosocial issues and made up Part B.1 of the PCG survey. Please see Appendix D. Participants were required to indicate a level of agreement to the statements included from “strongly disagree” to “strongly agree”. Six statements in the PATSPI that related specifically to childhood mental health were excluded giving a total of 15 items in the scale that were adapted for the purposes of this research.

The 15-item scale contained three subscales, each containing five items. The first subscale measured participants attitudes towards help seeking intentions and asked about when and why participants may seek support for family issues; for example, “I would get professional help if I was worried about issues at home”; and “It would be relatively easy for me to access professional help if I needed it”. The second subscale measured help seeking attitudes and asked participants to rate their agreement to statements to indicate how they felt about seeking support for family issues. For example; “*Problems and worries at home tend to work out by themselves*”, and “*There is something admirable about coping without seeking professional help*”. The third subscale measured stigma by asking participants to rate their agreement to statements about how they felt seeking support for family issues may be perceived by others. For

example; *“Important people in my life would think less of me if I needed help”*; and *“If I needed help at home I would feel it should be ‘kept secret’”*.

To account for respondents who did not have a firm opinion and in order to avoid responses being pushed to *“agree”* or *“disagree”*, a *“neither agree nor disagree”* option was included. While a concern that neutrality can be suggestive of avoidance by the respondent (Chang, 1994), including a neutral response has also been suggested to be indicative of a more discriminating response (Adelson & McCoach, 2010). Likert scale responses were given numeric codes from one to five, with one indicating *“strongly disagree”* and five indicating *“strongly agree”*. With 15 statements (see Appendix D) the total score ranged from 15 – 75, with 15 indicating the most positive attitude towards psychosocial assessment or support and 75 the least positive attitudes. The 15 statements were grouped into the three subgroups, giving a sub-total score out of a possible 25. These scores when added together gave an overall total score out of a possible 75. While some statements were reversed for data collection purposes, these were corrected for analysis. Further categorical variables were created by collapsing *“strongly disagree”* and *“disagree”* and *“agree”* and *“strongly agree”* while leaving *“neither disagree nor agree”* unchanged. Continuous variables were derived for each subscale and a summary variable for the total PATPSI score.

3.9.6 The healthcare provider survey

The HCP survey was also made up of three parts, A, and B. Part A.1 contained the modified *“Physicians Belief Scale”* which was adapted for to include nurses, doctors and allied health professionals. See Appendix G. Part A.2 contained the ten psychosocial predictors included in the proposed framework and asked participants to allocate a one of four levels of importance to each item from *“not at all important”* to *“very important”*. As indicated above with the primary caregiver survey, these psychosocial predictors are outlined in detail in the following subsection. Part B.1 included questions that asked the participants, their gender, professional role, the number of years in their roles, and the number of years in their role in the paediatric setting. It was considered important to examine data for similarities or differences in the levels of importance allocated to specific psychosocial issues by HCPs according to their experience.

The “Physicians’ Belief Scale” was adapted for the HCP sample in this study as it focused specifically on measuring differences between the psychosocial orientations of doctors who were practising in a variety of roles and settings. The instrument was developed in response to previous research examining avoidance of psychosocial aspects of healthcare by doctors in some medical settings (Williamson, Beitman & Katon, 1981). The subscales included in the instrument measured attitudes and beliefs about the physician’s role, what parents want, and physicians’ response to patients as individuals, and were considered equally relevant to paediatric HCPs who care for children and families in the paediatric setting. Contrary to the PATPSI, a lower score using this scale indicated more awareness about talking about and assessing the impact of psychosocial issues on patients and families while a higher score indicates less psychosocial awareness. The “Physician’s Belief Scale” was therefore adapted for inclusion in the HCP survey.

This instrument initially aimed to identify differences between physicians who adopted a psychosocial approach when assessing their patients compared to those who did not (Ashworth, 1984). As the 32 item instrument was adapted for completion by a range of HCPs in this research, the statements that related specifically to the physician role or statements that did not relate to the role of the paediatric health provider were excluded. Please see Appendix G.

The modified 19 item scale used a 5-Likert scale score measuring agreement from ‘strongly disagree’ to ‘strongly agree’ also contained the original three subscales. The first subscale asked participants to rate their agreement to statements about their beliefs about their professional role. For example; *“I can investigate psychosocial issues without losing my efficiency”*, and *“I focus on the physical signs not psychosocial problems”*. The second subscale measure the HCPs about their beliefs about what patients and families want. For example; *“Parents feel questions about psychosocial issues are irrelevant”*, and *“Parents will become more dependent on me if I open up psychosocial issues”*. The third and final subscale measured participants’ perceptions about their reactions to patients / parents as individuals. Examples of statements contained in this subsection included *“Consideration of psychosocial issues will require more effort than I have to give”* and *“My own psychosocial issues do not interfere with my ability to address psychosocial problems”*.

This instrument in its original form showed high internal consistency using the Kuder-Richardson Formula 20 (r_{KK}) which ranges from 0.0 for items with zero inter-correlation to 1.0 that represents perfect inter = correlation. Analysis for internal consistency of the original 32-item tool showed r_{KK} = 0.88 with good test-retest reliability, mean scores that did not deviate substantially from the midpoint, a dispersion of scores narrow enough to avoid “basement” or ceiling” effects, and reliable relationships with related variables (Ashworth, 1987). Likert scale responses were given numeric codes from 1 to 5, with 1 indicating “*strongly disagree*” and 5 indicating “*strongly agree*”.

With 19 statements the total score ranged from 19 – 95, where 19 indicated the most positive psychosocial orientation and 95 the least positive degree of psychosocial orientation. The 19 items were grouped into the three subscale groups giving subtotal scores. The subscale groups; “*beliefs about their role*” and “*beliefs about what the patents want*”, each contained six statements giving a maximum subtotal of 30 in each subscale group. The third subscale group measuring participants’ reactions to patients as individuals contained seven statements, therefore giving a subtotal maximum score of thirty five. Some statements were reversed for data collection purposes and these were corrected for analysis so that a higher score represented a negative attitude towards psychosocial assessment. Categorical (disagree, neither disagree nor agree, and agree) variables were created and continuous variables were derived for subscales and a continuous variable for the total attitude and belief score. As the attitudes and beliefs scale was modified for the purpose of this research it was also subject to reliability and validity analyses as outlined later in this chapter in the subsection named “*statistical analysis*”.

3.9.7 Evidenced based psychosocial predictors

Part B.2 of the PCG survey and Part A.1 of the HCP survey asked participants to assign a level of importance to the ten evidenced based psychosocial factors identified for inclusion in the original family psychosocial assessment outlined in section 1.1.3 of this chapter named: Overall aims of this research. These psychosocial factors included: low maternal education, poor maternal emotional well-being, and confidence; parental occupation; single parent family structure; dysfunctional family relationships; stressful life events; financial strain; poor social support; and lack of engagement in community activities. In order to provide relevant context to HCPs, Part A.1 of the HCP survey,

included a summarised sentence about evidence based findings relevant to psychosocial distress experienced by some families of children in hospital (See Appendix G). Statements addressing each of these evidence based predictors as important components of the family psychosocial assessment framework in development followed. As outlined previously, these family characteristics were: low maternal education, poor maternal emotional well-being, and confidence; parental occupation; single parent family structure; dysfunctional family relationships; stressful life events; financial strain; poor social support; and lack of engagement in community activities.

The question, “*How important do you believe the following factors are to a child’s health and wellbeing?*” was asked in relation to each of the 10 factors identified above. Participants were asked to allocate a level of importance to each statement, and responses were given a numeric code from one to four with one indicating “*very important*”, to four indicating “*not at all important*”. Categorical (important, somewhat important, and not at all important) and binary (important, of little or no importance) variables were created. These statements, based on evidenced based frameworks were also subject to validity and reliability testing outlined in the statistical analysis subsection later in this chapter. The survey questions were reviewed by eight healthcare providers including four nurses, two doctors and two allied health professionals for readability and face validity. The survey completion time ranged from five to ten minutes.

3.9.8 Sample size

Sample size calculations were conducted for both PCG and HCP quantitative samples based on the validated scales included in each survey. The “Parent Attitude towards Psychological Services Index” (PATPSI) was included in the PCG survey and the Physicians’ Belief Scale sat within the HCP survey. These calculations are presented in detail in the following subsections.

3.9.8.1 PCG sample size based on the PATPSI modified for this study

The attitudes of the participating PCGs about seeking help for, and managing psychosocial issues were measured using a modified version of the PATPSI developed and validated by Turner (2012). A number of items that related to psychological issues specifically were omitted from the original 24 item scale leaving a total of 15 items

five of which were contained in each of the three subscales to measuring help seeking intentions, health seeking attitudes, and attitudes about stigma for about psychosocial issues. To allow for participants who may not have a firm opinion and avoid responses that push to agree or disagree, a “*neither agree nor disagree*” option was included for the purposes of this research. While a concern that neutrality can be suggestive of avoidance by the respondent (Chang, 1994), including a neutral response can also be indicative of a more discriminating response; thereby adding to reliability scale scores (Adelson & McCoach, 2010). Each subscale item therefore used a 5-point Likert scale score to give a subscale score range of 5 – 15 and a total scale score range of 15 – 75. The score range was reversed so that a high score reflected the most psychosocial orientation and a lower score the least. This allowed the linearity of both scales used for HCPs and PCGs to be similar. As the scale was modified it was subject to validity and reliability testing outlined in the analysis section of this chapter.

Previous research using the PATPSI examined differences between participants who had previously sought psychological help and those who had not. Using the PATPSI, a higher score indicates a more positive attitude, while a lower score indicates a less positive attitude towards accessing psychological services. The findings of a recent study compared differences in attitudes between those with previous engagement with mental health services and those with no previous engagement by examining the psychometric data on the PATPSI, its test retest reliability, and internal consistency (Turner, 2012). Results showed a significant difference between the more positive help seeking attitudes of parents who had sought psychological help in the past (F statistic, 1.258; p value < 0.05; mean score of 24.98; SD \pm 11.36) compared to those who had not (mean score, 19.04; SD \pm 10.50) (Turner, 2012). A significant difference in stigma tolerance was also reported with (F statistic, 1.258; p value < 0.05). Parents who previously used psychological services reported more stigma tolerance (Mean score, 25.91; SD \pm 10.33), than those who had not accessed services previously (Mean score = 18.63; SD \pm 11.14; p value < .05) (Turner, 2012). Based on these findings and with consideration for the omission of some nine items from the original scale where the remaining it was decided to calculate the sample on finding that was relevant to the amended scale. Following adjustment of the scale a total of 15 items were evenly distributed across the three subscales, it was decided to calculate the sample based on a 6.0 point difference between two groups with a standard deviation of 11.0 for each

group. On this basis, the study would have 80 per cent power to detect a difference in means between two groups with a 0.05 per cent probability of incorrectly rejecting the null hypothesis that there were no differences if 108 PCGs participated. Based on a 60 per cent response rate 180 potential PCG participants would be approached to participate in a survey. Application of the amended PATPSI to this sample was subjected to statistical examination for internal consistency and reliability using the Cronbach's Alpha where a Cronbach's Alpha of 7 or greater was considered to be an accurate measure intended by the scale.

3.9.8.2 HCP sample size based on the Physicians' Belief Scale

The attitudes of the participating HCPs towards psychosocial assessment were measured using the belief scale for physicians developed and validated by Ashworth (1984). The belief scale was modified and adapted for use by all healthcare providers for the purpose of this study. The modified version also contained three subscales that represented participants' attitudes about their roles, attitudes about what parents want, and attitudes about their own reactions to psychosocial issues as an individual. A number of items that specifically related to medical doctors were omitted and a total of 19 items remained in the scale. These 19 items uniformly represented the three subscales with two of the three subscales containing six items in the first two subscales and seven items included in the third subscale. A lower score using this scale indicates more orientation towards psychosocial assessment while a higher score indicates less psychosocial orientation. In a study of 180 physicians' responses an internal consistency was performed using the Kuder-Richardson Formula 20 (rKK) which is a measure of the extent to which a set of items reflect a single underlying construct. Using the Kuder-Richardson Formula a validity coefficient is compared using a mathematical formula where values range from 0.0 for items with no inter-correlation to 1.0 where items inter-correlate perfectly (Polit & Beck, 2014). Validation of the Ashworth's (1984) "Physician's Belief Scale" was based on comparisons between physicians who had different roles in healthcare. A total of 99 physicians were included in the sample and showed an overall scale mean = 72.1, SD ±13. Findings showed that; the psychiatrists within the sample reported a mean scale score =59.8, SD±12.2; while the family physicians reported a mean scale score= 64.8, SD ±10.7; and finally, the interns reported a mean scale score =76.4, SD 12.5. A comparison t-test was used and showed a significant difference between the belief scale scores for

family physicians and psychiatrists as a combined group, and interns as another group ($t = 4.78$; $df = 80$; $p = <0.01$). Psychiatrists and family physicians reported more psychosocial orientation with a mean score of 63.3 than hospital based interns. Based on these findings, and given the diversity of experience between groups in the validation study, it was decided to calculate sample size reporting a 7.0 point difference between two groups with a standard deviation of 12 for each group. On this basis, and with consideration for the amendments made to the original scale, it was decided to calculate the sample based on the study having 80 per cent power to detect a difference in means between two groups with a 0.05 per cent probability of incorrectly rejecting the null hypothesis that there is no difference, if 102 healthcare professionals participated. As with the validity testing of the amended PATPSI, the amended Physician's Belief Scale used in the HCP sample was subject to statistical examination for internal consistency and reliability using the Cronbach's Alpha where a Cronbach's Alpha of 7 or greater was considered to be an accurate measure intended by the scale. While survey response rates have been in decline in recent decades with no reported evidence that defines an acceptable response rate, a response rate of 60 per cent has been used as acceptable by many and has face validity as a measure of survey quality (Johnson & Wislar, 2012). Based on this understanding allowing for a 60 per cent response rate, 160 health professionals were approached at each hospital.

3.9.9 Statistical analysis

Frequencies were tabulated to represent the prevalence and distribution of characteristics for the primary caregiver and healthcare provider samples. Frequency distributions measuring the mean, median, standard deviation were also tabulated for the two adapted attitudinal instruments, each using the one to five numeric codes representing the 5-Likert scale score for both primary caregiver and healthcare provider data. The same descriptive analyses were applied to the categorical variables derived from the primary caregiver and healthcare provider attitudinal scale dataset along with the continuous variables representing the subtotal and total scores using the 5-point Likert scale. The means, medians and standard deviations were also tabulated for the variables representing the categorical and binary evidenced based psychosocial factor variables included in each of the questionnaires. All frequencies included examination for skewness and kurtosis and standard error of skewness and kurtosis to

show that data collected was normally distributed and that non-parametric testing was not required for the primary caregiver or healthcare provider samples.

3.9.9.1 Bivariate analysis

The relationships between participant characteristic variables and their attitudes towards family psychosocial assessment, and the degree of importance they applied to the evidenced based psychosocial predictors were examined in both the primary caregiver and healthcare provider datasets. Analyses were performed using each of the individual variables included in the PATPSI and the attitudes and beliefs scale as outcome variables. This was repeated for each of the subscale totals and the overall totals for each scale.

Using the individual items included in the PATPSI for primary caregivers or the attitudes and beliefs scale for healthcare providers as outcome variables, independent t tests were performed to illustrate the significance of relationships between binary variables representing the participants' characteristic variables and their attitudes towards aspects of family psychosocial assessment. These analyses were repeated using PATPSI and attitudes and beliefs subscale scores and total scores as outcome variables to examine the relationships between participants subscale and total attitudinal scores and the transformed binary variables representing the degree of importance applied to the evidenced based psychosocial factors that are central to the framework in development.

One way analyses of variance with Bonferroni correction was undertaken using categorical variables in both the primary caregiver and healthcare provider datasets. Using subscale scores for the PATSPI and the attitudes and beliefs scale as outcome variables, the degree of significance between participants' demographic information and their attitudes towards family psychosocial assessment was explored. These calculations were repeated using the overall total scores for the PATPSI and attitude and beliefs scale. One way analysis of variance was also applied to illustrate the relationships between the evidenced based family psychosocial factors as categorical variables and PATSPI and attitudinal subscale and total scores as dependent variables in both datasets. While the Bonferroni test can overcorrect for Type I error it remains the most commonly used test to compare categories within a variable as it is flexible and can be applied to any statistical test (Allen & Bennett, 2010).

With a p value 0.05, chi-square analyses were conducted and cross tabulations were performed to examine differences between the characteristics of participants and the levels of importance they assigned to the psychosocial components of the framework in development. Where assumptions for frequencies were violated where cells had an expected count of less than 5 in number or 20 per cent; non-parametric testing was conducted using the Fisher exact test. Fisher's exact test is performed to accommodate violation of frequencies when cell size is less than 20 per cent where a p value of $< .017$ indicate a statistically significant difference with three by two tables assumptions for frequencies are violated (p value $.05 / 3 = p$ value $.017$) (MacDonald & Gardner, 2000).

Finally, standard multiple regression analysis was considered and found not to provide any meaningful contribution to analysis of the PCG or HCP sample. Assumptions for both sample sizes were met and dummy variables were created for variables that were not dichotomous. In each sample, after accounting for linearity, impossible tolerances were generated with all variables entered into each model. Some were found to be too highly correlated with Pearson's correlations less than the required 0.3 or higher than 0.7. The combination of all the predicting variables in combination did not result in a 'good fit' model in either sample (Tabachnik & Fidell, 2007). Therefore multiple regression analysis was not included as it was likely to provide any consequential additions to this research.

3.9.9.2 Consistency of measures

The consistency of the evidenced based family psychosocial factors was examined using Pearson's correlations to establish that the evidence based psychosocial predictors / risk factors included within the proposed family psychosocial assessment framework consistent.

Reliability testing was performed to measure correlations between items included in the modified scales. Cronbach's Alpha was conducted for the PATSPI for the attitude and belief scale adapted for the healthcare provider sample in this study.

3.10 The qualitative component

3.10.1 Philosophical underpinnings

The aim of the qualitative component of this formative evaluation was to examine in more depth the perspectives, feelings, and experiences of participants about their interactions with HCPs where their children were in hospital. Thematic analysis was selected as a methodology for the qualitative sample because it is flexible and not tied to any pre-existing theoretical framework (Braun & Clark, 2006). This flexibility also supported an inductive or “bottom up” approach which was applied to the six steps of thematic analysis selected for this qualitative sample whereby examination and re-examination of the transcripts and reflexive records was conducted throughout the interpretive process (Braun & Clark, 2006; Creswell, 2013).

Thematic analysis is situated between the philosophical approaches of essentialism where the focus is on the reality of the individual, and constructionism where ways in which these realities, meanings, and events influence the wider societal context are the focus (Braun & Clark, 2006). The contextualist approach taken in this thematic analysis is supported by theories, such as critical realism, which aim to better understand the experiences of participants while also acknowledging the broader social context (Willig, 2012). The analysis in this study is supported by a phenomenological approach where commonalities in the lived experiences of participants are identified rather than the detailed stories of individual participants in narrative research (Creswell, 2007).

3.10.1.1 Reflexivity

Considering the philosophical background of the thematic analysis, it was important for participants to be informed about the Candidates background, what motivated the study, and how findings would be reported and disseminated. It is a right of participants to understand how the professional, cultural, and relevant personal experiences of the researcher may inform a study and what may be gained as a result of the study (Creswell, 2013). With many years of experience in paediatric nursing practice in a specialist nursing role where long-term relationships with children and families were built and accommodated over time, it was important that the Candidate remain impartial in the role of researcher while also consciously noting and reflecting on any inclinations to respond as a clinician. Throughout the process of recruitment,

data collection, and thematic analysis, reflexive notes were recorded to ensure that the Candidate's position in the research was constantly being examined (Creswell, 2013). These reflexive notes were recorded during, and following each stage of thematic analysis and included thoughts, reflections, and feelings at the time of data collection and during examination and re-examination of the transcripts. During thematic analysis, the feelings and experiences included in these reflexive notes were consistently discussed with the supervisory team with a view to how these feelings and experiences could potentially influence interpretation of the data.

3.10.2 Recruitment of PCGs and HCPs in Western Australia and Victoria

The sensitive interpersonal approach outlined earlier in this chapter was also applied to recruitment of PCGs and HCPs to participate in a one-on-one interview and HCPs to participate in a focus group within participating areas at both tertiary settings. At the time of recruitment of PCGs to survey data collection, potential participants who expressed an interest in participating in a one-on-one interview were identified. This process was aided by stakeholders from participating wards and departments who also identified and approached potential participants who appeared to be available. Stakeholders also extended an invitation to consider participation by briefly explaining the purpose of the project and offering an information sheet. To follow, the stakeholders made contact with the Candidate to meet with PCGs or HCPs who expressed an interest at a convenient time to discuss the project further and answer any questions before proceeding with a one-on-one interview.

Authorisation granted for the recruitment of participants to complete a survey in both tertiary settings included the recruitment of PCGs and HCPs in a one-on-one interview or a focus group. Confidentiality was assured and consent obtained when an interview was arranged with those who were interested (See Appendices I and L). The interview setting was considered whereby a quiet location free from distractions was promoted. One-on-one interviews conducted at PMH and RCH took place in quiet areas in the hospital wards, vacant consulting rooms that were made available, or the hospital grounds in Western Australia, and similarly, the ward areas, or The Family Resource Centre in the hospital in Victoria. This way the interview was not likely to be interrupted.

Consent was obtained and an interview arranged with those who agreed. As the stakeholders were well informed about the project and sensitive in their approach, most participants who expressed an interest and met with the Candidate agreed to participate. For one potential PCG participant who chose not to participate, the reason was related to the need to attend to an arising issue in the family rather than the research topic or design. Likewise, HCPs were invited to participate using the same sensitive non-intrusive approach and were asked to make contact either through the stakeholder or by contacting the author directly whose mobile telephone number was included on the information sheet. All one-on-one interviews and focus groups were undertaken by the Candidate who is based in Western Australia. The one-on-one interviews conducted in Victoria were completed during a visit by the Candidate to the hospital in April 2015 specifically dedicated to recruitment and data collection.

3.10.3 Interview and focus group protocol

Interview guides contained semi-structured questions that were developed for PCG based on the PCG survey questions and for HCPs one-on-one interviews and focus groups also based on the HCP survey. The semi-structured questions also served to guide the interview so that it could be conducted within an adequate time frame while allowing participants to express their feelings without prolonging the interview unnecessarily. The interview and focus group protocol included attention to respectful and proficient interview procedures. Here the Candidate stayed with the questions throughout the interview, demonstrated active listening, avoided speaking unnecessarily and maintained eye contact. Regular nods of affirmation were shared with attention to body language to provide encouragement and reassurance to the participant. Observation which is acknowledged as a key tool in the conduction of qualitative research was used during the interviews and focus groups. This included noting aspects of the physical environment, the activities and interactions of the participant as well as reflecting on the Candidate's own behaviours and feelings throughout (Angrosino, 2007).

With permission from the participants the interviews and focus groups were audiotaped for ease of transcription, whereby all identifying information was removed. Following transcription the audio recordings were deleted.

3.10.3.1 One-on-one interviews with PCGs

Five of the ten interviews with PCGs took place in ward areas where their children were hospitalised. Four of these were conducted at the child's bedside while one PCG opted to have the interview conducted away from her child's ward area in the quiet location in the hospital grounds. Of the remaining five one on interviews one was conducted in a room in the Outpatient Department where the PCG was recruited while the remaining four interviews with PCGs were conducted in the Family Resource Centre at the research setting in Victoria. Permission was sought for the interviews to be audiotaped where identifying information would be removed as per ethical approval. Also with permission from the participants the Candidate recorded reflexive notes during each interview to include environmental, non-verbal, and reflective observations.

Because the date of births of the children of participating PCGs were not specifically asked, the ages of their children were categorised in keeping with the quantitative sample being; infants, toddlers, young children, older children, and adolescents. As with the quantitative sample, infants were children aged less than one year. Those identified as toddlers were older than one and less than three years of age. Young children were aged over three and less than six years of age. Older children were more than eight and less than 12 years of age while participating PCGs with children older than 12 years of age were identified as adolescents

The semi structured questions were developed from the survey questions and phrased in a way that could be easily understood by participants. The questions aimed to gain deeper insights from PCGs about talking about aspects of family life with HCPs (see Appendices J and M). "*How do you feel about doctors and nurses asking parents about family life?*", and "*What communication qualities do you expect hospital staff to have when they are talking with the parents of children who are in hospital?*" were asked. These questions invited PCGs to draw on their experiences in hospital as well as allowing preferences to be expressed. A further two semi-structured questions asked about what specific communication qualities and approaches PCGs considered to be helpful followed by those considered to be unhelpful based on their experiences in hospital.

A further three open-ended semi-structured questions each asked each PCG their perspectives about discussing their educational attainment and occupation, their family

relationships, and exposure to family life stresses they may have been experiencing, (See Appendix J). This was considered important because shared perspectives about whether talking about some psychosocial issues were considered important over others was likely to provide deeper understandings of why this may or may not be the case. Further to this PCGs were asked their feelings about discussing psychosocial factors included in the proposed framework as a matter of routine. The interviews with PCGs concluded with an open-ended question asking each of the participants if there was anything they wished to add.

3.10.3.2 One-on-one interviews with HCPs

Eight one-on-one face to face interviews were conducted with HCPs, four in Western Australian and four in Victoria. Following information and consent by participants seven of the eight interviews were conducted in available consulting rooms attached to ward areas or departments where privacy was ensured while the final interview was conducted in a quiet area in the hospital grounds.

During one-on-one interviews, participating HCPs were asked eight semi-structured open ended questions about talking with PCGs and providing FCC. The first question asked “*What does FCC mean to you?*” to explore the perspectives and experiences of HCPs about their care of families in the hospital. A further question asked “*What are your thoughts about asking parents questions about family life stresses they may be experiencing other than that of their child’s condition?*” This question provided an opportunity for HCPs to express their feelings and experiences about embarking on conversations with PCGs about family life and aimed to explore factors that made this easier or more difficult from their perspectives.

In a similar way to PCGs, HCPs were asked to share their perspectives on the communication qualities they considered to be most important when communication with PCGs of children who were seriously or chronically ill. “*What communication qualities do you expect hospital staff to have when they are talking with the parents of children who are in hospital?*” was asked. Also similar to the PCG interview guide three open-ended semi-structured questions asked HCPs perspectives about asking PCGs about their educational attainment and occupation, family relationships, and family life stresses they were experiencing, (See Appendix M). Here deeper understandings about the experiences of HCPs and factors that helped or hindered talking about family issues

with PCGs were sought. Further to this HCPs were asked if they felt that asking questions about these psychosocial factors as a routine during admission would be helpful or otherwise and why this may be the case. The HCP interview guide also concluded with a question asking if participants had anything to add.

3.10.3.3 Focus groups with HCPs

Focus groups were conducted with HCPs in WA only where the author was based. While the author travelled interstate to collect survey data and conduct one-on-one interviews at the participating hospital in Victoria, the pre-organisation of focus groups proved to be impractical and was therefore not pursued. It was also important that the goodwill of stakeholders in Victoria who were already supporting recruitment for the author's short visits was not overextended. Therefore focus groups were conducted with HCPs in WA only.

Following information sharing about the project by the stakeholders and author, focus groups were arranged in ward and department areas. The times and venues for the focus groups were secured and advertised in staff room calendars within the participating areas. These times occurred during the overlap of shift workers on the ward areas when professional development activities were usually scheduled to accommodate attendance without interrupting clinical care. To encourage free expression of opinions and experiences, participation in focus groups were confined to a single discipline. For example, nurses only or physiotherapists only participated in a single focus group.

Focus groups were included as a method of collecting qualitative data because it was anticipated that informal discussion would be generated by the shared perspectives of participants while the Candidate acted as a moderator to keep the discussion flowing and encourage all participant to share their views. The same questions asked in the one-on-one interviews with HCPs also guided the focus groups, however, the emphasis was more on the flow of discussion and how participants interacted with each other as perspectives were shared. (See Appendix M). This generation of discussion and expression of similar and differing perspectives related to the topics of discussion are identified as key components of focus groups as distinct from one-on-one interviews (Ivey, 2011). It was anticipated that the wide range of experiential data and

perspectives generated in focus groups transcripts would add to insights in the one-on-one interview transcripts.

A total of four focus groups were conducted. Three with nurses and one with allied health staff. One nursing focus groups consisted mostly of nurses with less than three years of experience in paediatric nursing while nurses with more than five years of experience in paediatric nursing represented the majority of participants. Of the allied health staff one participant had practiced in paediatric healthcare for more than 10 years while the remaining participants had been in practice for more than three years. The focus groups were conducted in meeting rooms away from ward activities and were conducted within a one hour period. Data collection ceased when no new data were being recorded.

3.10.4 Thematic analysis

An inductive approach was applied to analysis of one-on-one interview and focus group transcripts using Braun and Clarke's (2006) six phases of thematic analysis. These steps are outlined in Figure 3.3 below.

Phase	Description of process
1. Familiarizing yourself with your data:	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2. Generating initial codes:	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes:	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.
5. Defining and naming themes:	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6. Producing the report:	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

Figure 3.3

Phases of thematic analysis from Braun & Clarke (2006) Using thematic analysis in psychology, *Qualitative Research in Psychology*, 3:2, p 87.

Phase One: Familiarisation with the data. Data transcription was conducted at the time of data collection. Each one-on-one interview and focus group audio recording were

listened to in order of collection as a way to remain immersed in the interview setting and interaction. Any identifying information was removed during the transcription stage to ensure anonymity was maintained and participants were allocated pseudonyms. The Candidate elected to complete the transcripts as a way to be immersed in the interview setting, the data and non-verbal and physical gestures expressed during the interviews and focus groups. Each interview and focus group was transcribed in order of collection, also as a way to remain connected to the interview setting. During transcription additional reflexive notes were made to ensure the aspects of body language and the interview environment were included. In this way subtle aspects within the interview were addressed. For example, pauses in speech were marked and audible or inaudible aspects of the interview such as laughter, or gestures were included.

To ensure accurate transcription records the audio recordings of two interviews and transcripts were randomly selected and reviewed by a member of the supervisory team. During this process, the transcripts were examined and re-examined and initial impressions were noted. The transcripts were recorded, entered, and managed using the NVivo 11 software package, Pro Edition Version 11.3.1.777 (QSR International Limited, Warrington, UK). Each transcript was read and re-read and reflexive notes already made were considered and additional reflexive notes were made where observations and further reflections were recorded.

Phase Two. Initial codes were generated where similar data were identified and coded together. These codes were named and entered in the NVivo programme which served as a way to organise examine and record the interpretive process. This process of examination and re-examination of the data allows for codes to be allocated to represent text segments. Words and expressions that were used frequently were noted. This process can be referred to as “winnowing” of the data where not all the information in the transcript is used and some may be discarded (Wolcott, 1994). Using an inductive approach also supported coding where data were not being made to “fit” into any pre-existing coding framework allowing analysis to be data driven (Braun & Clark, 2008). As it is almost impossible for researchers to eliminate their theoretical perspectives, the coding process was accompanied by further reflexive note taking and conducted and discussed in collaboration with supervisory team.

Phase Three: Grouping and categorising codes. After codes were applied to data these were organised into groups or categories. The transcripts were again examined and re-examined and the codes were grouped together according to commonalities. Applying codes or categories represents the heart of qualitative data where commonalities are grouped and detailed descriptions and dimensions begin to emerge (Creswell, 2013). To ensure robustness during this phase of analysis, categorisation of codes was discussed and reviewed during supervisory meetings. Here as well as organising codes into communal groups data that were anticipated or unusual or surprising were noted.

Phase Four: Identifying themes. During the third step of thematic analysis these codes were then subjected to a further process of re-examination whereby the coded data that were found to be similar or related were identified and categorised into groups. The process of examination and re-examination was conducted in conjunction with the supervisory team whereby coded groups in conjunction with reflexive notes were examined, re-examined and discussed during supervisory meetings. A thematic map was generated to visualise emerging of these groups using both the NVivo programme and manually by grouping and moving codes using colour codes on paper during supervisory discussions. Throughout, by using an inductive approach, the themes identified remained strongly linked to the data itself (Braun & Clark, 2006).

Phase Five: Naming the themes. The groups of coded data were examined and re-examined. This stage is important because some groups may not hold enough data to represent them while others may be too diverse (Braun & Clark, 2008). Further to this some larger themes may need to be divided to incorporate sub-themes or process themes to represent themes because these thematic groups were defined and named. Through a process of defining and refining, themes were identified and named. This was also subject to review examination and re-examination and discussion with the supervisory team. The named themes represented the fundamental nature of the data with attention to key meanings and interpretations.

Phase Six: Writing the report of findings. Finally the findings from thematic analysis were reported and illustrated in a resultant conceptual model to represent the identified and named themes. The written report was guided by the emergent conceptual model and presented in order of the identified and named themes. As outlined by Braun & Clarke (2008), the final report aims to be a coherent methodical and interesting account of the story the data represents.

Selection of thematic analysis was also ideal within the concurrent mixed methods design of triangulation where the results were reported in the results chapter followed by discussion in relation to the extant literature and the research questions at the centre of this study in the discussion chapter of this thesis.

3.11 Ethical considerations

This study was approved by the Human Research Ethics Committee (HREC) at Curtin University and the Child and Adolescent Health Services (CAHS) and the HREC at the Royal Children's Hospital in Melbourne. The procedure for recruitment of participants was established collaboratively with the Candidate and key representatives from areas where Heads of Departments had given authorisation for recruitment of primary caregivers and healthcare providers in their areas. The information sheets (Appendix B) and consent form (Appendix C) informed PCGs that their decision to participate or not would not in any way affect their child's care. Similarly the information sheet (Appendix E) and consent form (Appendix F) for HCPs stated that their relationship with their employer would not be compromised by their choice to participate or not.

To ensure confidentiality, survey data was de-identified and could not be traced back to the participant. Hard copy data was accessible by the author and supervisory team only and is kept in a locked filing cabinet in a secure office that remains locked when not in use at the School of Nursing and Midwifery at Curtin University. Electronic information was kept on a password protected hard drive assigned specifically for research data at Curtin University and accessible only by the Candidate and supervisory team. Participants were informed to contact the author with any questions related to participation or the content of the survey. In the event of having any concerns of an ethical nature participants were asked to contact the ethics officer at the relevant hospital's Human Research Ethic Committee on the number supplied. Following completion of the study electronic and hardcopy data including copies of surveys will continue to be stored indefinitely as required by the Western Australian Health Department and the policy for retaining and destroying data by the University.

3.12 Chapter Summary

In this chapter the mixed methodology for this formative evaluation was justified. The concurrent collection of quantitative and qualitative data was outlined through the detailed description of the research setting, sampling approach, and the procedure for

the engagement of stakeholders and the recruitment of participants. The selection of instruments contained in each of the two surveys was described and justified, and the statistical approach was explained. The qualitative methodology was detailed in which one-on-one interviews and focus groups were conducted concurrently with survey data collection.

In the following chapter the results of the analysis of survey data are presented followed by the findings of the thematic analysis of interview and focus group data.

4. Results

4.1 Introduction

This chapter is divided into two sections. In the first section quantitative analyses of survey data from PCGs and HCPs are detailed and tabulated. In the second section of this chapter findings thematic analysis of qualitative data from PCG and HCP transcripts are presented where emergent themes are identified and named. An emergent conceptual model which is used to guide presentation of these findings is presented.

4.2 Quantitative findings

In this section the findings from statistical analysis of the survey data collected from participating primary caregivers and healthcare providers at the two participating tertiary paediatric hospitals are presented. Two datasets were organised using SPSS software, containing the survey data collected from primary caregivers and healthcare providers respectively. Data were entered in the SPSS dataset. Findings from analyses conducted using the primary caregivers' dataset will be outlined followed by the results of analyses from the healthcare provider sample. Response rates and sociodemographic characteristics of the participants are described. Descriptive analyses are presented and frequency distributions and findings are tabulated. Sub-scale and total scale scores of the validated instruments contained within the surveys are presented. Correlations are examined and reliability testing is outlined and presented. The appropriate statistical analyses are applied to account for normal distribution, and statistical analyses examining relationships between continuous, categorical, and binary variables are reported. Cross-tabulation findings between the demographic characteristics of the participants and the ten components of the family psychosocial assessment framework that are predictive of improved, or conversely reduced child health outcomes, are reported for each dataset and statistically significant relationships are noted. Finally, bivariate analyses examined the relationships between the degrees of importance participants' assigned to each of the psychosocial components of the family psychosocial assessment framework in development and their recorded scores for psychosocial orientation.

4.2.1 Primary caregiver survey results

4.2.1.1 Response rates

A total of 141 surveys were received from participating PCGs in Western Australia and Victoria. In Western Australia, a total of 175 hardcopy survey packs were displayed or distributed between February and April 2014 in the clinic and ward areas of PMH and 111 people completed a hard copy surveys were returned giving a response rate of 63 per cent at PMH. From April 20th to May 15th 2015 a further 30 PCGs attending RCH in Victoria completed a hard copy survey. A total of 50 surveys were displayed or distributed by staff and 12 remained after a four week data collection period. As thirty completed consent forms and surveys were received through Australia Post, a 60 per cent response rate from PCGs in Victoria was calculated.

4.2.1.2 Sociodemographic characteristics of participating PCGs and comparison with the general Australian population

Figure 4.1 illustrates sample distribution relating to level advantage using Socio-economic index for advantage (SEIFA) from the Australian Bureau of Statistics outlined in the Methodology Chapter. (See Figure 4.1)

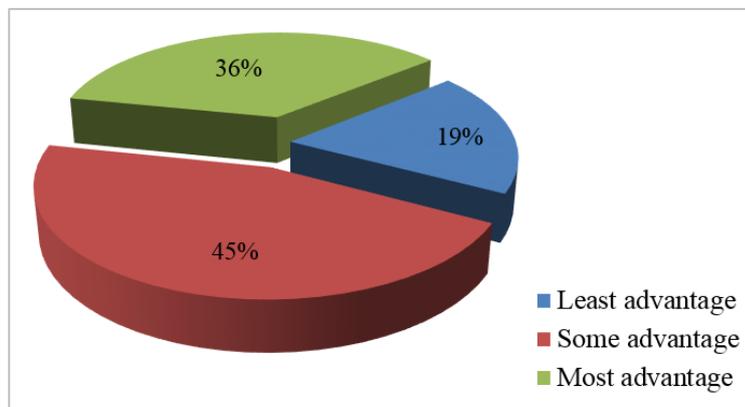


Figure 4.1

Distribution of primary caregivers according to level of advantage using SEIFA from ABS (2011)

In Table 4.1 sociodemographic characteristics of participating primary caregivers from Western Australia and Victoria are compared to the Australian population from Australian Bureau of Statistics (ABS, 2011). (See Table 4.1)

Table 4.1
Sociodemographic characteristics of participating primary caregivers from WA and VIC compared with the Australian population

Characteristic	WA %	VIC %	ABS %
Gender			
Female	91	90	49
Male	9	10	51
Education			
Did not complete high school	15	7	23
Finished Year 12	21	13	20
Trade or diploma	31	23	32
University degree	33	57	25
Country of birth			
Australia / New Zealand	83	82	63
Asia	5	4	2
Canada / USA	5	3	< 1
Europe	5	11	10
South Africa / Africa	2	0	1
Other	0	0	23
English spoken at home			
Yes	97	98	79
No	3	2	21

Almost 80 per cent of the sample was made of participants from Western Australia (n = 111). Of these 91 per cent (n = 101) were female and 9 per cent (n = 9) were male while 90 per cent (n = 27) were female and 10 per cent (n = 3) were male in the Victoria sample. This was not in keeping with the state population, however, this was not expected as the nature of this research meant that the larger proportion of participants were likely to be mothers. A higher incidence of Australian born participants was seen across the sample in comparison to records from the Australian Bureau of Statistics (ABS, 2011). A higher proportion of participants who completed the survey spoke only English at home in comparison to ABS records. Three per cent (n = 4) of participants in WA and 3 per cent (n = 1) reported speaking another language at home compared to 21 per cent reported in census data. Eighty five per cent of participants completed high school (VIC n = 25; WA, n = 94) and 33 per cent of these held a university degree (n = 37). See Table 4.1

4.2.1.3 Demographic and health characteristics of seriously or chronically ill children

The characteristics of the children from the combined sample of primary caregivers are presented on Table 4.2. Forty three per cent of the children of participating primary

caregivers were female (n = 60) while 55 per cent were male. The sample represented a uniform range across age groups and a wide range of the primary health concerns of the participants' children. Major health problems related to neurological function while developmental problems accounted for 31% of the sample (n = 45). Respiratory disease, infection and cardiac disease followed. See Table 4.2. Seventeen per cent (n = 25) of the children were reported as having additional health problems. See Table 4.2.

Table 4.2
Characteristics of participating primary caregivers' children

Characteristic	n	%
Gender		
Female	61	43
Male	77	55
Missing	3	2
Age range		
Birth to one year	28	21
> 1 and < 3 years	26	18
> 3 and < 6 years	26	18
> 6 and < 10 years	25	17
> 10 years	33	24
Missing	3	2
Primary chronic illness		
Allergy and autoimmune	6	4
Behavioural	3	2
Cancer	3	2
Developmental / Neurological	45	31
Endocrine	5	3
Gastrointestinal tract	10	7
Heart disease	15	11
Infection	17	13
Metabolic disease	8	6
Renal disease	5	3
Respiratory problems	20	15
Trauma	4	3
Missing	0	0
Additional major health problems		
Asthma	10	7
Diabetes / other endocrine problem	2	1
Digestive / feeding	6	4
Sleep apnoea	3	2
Tracheostomy / ventilator dependent	4	3
No additional problems reported	116	83
Missing	0	0

Respiratory disease was reported as their child’s principal health concern by 15 per cent of participating primary caregivers’ (n = 20) while serious infection and heart problems were reported by 13 per cent (n = 17) and 11 (n = 15) per cent respectively. The prevalence of the remaining conditions represented on Table 4.2 above ranged from one to seven percent.

4.2.1.4 PCG attitudes about psychosocial assessment

The adapted version of the PATPSI contained in the PCGs survey contained three subscales. Figure 4.2 below shows the frequency distribution of the first subscale score which measured participating primary caregivers’ attitudes (n = 141) about “health seeking intentions” with a possible score range from 5 to 25 representing least to most positive attitudes. The frequency distribution showed Skewness $-.73$ and Kurtosis 1.16 which was indicative of a normal distribution and reflected with the normal curve imposed in this figure. It was, therefore, appropriate to use parametric statistics. The scores ranged from the lowest score of 7 to the highest score of 23 with a mean score of 19.11 , and standard deviation (SD) of ± 3.22 (see Figure 4.2).

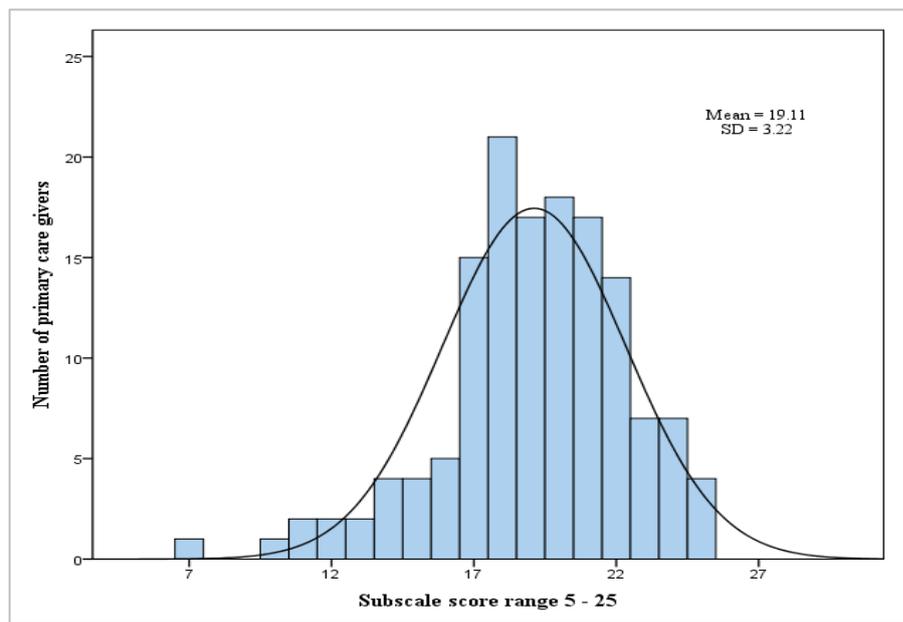


Figure 4.2
Distribution of primary caregivers subscale scores “Help seeking intentions”

The range of scores for the second subscale named “help seeking attitudes” is illustrated in Figure 4.3 which was also found to be normally distributed with a Skewness value of $-.350$ and a Kurtosis value of $.878$.

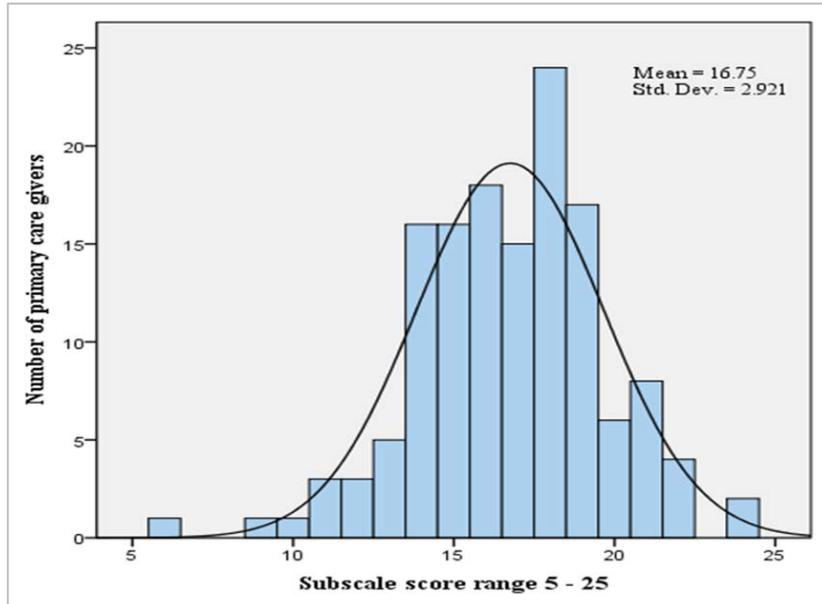


Figure 4.3

Distribution of primary caregivers subscale scores “Help seeking attitudes”

The subscale score range for “help seeking attitudes” about psychosocial issues ranged from 7 to 24 with a mean score of 16.75 (\pm SD 2.91). Skewness of -.80 and Kurtosis - 1.59 was also indicative of a normal distribution which is illustrated in this figure with an imposed normal curve for this subscale. See Figure 4.3.

Figure 4.4 shows the subscale score measuring primary caregivers “attitudes about stigma in relation to psychosocial issues”.

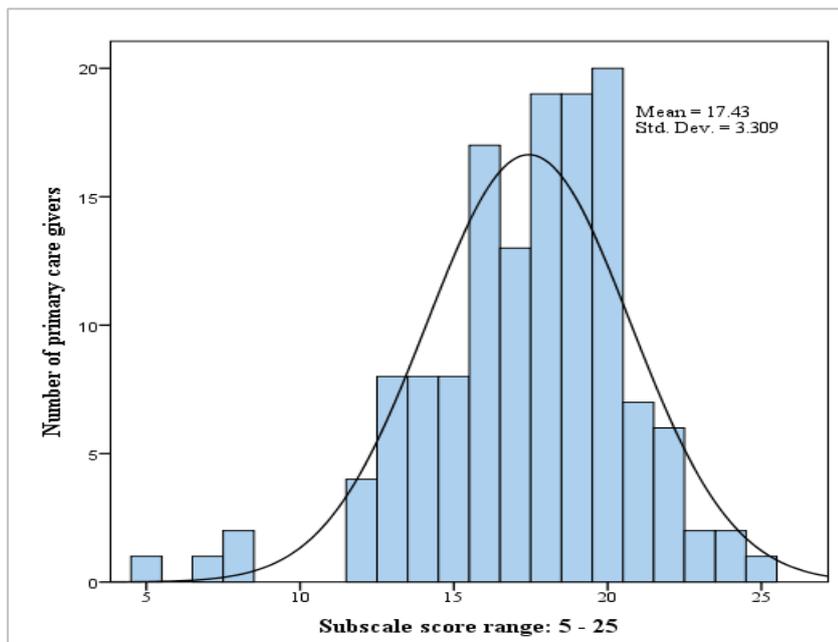


Figure 4.4

Distribution of primary caregivers subscale scores
“Attitudes about stigma in relation to psychosocial issues”

The frequency distribution for participants' attitudes about stigma in relation to discussing or seeking support for psychosocial issues showed Skewness of $-.802$ and Kurtosis of 1.59 indicating a normally distributed sample for this subscale score as shown with imposed normal curve. The scores ranged from 5 to 25 with a mean score of 17.43 ($SD \pm 3.30$).

The total *PATPSI* scores represent the combined scores for the three subscale scores are shown on Figure 4.5. As with the subscales scores the distribution of the *PATPSI* scores was found to be normally distributed with Skewness value of $-.85$ and Kurtosis of 2.68 . This is highlighted in the figure using a normal curve. The total *PATPSI* scores recorded ranged from a least positive attitudinal score of 23 to 73 indicating the most positive attitudes with a mean score of 52.93 ($SD \pm 6.93$). See Figure 4.5.

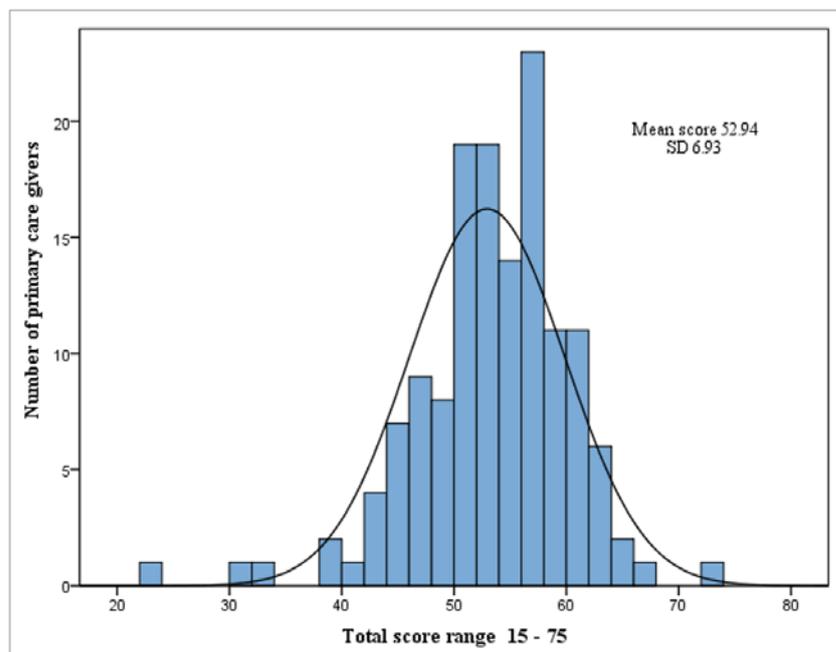


Figure 4.5

Distribution of primary caregivers total psychosocial attitudinal scores using a modified version of the *PATPSI* ($n = 141$)

4.2.1.5 Consistency of the *PATPSI* scale modified for the survey

As the *PATPSI* scale was modified for the purpose of this study it was important to examine that the items included in the subscales remained closely interrelated and were examined for internal consistency. Table 4.3 shows that the three modified *PATPSI* subscales remained closely correlated with stigma with p value less than 0.01 using Pearson Correlation test. See Table 4.3.

Table 4.3
Distribution of primary caregivers total psychosocial
attitudinal scores using a modified version of the *PATPSI*

		Intentions <i>n = 141</i>	Attitudes <i>n = 141</i>	Stigma <i>n = 134</i>
Help seeking intentions	Pearson Correlation	1.0	0.140	0.250
	Sig. (2 tailed)		0.000	0.004
Help seeking attitudes	Pearson Correlation	0.546	1.0	0.570
	Sig. (2 tailed)	0.000		0.000
Stigma	Pearson Correlation	0.544	0.570	1.0
	Sig. (2 tailed)	0.000	0.000	

All correlation is significant at the 0.01 level of significance

A Cronbach's alpha of .79 indicated that the items on the modified sub-scales "help seeking intentions", "help seeking attitudes" and "stigma" were a reasonable measure of attitudes towards psychosocial issues (DeVon et al., 2007).

4.2.1.6 Levels of importance assigned to the psychosocial components of the psychosocial framework by PCGs

Table 4.4 shows the allocation of importance assigned by PCGs to each of the psychosocial components included in the framework as "very important", "of some importance", and "of little or no importance".

Over 70 per cent of participants indicated that emotional support and self-confidence were very important, while over 50 per reported this was the case for family relationships and social support. "Some importance" or "very important" was also assigned to engagement in community activities and financial strain by participants. Less importance was assigned to education with 26 per cent (n = 36) of primary caregivers while 11 per cent (n = 16) assigned little or no importance to the influence of their occupations on their children's health. See Table 4.4.

Table 4.4
Levels of importance allocated to the psychosocial components by PCGs

Psychosocial component	n	%
Your education		
Very important	35	25
Of some importance	68	48
Of little or no importance	37	26
Missing	1	1
Your occupation		
Very important	16	11
Of some importance	89	63
Of little or no importance	36	26
Your emotional health		
Very important	103	73
Of some importance	37	26
Of little or no importance	1	1
Your self- confidence		
Very important	113	80
Of some importance	26	18
Of little or no importance	2	2
Family structure		
Very important	68	49
Of some importance	66	46
Of little or no importance	7	5
Family relationships		
Very important	71	51
Of some importance	64	45
Of little or no importance	6	4
Family life stress		
Very important	52	36
Of some importance	84	60
Of little or no importance	5	4
Family financial strain		
Very important	29	21
Of some importance	89	63
Of little or no importance	23	16
Your social support		
Very important	80	57
Of some importance	61	43
Of little or no importance	0	0
Your engagement in community activities		
Very important	30	21
Of some importance	94	67
Of little or no importance	16	12

4.2.1.7 Relationships between sociodemographic characteristics of PCGs and total attitudinal scale scores

Bivariate analyses were performed using T-tests and One-way ANOVA to examine the relationships between sociodemographic characteristics of primary caregivers and *PATPSI* scores. These findings are presented in Table 4.5

Table 4.5
Bivariate and ANOVA analyses of participating primary caregivers’ sociodemographic characteristics and attitudinal subscale and total scale scores using the *PATPSI* modified for this sample

Characteristic	Help seeking intentions		Help seeking attitudes		Attitudes about stigma		Total Score	
	mean	(SD)	mean	(SD)	mean	(SD)	mean	(SD)
Gender								
Female	19.31	(3.03)	16.76	(2.82)	17.44	(3.44)	53.18	(6.42)
Male	17.15*	(4.37)*	16.92	(3.86)	16.46	(3.59)	50.54	(10.83)
Australian born								
Yes	19.13	(3.07)	16.79	(3.02)	17.38	(3.30)	52.93	(6.45)
No	18.96	(3.81)	16.75	(2.56)	17.18	(4.13)	52.89	(8.80)
Education								
High school incomplete	19.95	(3.71)	16.37	(3.43)	17.61	(3.41)	53.47	(8.90)
Finished Year 12	19.11	(3.80)	16.59	(2.99)	17.96	(2.70)	53.00	(5.42)
Trade or diploma	19.66	(3.60)	16.83	(3.54)	17.54	(3.95)	53.61	(8.35)
University degree	18.41	(3.84)	16.91	(2.44)	17.04	(3.03)	52.20	(5.64)
SEIFA								
Least advantage	19.27	(2.14)	15.88	(2.79)	17.04	(3.14)	51.88	(5.98)
Some advantage	19.14	(3.45)	16.85	(3.03)	17.31	(3.29)	52.86	(7.07)
Most advantage	19.00	(3.42)	17.14	(2.79)	17.54	(3.85)	53.58	(7.25)
State								
Western Australia	18.23	(2.06)	16.77	(2.31)	17.43	(3.39)	52.43	(5.23)
Victoria	19.35*	(3.43)*	16.77	(3.07)	17.32	(3.49)	53.07	(7.33)

Statistically significant difference: * p-value < .05, ** p-value < .01, *** p-value < .001
n = 130

Table 4.5 shows that there was a significant difference between males and females for the subscale measuring “help seeking intentions” with female participants reporting more positive attitudes towards helping seeking intentions ($t = 2.33$; $p = .021$ two tailed). The table also shows that primary caregivers from Victoria expressed more positive intentions about seeking support for psychosocial issues than those from Western Australia for this sample ($t = 2.2$; $p = .028$). However, there were no significant differences between participants’ attitudes about seeking help ($t = .10$; $p = .921$), or stigma ($t = .19$; $p = .852$), or the total scale score ($t = .76$; $p = .451$) across Victoria and Western Australia. No significant differences in attitudes were reported

between the participating primary caregivers who were born in Australia and those who were not for help seeking intentions ($t = .23; p = .81$), help seeking attitudes ($t = .07; p = .94$), attitudes about stigma ($t = .27; p = .78$) and the total attitudinal scale scores using the modified *PATPSI* ($t = .02; p = .98$). Table 4.6 also shows that there were no statistically significant differences between the help seeking intentions ($F = 1.7; p = .16$), help seeking attitudes ($F = .21; p = .88$), attitudes about stigma ($F = .22; p = .87$) and the total attitudinal scores for this sample ($F = .36; p = .77$) for primary caregivers related to their level of educational attainment. Likewise there were no reportable differences in the attitudes of participating primary caregivers who resided in areas of least, some, or most advantage for help seeking intentions ($F = .06; p = .93$), help seeking attitudes ($F = 1.6; p = .20$), attitudes about stigma ($F = .18; p = .83$), and the total modified attitudinal score ($F = .51; p = .59$). See Table 4.5.

4.2.1.8 Relationships between PCG sociodemographic characteristics and the level of importance allocated to psychosocial components

Chi-square analysis and Fisher's exact test which was conducted when assumptions for frequencies were violated showed no statistically significant differences between the levels of importance allocated to the psychosocial components and the sociodemographic characteristics of the participants. These characteristics were gender, level of educational attainment, and the State where participants were recruited. While undertaking these analyses was important, the results were found to be inconsequential. To ensure presentation of the results are meaningful and efficient while ensuring a record of these analyses are included in this thesis, the tables representing these analyses have been placed in in Appendix N. See Table N for Table 4.14, 4.15 and 4.16 for levels of importance allocated by participating primary care giver to components of the proposed psychosocial assessment framework by gender, levels of education attainment, and State of recruitment respectively. (See Appendix N).

4.2.1.9 Relationships between the levels of importance assigned to the psychosocial components by PCGs and their total attitudinal scores

To assess if the components of the proposed psychosocial framework were related to high levels of psychosocial orientation, relationships between the levels of importance assigned to the components and total psychosocial attitudinal scores were examined (see Table 4.6).

Table 4.6
Association between levels of importance assigned to
psychosocial components by total PATPSI scores using one way ANOVA

Component	Little or no importance		Some importance		Very important	
	mean	(SD)	mean	(SD)	mean	(SD)
Your education	51.33	(7.37)	52.55	(6.92)	55.35	(5.98)*
Your occupation	51.72	(7.19)	53.18	(6.41)	53.56	(6.28)
Your emotional health	48.00	(8.02)	49.08	(8.59)	54.26	(5.60)***
Your self confidence	53.50	(7.77)	48.50	(8.57)	53.85	(6.06)***
Family structure	43.86	(14.92)	52.77	(6.02)	53.94	(5.84)***
Family relationships	42.17	(9.01)	52.09	(6.86)	54.61	(5.86)***
Life stress	44.40	(7.40)	52.23	(6.17)	54.96	(6.55)***
Money worries	50.78	(10.56)	52.98	(5.39)	54.52	(7.40)
Social support	-	-	51.52	(6.79)	54.04	(6.88)*
Your engagement in community activities	51.88	(9.27)	52.67	(6.63)	54.37	(7.10)

Statistically significant difference * p-value < .05, ** p-value < .01, *** p-value < .001

PCGs who reported that maternal education was important to their child’s health and wellbeing reported more positive psychosocial attitudinal scores than those who considered maternal education to be of no importance (F statistic 3.48; $p = .03$).

The differences in mean scores were found to be statistically significant between those who reported emotional wellbeing was very important and those who considered it to be of some importance (F = 6.51; $p = .001$). Bonferroni correction did not apply to emotional wellbeing or social support because no participants selected “*little or no importance*” for either of these psychosocial factors. For social support the difference was also statistically significant at a p value of .05 as there were no violation of frequencies (F Statistic of 4.5; $p = .034$). The mean scores of participants who allocated more importance to the components of the psychosocial assessment framework were consistently higher for the remaining components. Differences between mean scores were examined for the remaining psychosocial components using Bonferroni correction. Participants who considered the psychosocial predictors to be “*very important*” scored higher attitudinal scores than those who considered them to be “*of little or no importance*” for self-confidence (F = 6.92; $p = .001$), family structure (F = 7.43; $p = .001$), family relationships (F = 11.19; $p = .001$), and life stress (F = 6.90; p

= .001). While importance was assigned to money worries ($F = 1.89$; $p = .15$), occupation, ($F .67$; $p = .51$) and engagement in the community ($F = .903$; $p = .41$), these were not found to be related to higher or lower attitudinal scores. See Table 4.6.

4.2.2 Healthcare provider survey results

4.2.2.1 Response rates

A total of 350 surveys were received from the two participating healthcare providers at the two tertiary paediatric hospitals.

In Western Australia, 150 hardcopy survey packs were distributed. One hundred and twenty three consent forms were completed and returned with surveys of which 120 were completed giving response rate of 80 percent for the HCP sample in WA.

At the participating paediatric hospital in Victoria, online surveys were completed by two hundred and thirty participants. The response rate was calculated within the Qualtrics programme that was used to generate the survey. The total number of recipients who received an email was calculated as 580. Therefore, a response rate of 40 per cent was recorded for the online survey in Victoria.

4.2.2.2 Characteristics of the participating HCPs

The proportions of years of experience participants had practised in their roles is shown on Figure 4.6

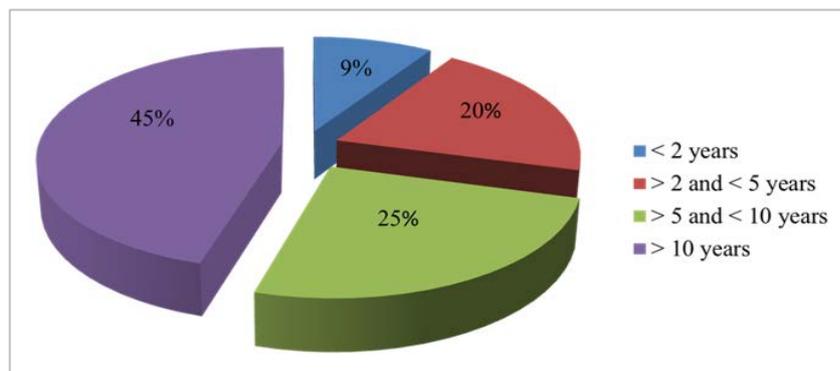


Figure 4.6
Health care providers' years of experience
in health professional roles

Seventy per cent of the sample reported having more than five years of experience in their professional roles, while less than two per cent reported being in practice for less than two years. (See Figure 4.6).

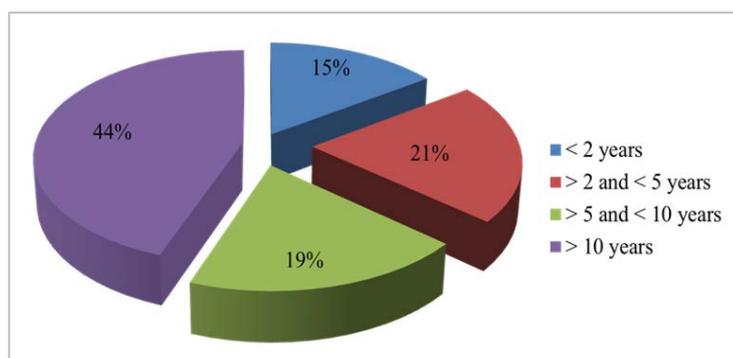


Figure 4.7

Health care providers' years of experience in professional role in the paediatric setting

Over sixty per cent of participants reported being in practice in their professional roles in the paediatric setting for more than five years while 15 per cent reported being in their first two years of paediatric clinical practice. See Figure 4.7.

The HCP sample consisted largely of female nurses. Prevalence rates for HCP demographic and professional characteristics are presented in Table 4.7.

Table 4.7
Sociodemographic characteristics of participating HCPs

Characteristic	n	%
Gender		
Female	322	92
Male	26	7
Missing	2	1
Profession		
Nurse	289	82
Other allied health	34	10
Doctor	17	4
Psychologist/social worker	10	2
Years in practice		
0 to 2 years	32	9
> 2 and < 5 years	70	20
≥ 5 and < 10 years	85	25
≥ 10 years	158	45
Missing	5	1
Years of practice in paediatrics		
0 – 2 years	52	15
> 2 and < 5 years	75	21
≥ 5 and < 10 years	68	19
> 10 years	154	44
Missing	1	1
State		
Victoria	230	66
Western Australia	120	34

Sixty six per cent (n = 230) of the overall sample came from the online survey generated for participation at the participating tertiary paediatric hospital in Victoria. The online survey link remained active for a four week period following publication on and was deactivated on Tuesday 19 May 2015. Most survey responses were completed within three days of publication with the survey programme recording 223 responses in this time. The remaining seven were completed before conclusion of the third week while no responses were submitted in the fourth week before the online survey link was closed. Thirty four per cent (n = 120) of the healthcare provider sample came from Western Australia in the form of completed hardcopy surveys which were returned by prepaid post to the author from the participating hospital within the two month recruitment period.

4.2.2.3 Attitudes of participating HCPs about psychosocial assessment

Healthcare providers' attitudes about psychosocial assessment were measured using the Physician Belief Scale which was adapted for this sample and contained three subscales each measuring different aspects of psychosocial orientation. These frequencies and distributions were tabulated for the three subscale scores and overall total score and are represented in the following four figures. All were found to be normally distributed which is illustrated in each with the inclusion of a normal curve.

Figure 4.8 shows the frequency distribution for HCP scores representing the subscale 'attitudes about roles in relation to psychosocial issues'. This figure shows a score range of 13 – 30 with a mean score of 22.87 out of 30 and a standard deviation of ± 3.38 . A skewness value of -0.25 and Kurtosis -0.075 indicated of a normal distribution which is illustrated in the figure of this subscale with an imposed normal curve. See Figure 4.8.

Figure 4.9 shows the range of scores for the second subscale. This subscale measured the attitudes of HCPs about addressing psychosocial issues in relation to what parents want. See Figure 4.9. The scores for this subscale ranged from 12 indicating the least psychosocial orientation for this sample to 30 indicating the most psychosocial orientation. Skewness of -0.105 and kurtosis of -0.120 also supported a normal distribution. See Figure 4.9.

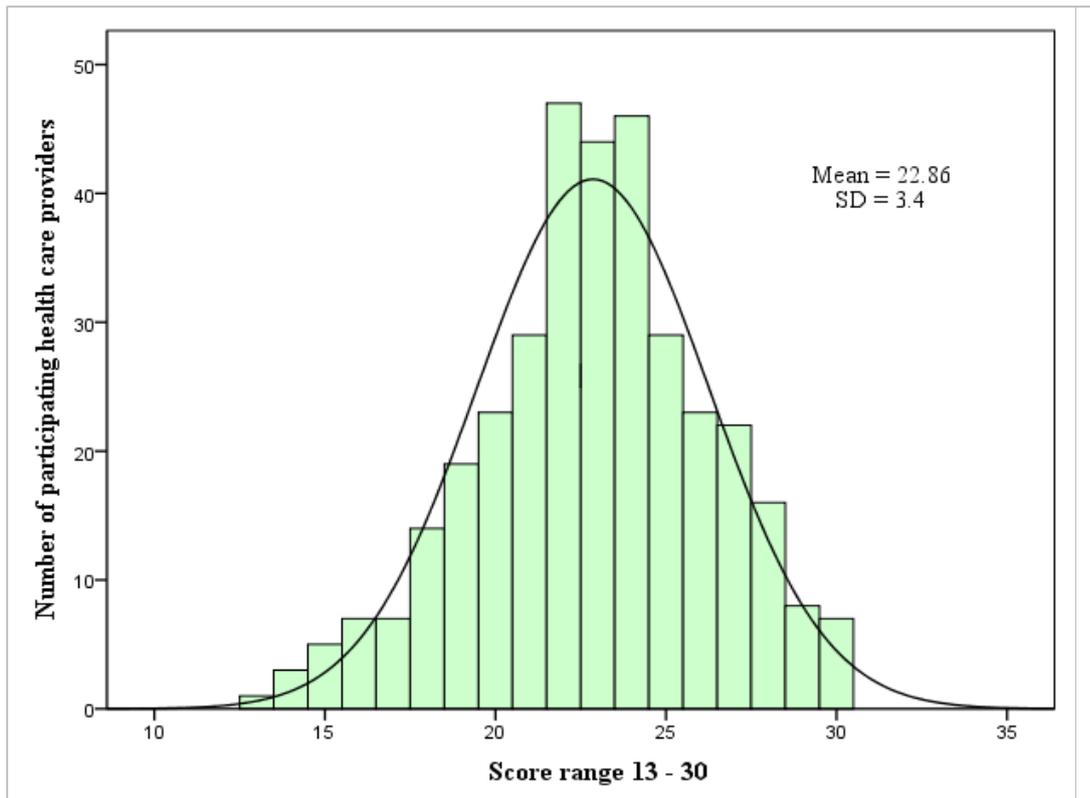


Figure 4.8
 Distribution of health care providers subscale scores
 “Attitudes about psychosocial issues in relation to their roles”

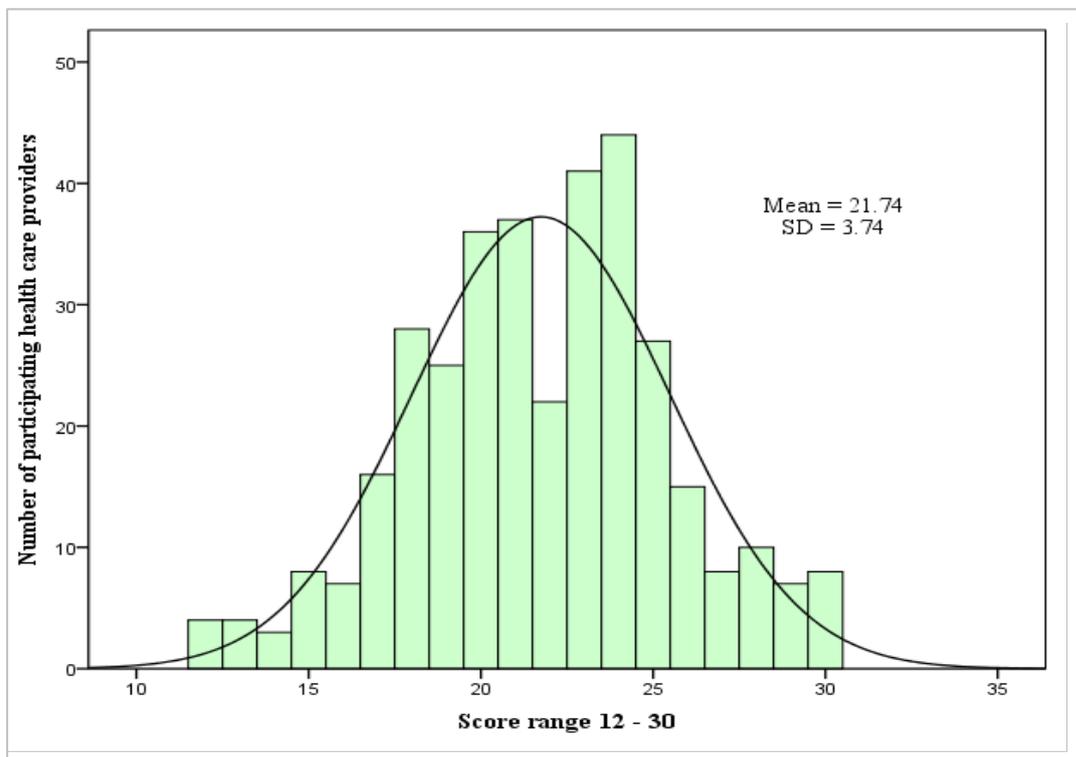


Figure 4.9
 Distribution of health care providers subscale scores
 “Attitudes about what parents want in relation to psychosocial issues”

The third subscale measuring HCPs attitudes about their reactions to parents as individuals in relation to psychosocial issues is presented in Figure 4.10. This figure shows a mean score of 27.36 and SD of 3.9 where the score ranges from 16 showing least positive attitudes to 35 representing the most positive attitudes. The sample representing this subscale also reflected a normal distribution with Skewness of $-.300$ and Kurtosis of $-.095$. See Figure 4.10.

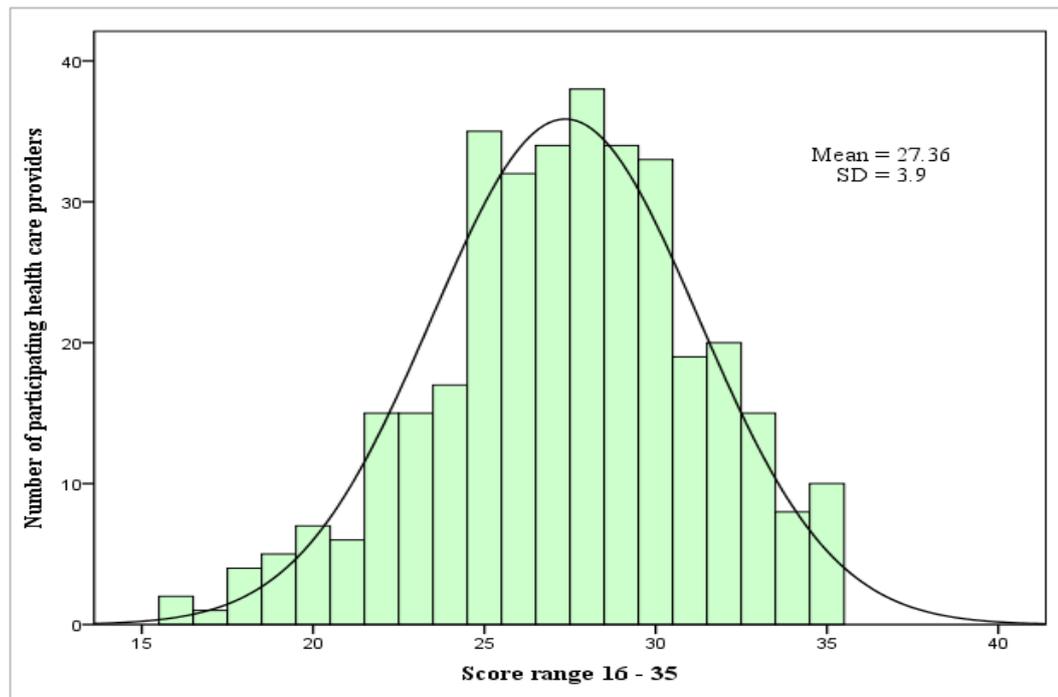


Figure 4.10
 Distribution of health care providers subscale scores
 “Attitudes about HCPs reactions to parents as individuals”

With six items each in the subscale measuring participants attitudes about their role and what parents want in relation to psychosocial assessment, the 5 point Likert Scale-Score gave a possible score range of 5 to 30. The seven items in the third subscale score measuring participants’ attitudes about their reactions to parents as individuals in relation to psychosocial assessment also used a 5 point Likert-Scale Score and gave a score range of 5 – 35. The combined total belief scale scores therefore ranged from 19 to 95 where again the lower score indicated the least psychosocial orientation; and the highest scores, the most. The overall total scores for the Belief Scale modified for this research are shown in Figure 4.11. This distribution was also found to be normally distributed with Skewness of $-.116$ and Kurtosis of $.225$. The total scale mean score was 71.97 with a standard deviation of 9.24. See Figure 4.11.

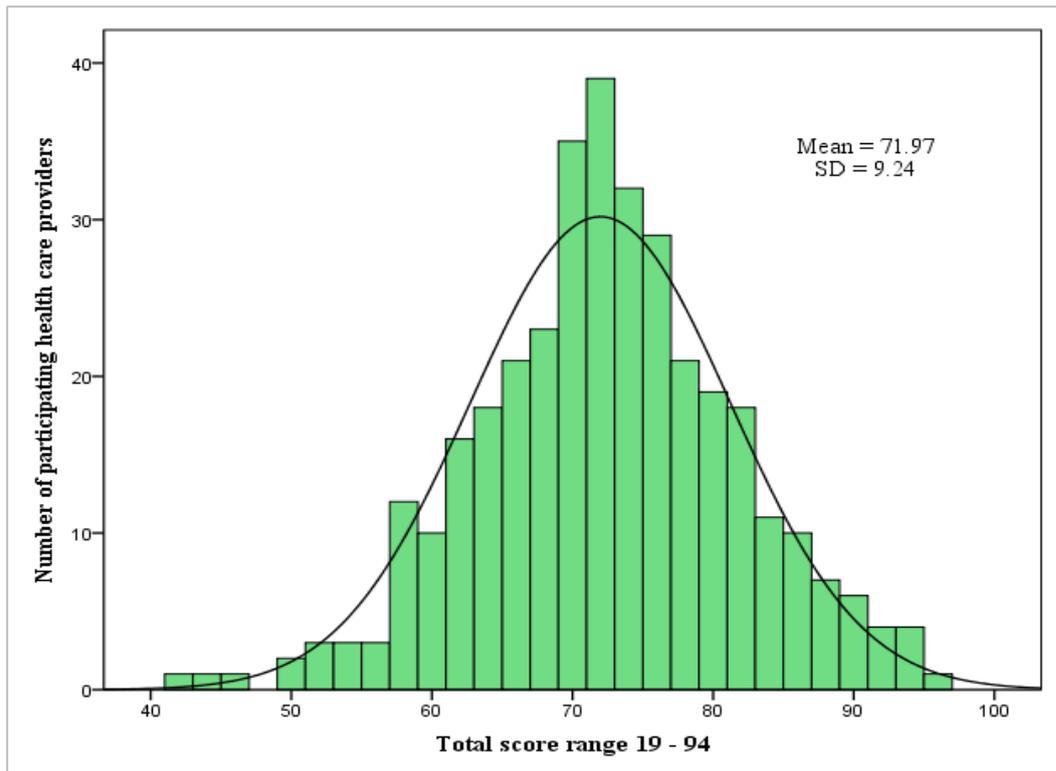


Figure 4.11
Distribution of health care providers total scale scores for modified belief scale measuring psychosocial awareness/orientation

4.2.2.4 Consistency of modified scale used in the HCP survey

Table 4.12 shows correlation of the variables making up each of the subscales. As expected, the three modified subscales remained highly correlated with p value less than .001. In addition a Cronbach's alpha of 8.4 indicated that the items on the amended scale remained a reasonable measure of psychosocial orientation in relation to health providers' roles, responding to what parents want and reactions about responding to psychosocial issues as an individual.

Table 4.8
Correlation between belief sub-scale attitudinal scores by health care providers

		Role	Parents	Reactions
Role	Pearson Correlation	1.0	0.546**	0.544**
	Sig. (2 tailed)		0.000	0.000
What parents want	Pearson Correlation	0.546**	1.0	0.570**
	Sig. (2 tailed)	0.000		0.000
Own reactions	Pearson Correlation	0.544**	0.570**	1.0
	Sig. (2 tailed)	0.000	0.000	

** Correlation is significant at the 0.01 level of significance ($n = 350$)

4.2.2.5 Relationships between sociodemographic characteristics of HCPs and their total attitudinal scale scores

Bivariate analyses were conducted to examine the relationships between binary and categorical variables representing the sociodemographic characteristics of the participating healthcare providers with the belief subscale and total scale scores as outcome variables. These findings are illustrated in Table 4.9.

Independent t tests were conducted to compare the subscale and total scale belief scores for binary variables representing gender and State. Two-tailed independent t tests indicated that Levene's test for equality of variances was assumed. Findings showed there were no significant differences between males and females for the subscale scores measuring participants' attitudes about their roles, ($t = .59$; $p = .56$ two tailed) and reactions to psychosocial assessment ($t = .26$; $p = .79$ two tailed), and the overall total belief scale scores ($t = .99$; $p = .32$ two tailed) (see Table 4.10). A significant difference between male and female subscale scores was reported with male participants scoring higher in their psychosocial orientation of what parents wanted in comparison to females ($t = 2.2$; $p = .028$) with (See Table 4.9).

HCPs from Victoria scored higher than participants from Western Australia for each of the belief subscale scores. With equal variances assumed and using a p value $< .01$, a significant difference in mean subscale scores were reported indicating higher psychosocial orientation among healthcare providers in Victoria in relation to their roles ($t = .59$; $p = .004$), what parents want ($t = 2.2$; $p = .001$), and their reactions to psychosocial issues as individuals ($t = .26$; $p = .002$). However, the difference reported between the groups for overall belief scale scores were not found to be significantly different ($t = .99$; $p = .24$). See Table 4.9.

One way analyses of variances using Bonferroni correction showed no significant differences in mean subscale scores for participants' attitudes about their individual roles ($F = 1.3$; $p = .25$), what parents want ($F = 1.67$; $p = .17$), and individual reactions to psychosocial issues ($F = 2.07$; $p = .10$). Similarly, one way ANOVA analysis showed that total belief scale scores were similar across the professional roles of participants with F statistic = 1.9 and a p value of .11. See Table 4.9.

Table 4.9
Relationships between health care providers' sociodemographic characteristics and subscale and total belief scale scores

Characteristic	"Role" subscale		"Parents want" subscale		"Reactions" subscale		Total belief score	
	mean	(SD)	mean	(SD)	mean	(SD)	mean)	(SD)
Gender								
Female	22.86	(3.39)	21.64	(3.72)	27.40	(3.85)	71.90	(9.20)
Male	23.27	(3.08)	23.31	(3.39)*	27.19	(4.14)	73.77	(8.53)
Profession								
Nurse	22.85	(3.30)	21.64	(3.60)	27.18	(3.83)	71.67	(8.92)
Doctor	22.41	(3.37)	22.88	(4.59)	28.59	(3.84)	73.88	(9.67)
Psych/social worker	24.67	(5.87)	23.44	(6.28)	29.56	(5.68)	77.67	(16.74)
Other allied health	23.03	(2.98)	21.29	(3.32)	27.87	(3.93)	72.19	(8.37)
Years of practice								
0 – 2 years	22.91	(3.87)	20.38	(3.91)	27.72	(3.98)	71.00	(10.17)
> 2 and < 5 years	22.04	(3.17)	20.67	(3.45)	27.03	(3.46)	69.74	(7.67)
> 5 and <10 years	22.69	(3.16)	21.46	(3.69)	26.76	(4.02)	70.92	(9.06)
> 10 years	23.41	(3.31)*	22.66	(3.56)***	27.75	(3.85)	73.81	(9.19)**
Years in paediatrics								
0 – 2 years	22.85	(3.38)	20.83	(3.84)	27.92	(3.55)	71.60	(8.82)
> 2 and < 5 years	22.04	(3.47)	20.60	(3.63)	26.99	(3.74)	69.63	(8.89)
> 5 and <10 years	22.78	(3.10)	21.60	(3.87)	26.69	(4.22)	71.07	(9.47)
> 10 years	23.37	(3.38)*	22.69	(3.48)***	27.66	(3.90)	73.73	(9.17)**
State								
Western Australia	22.16	(3.45)	20.78	(3.67)	28.25	(3.64)	71.19	(8.89)
Victoria	23.24	(3.30)**	22.24	(3.70)**	26.90	(3.94)**	72.38	(9.42)

Statistically significant difference: * p-value < .05, ** p-value < .01, *** p-value < .001

Also on Table 4.9, the total belief scale mean scores for HCPs with more than 10 years' experience in their roles scored higher in their belief scale scores than those with between two and five years of experience (F Statistic of 4.165 and a *p* value of .006). Post hoc comparisons using Bonferroni correction showed similar differences between mean subscale attitudinal scores between HCPs roles with more than ten years in their roles and those with two to five years in practice ($F = 2.83$; $p = .039$). Similar differences were reported between these two groups for scores measuring HCPs attitudes about what parents want with HCPs with more than ten years' experience also scored higher than those with two to five years' experience in their professional roles ($F = 7.15$; $p = .000$). However differences were not found to be statistically significant between HCPs attitudes about their reactions to parents as individuals and their professional roles ($F = 1.48$; $p = .221$) and years in paediatric practice ($F = 1.58$; $p = .195$). See Table 4.9.

Total belief subscale scores were also reported to be higher among HCPs who were longer in their professional roles in paediatric practice than those with less experience. These differences were also found to be statistically significant between those in practice for more than ten years and those with two to five years of experience for attitudes about their role ($F = 2.71; p = .045$), attitudes about what parents want ($F = 7.06; p = .001$) and total belief scale scores ($F = 3.80; p = .011$). There were no statistical differences between participants' attitudes about their reactions to parents as individuals and their years' of paediatric practice ($F = 1.58; p = .195$). See Table 4.9.

4.2.2.6 Levels of importance assigned by HCPs to the psychosocial components

Participating healthcare providers assigned a level of importance from “*not at all important*” to “*very important*” to the psychosocial components of the assessment framework in development. The level of importance was sought for its importance to the child and the family's health and wellbeing.

Descriptive findings showing the levels of importance assigned by HCPs to the psychosocial components included in the proposed framework are tabulated in Table 4.10.

Seventy seven per cent ($n = 268$) of participants indicated that emotional health was very important and 81 per cent ($n = 281$) reported that self-confidence was very important. Access to social support was also found to be very important amongst the majority of this sample (79 %; $n = 278$). Over ninety per cent of participants indicated that exposure to life stress (97%; $n = 341$), family relationships (95%; $n = 334$), family structure (91%; $n = 320$), financial strain (91%; $n = 319$), and engagement in the community (89%; $n = 304$), were moderately or very important.

As with the PCG sample, less importance was assigned to education with 42 per cent ($n = 149$) reporting it to be of some or very important. This was also found to be the case for occupation in this sample with 38 per cent ($n = 132$) of HCPs allocating importance to parental occupation. See Table 4.10.

Table 4.10
Levels of importance allocated to the psychosocial components
by participating health care providers

Psychosocial component	n	%
PCG education		
Very important	59	17
Of some importance	91	26
Of little or no importance	200	57
PCG occupation		
Very important	19	6
Of some importance	113	32
Of little or no importance	218	62
PCG emotional health		
Very important	268	77
Of some importance	71	20
Of little or no importance	11	3
PCG self- confidence		
Very important	281	80
Of some importance	63	18
Of little or no importance	6	2
Family structure		
Very important	187	53
Of some importance	133	38
Of little or no importance	30	9
Family relationships		
Very important	229	65
Of some importance	105	30
Of little or no importance	16	5
Family life stress		
Very important	227	65
Of some importance	114	32
Of little or no importance	9	3
Family financial strain		
Very important	153	43
Of some importance	167	48
Of little or no importance	30	9
PCG social support		
Very important	279	80
Of some importance	67	19
Of little or no importance	4	1
PCG engagement in community activities		
Very important	155	44
Of some importance	149	43
Of little or no importance	46	13

4.2.2.7 Relationships between the levels of importance assigned to the psychosocial components by demographic and professional characteristics of HCPs

As with analyses of the PCG sample, Chi-square analysis and Fisher's exact test showed no statistically significant differences between the levels of importance allocated to the psychosocial components and the sociodemographic characteristics of the participants. These characteristics were gender, healthcare profession, years' of experience in their role, years of experience in paediatric healthcare, and the State where HCPs were recruited. No significant findings were found. While aiming to present results comprehensively and because the results of these analyses were found to be inconsequential these analyses are tabulated in Appendix O at the end of this thesis. Please see Appendix N for Table 4.17, 4.18, 4.19, and 4.20. Findings related to the levels of importance allocated by HCPs to the psychosocial components for gender, professional role, years in professional role and years spent paediatric practice, respectively. (See Appendix O).

4.2.2.8 Relationships between the levels of importance allocated to psychosocial components by HCPs and their attitudinal scores

To further examine the potential suitability and acceptability of the components of the family psychosocial assessment framework, the relationships between the levels of importance allocated to the components and participants total psychosocial scores were examined. One way analysis of variance was conducted using the total belief scale scores for psychosocial orientation as an outcome variable and each of the psychosocial components as independent variables. It was considered more likely that components that were related to more positive attitudinal scores could be considered as potentially acceptable for inclusion in the psychosocial framework in development. See Table 4.11.

Table 4.11 shows that higher levels of importance allocated to emotional health were found to be related to more positive attitudinal scores among the HCPs recruited ($F = 11.29; p < .0001$). This was also found to be the case for family relationships ($F = 12.66; p = .000$), exposure to life stress ($F = 8.96; p = .000$), financial strain ($F = 9.12; p = .000$) and the importance of engaging in community activities ($F = 9.32; p = .000$). Higher levels of importance assigned to parental occupation ($F = 7.52, p = .001$), access to social support ($F = 7.36; p = .001$) and self-confidence ($F = 3.74, p = .025$) were also related to higher belief scale scores at a level of significance less than .05.

Table 4.11
Importance of psychosocial components and total belief scale scores

	“Of little importance”		“Of some importance”		“Very important”	
	mean	(SD)	mean	(SD)	mean)	(SD)
PCG education	72.02	(8.2)	72.05	(10.3)	71.43	(9.2)
PCG occupation	70.53	(9.3)	74.14	(8.7)	75.63	(9.2)**
PCG emotional health	65.09	(7.1)	68.41	(7.6)	73.20	(9.4)***
PCG self confidence	69.33	(5.6)	69.25	(8.0)	72.64	(9.5)*
Family structure	68.00	(8.1)	70.26	(9.2)	73.82	(9.1)***
Family relationships	65.13	(9.2)	69.45	(7.7)	73.61	(9.4)***
PCG family life stress	64.67	(8.8)	72.02	(8.2)	73.36	(9.6)***
PCG financial strain	66.90	(7.8)	71.08	(8.4)	73.94	(9.9)***
PCG social support	65.50	(11.9)	68.54	(8.5)	72.93	(9.2)**
PCG engagement in the community	68.26	(8.6)	70.89	(8.6)	74.12	(9.5)***

Level of statistical significance * p-value < .05, ** p-value < .01, *** p-value < .001

4.2.2.9 Comparisons between the levels of importance assigned to the psychosocial components by PCGs and HCPs providers

Finally, while participating PCGs and HCPS allocated importance to the psychosocial components, differences in these levels of importance assigned were examined. Using Chi-square analysis and a Bonferroni method to adjust for comparison of column proportions, differences between the levels of importance allocated by participants were assessed and tabulated (See Table 4.12).

In Table 4.12 importance was allocated to education by 74 per cent of PCGs compared to 42 per cent allocated by HCPs. Fifty seven per cent (n = 200) of HCPs indicated that maternal education was of little or no importance to a child’s health and wellbeing compared to 25 per cent (n = 36) allocated by PCGs. These differences were statistically significant $X^2(2, n = 491) = 41.03, p < .0001$. See Table 4.12. A statistically significant difference was found between the allocation of importance to parental education where 73 per cent (n = 102) of PCGs assigned ‘very important’ to parental occupation in comparison to five per cent (n = 19) allocated by HCPs [$Chi\ square\ X^2(2, n = 491) = 270.06, p < .0001$]. (See Table 4.12).

Table 4.12
Comparisons between primary caregivers and health care providers' allocations
of importance to the psychosocial components

Psychosocial component	PCGs		HCPs	
	n	%	n	%
PCG education				
Very important	36	26	58	17
Of some importance	68	48	91	26
Of little or no importance	36	25	200 ¹	57
PCG occupation				
Very important	16	11	19	5
Of some importance	88	63	113	32
Of little or no importance	26	36	218 ¹	62
PCG emotional health				
Very important	102	73	268	77
Of some importance	37	26	71	20
Of little or no importance	1	1	11	3
PCG self- confidence				
Very important	112	80	281	80
Of some importance	26	19	63	18
Of little or no importance	2	1	6	2
Family structure				
Very important	67	48	187	53
Of some importance	65	47	133	38
Of little or no importance	7	5	30	9
Family relationships				
Very important	71	50	229	65
Of some importance	64	46	105	30
Of little or no importance	6	4	16 ¹	5
PCG family life stress				
Very important	51	36	227	65
Of some importance	84	61	114	32
Of little or no importance	5	3	9 ¹	3
PCG financial strain				
Very important	29	21	152	44
Of some importance	89	63	167	48
Of little or no importance	23	16	30	8
PCG social support				
Very important	195	57	278	80
Of some importance	33	43	67	19
Of little or no importance	1	0	4 ²	1
PCG engagement in community activities				
Very important	30	12	155	44
Of some importance	94	67	149	43
Of little or no importance	17	12	46 ¹	13

Statistically significant difference ¹Chi square p-value < .05, ²FET p-value < .017 (n = 350)

PCGs and HCPs allocated importance to maternal emotional health similarly [$X^2(2, n = 491) = 4.30, p = .116$]. This was also the case for self-confidence with no statistically significant differences between groups [$X^2(2, n = 491) = .069, p = .966$]. Family structure was also considered important similarly across the combined sample of PCGs and HCPs $X^2(2, n = 491) = .405, p = .132$). How importance was allocated to family relationships differently with more PCGs allocating some importance (46%, $n = 64$) than HCPs (30%, $n = 105$) and more HCPs reporting family structure to be very important (66%, $n = 229$) in comparison to PCGs (50%, $n = 71$). Chi-Square = $X^2(2, n = 491) = 10.67, p = .005$). See Table 4.12.

Interestingly, exposure to life stress was considered to be very important by more HCPs (65%; $n = 227$) than PCGs (36%; $n = 51$). The reverse was seen where 60 per cent ($n = 84$) of PCGs allocated some importance to the importance of life stress in comparison to (32%; $n = 114$) of HCPs. This difference was also found to be statistically significant [$X^2(2, n = 491) = 33.21, p = .001$]. Similar allocations of importance were seen for financial strain with 63 per cent ($n = 89$) of PCGs indicating that financial strain was of some importance in comparison to 48 per cent ($n = 167$) of HCPs. $X^2(2, n = 491) = 24.37, p = .001$. More importance was also allocated to engagement in community activities by HCPs (44%; $n = 155$) who considered this component to be very important compared to 21 per cent ($n = 30$) in the PCG sample. $X^2(2, n = 491) = 26.0, p = .000$). (See Table 4.12).

Finally, Fisher's exact test was applied to examine differences between the levels of importance assigned to social support. While over 90 per cent of PCG and HCP participants considered access to social support to be important, 80 per cent ($n = 278$) of HCPs considered access to social support to be very important in comparison to 57 per cent ($n = 80$) of the PCH sample ($n = 491; p = .000$). (See Table 4.12).

4.2.3 Summary

In this section the analysis from two samples of survey data were presented. The characteristics of participating PCGs and HCPs showed that over 90 per cent of PCGs and over 80 per cent of HCPs were female. Over 95 per cent of PCGs spoke only English at home and 30 per cent of PCGs reported having a university degree. Of the HCPs over 45 per cent reported having more than ten years of experience in their role assigned while 40 per cent reported more than ten years of experience in the paediatric

setting. Over 80 per cent of PCGs and HCPs reported that emotional health, self-confidence, family structure and relationships, exposure to life stress and social support were very important. However, despite levels of maternal education attainment and parental occupation accepted as determinants of child health outcomes both were reported to be of some or little or no importance by over 70 per cent of PCGs and over 40 per cent of HCPs. It is anticipated that thematic analysis of transcripts from one-on-one interviews with PCGs and HCPs and focus groups with HCPs may provide some insight into these findings.

Distribution of the psychosocial attitudinal scores from PCGs and HCPs were found to be normally distributed eliminating the need for non-parametric analysis. No statistically significant associations between PCGs levels of education, geographical location of residence, gender and both attitudinal scores and levels of importance assigned to the psychosocial predictors were reported. HCPs who reported more than ten years in practice in their roles and more than ten years of experience in paediatric practice reported statistically significantly higher psychosocial attitudinal scores.

In the following subsection thematic analysis of transcripts from one-on-one interviews with PCGs and HCPs and focus groups with HCPs are presented.

4.3 Qualitative findings

In this section findings from the thematic analysis of transcript data are presented. As outlined in the methodology chapter of this thesis, one-on-one interviews and focus groups were conducted to gain deeper insights into the perspectives and experiences of PCGs and HCPs about discussing and managing psychosocial issues in hospital. The characteristics of the participants are tabulated and the themes that evolved from thematic analysis are identified and named. The conceptual model that emerged from analysis of the transcripts is presented and provides a guide for presentation of the findings throughout this subsection.

4.3.1 Characteristics of interview and focus group participants

The sample was made up of 18 one-on-one interviews, 10 with PCGs and eight with HCPs. Of the ten interviews conducted with PCGs; three were attending the participating hospital in WA and seven were recruited in the participating hospital in VIC. Eight interviews were conducted with HCPs: two nurses, one allied health professional and one consumer support professional in WA; and two medical doctors,

one nurse, and a consumer support officer in VIC. The duration of the interviews ranged from 22 to 50 minutes. Participants were recruited and data were collected until saturation was reached. This occurred when all categories were well defined and little or no new data was emerging (Creswell, 2007).

4.3.1.1 Participating primary caregivers

Ten face to face interviews were conducted with PCGs. Interviews were recorded, transcribed and subjected to the thematic analysis outlined in the methodology chapter of this thesis. Participants were allocated pseudonyms following transcription. Each PCG was the parent of his or her child and nine mothers and two fathers made up the sample. This is because in one interview, both parents of a young child who was chronically ill participated and shared their views concurrently. PCGs who were guardians or foster parents were not identified in this sample. The remaining nine interviews were conducted with one parent only. The characteristics of the participating primary caregivers and their children are described in Table 4.13.

Table 4.13
Demographic characteristics of participating PCGs

Characteristic	n	%
State		
VIC	7	72
WA	3	28
Gender		
Female	9	82
Male	2	18
Age ranges primary caregivers' children		
Infant (Sara and Tom)	2	18
Toddler (Joe & June, Rose)	3	28
Young child (Annie, Olive)	2	18
Older child (Maggie, Barb)	2	18
Adolescent (Helen, Eve)	2	18
Primary serious or chronic illness		
Developmental and mobility	1	10
Cancer	1	10
Neurological	2	20
Gastrointestinal tract	2	20
Metabolic disease	1	10
Renal disease	2	20
Respiratory problems	1	10

The three PCGs in WA were recruited in wards at the participating hospital. Two of these interviews were conducted on the ward areas and the third in a quiet area away from the ward with a PCG who elected to sit outside.

The remaining seven interviews were conducted with PCGs at the tertiary hospital in VIC. Five of these interviews were conducted by the author at the Family Resource Centre, outlined in the methodology chapter, where parents and families in hospital could visit during the day. Of the remaining two interviews, one was conducted in a ward area while the other took place in a quiet room in the outpatient clinic.

For editorial flow and confidentiality, all PCGs were given pseudonyms and their children referred to as male. The ages of the children of PCGs have been grouped as follows: infant (less than one year of age); toddler (greater than one and less than three years of age); young child (older than three and less than six years); older child (older than six and less than 12 years); and adolescent (older than 12 years). The duration of the PCG interviews ranged from twenty to forty-five minutes.

4.3.1.2 Participating healthcare providers

A total of 31 HCPs participated in eight one-on-one semi-structured interviews and four focus group sessions. Interviewees were each allocated a pseudonym. The health disciplines and location of the participating HCPs are presented in the Table below. Two male nurses participated in focus groups and all remaining participants were female.

Table 4.14
Health disciplines and locations of participating HCPs

	n	%
Australian State		
VIC	4	13
WA	27	87
Interview participants		
Nurse (Cath, Liz, Susie)	3	10
Medical doctor (Marg, Tina)	2	7
Allied health professional (Kim)	1	3
Parent Advocate (Gill, Jen)	2	7
Focus group participants		
FG1: Nurses – general paediatric ward	6	19
FG2: Nurses – specialist paediatric ward	8	25
FG3: Nurses – specialist outpatient setting	6	19
FG4: Allied health – specialist department	3	10

Of the interviewees one nurse worked in paediatric practice for five years while the remaining two had each practised in paediatric nursing for over ten years. Both participating medical doctors were practising paediatricians, each working in a specialty department while the participating allied health professional was in paediatric practice for two years. Finally, two consumer advocacy officers, one from each tertiary hospital, participated in a one-on-one interview.

4.3.1.3 Focus group participants

A total of four focus groups with a collective total of 23 HCPs were conducted in WA where the author is based. As outlined earlier, no focus groups were conducted in VIC. The duration of the HCP focus groups ranged from thirty to fifty-five minutes. Interviews with HCPs were identified in this study using assigned pseudonyms and their professional discipline while FG participants were identified according to their professional discipline and FG number. The durations of the focus groups were between twenty five and sixty minutes. No HCP participating in a one-on-one interview participated in a focus group.

As with one-on-one interviews data saturation was reached when similar perspectives were being heard and no new data were identified.

4.3.2 Emergent conceptual model

An emergent conceptual model was constructed from three overarching themes that emerged from analysis of the transcripts (see Figure 1). These themes were identified and named: 1. *building relationships*; 2. *the whole family*; and 3. *the hospital and services*. In addition to the three themes, two process themes emerged that were integral to the three major themes. Furthermore, the third theme contained a sub-theme named “*culture and people*”. This sub-theme emerged from data pertaining to the people and behaviours within the hospital environment. A brief outline of the conceptual model is presented in the following paragraphs. This is followed by an in-depth explanation of the components of the themes that emerged from analysis of the transcripts.

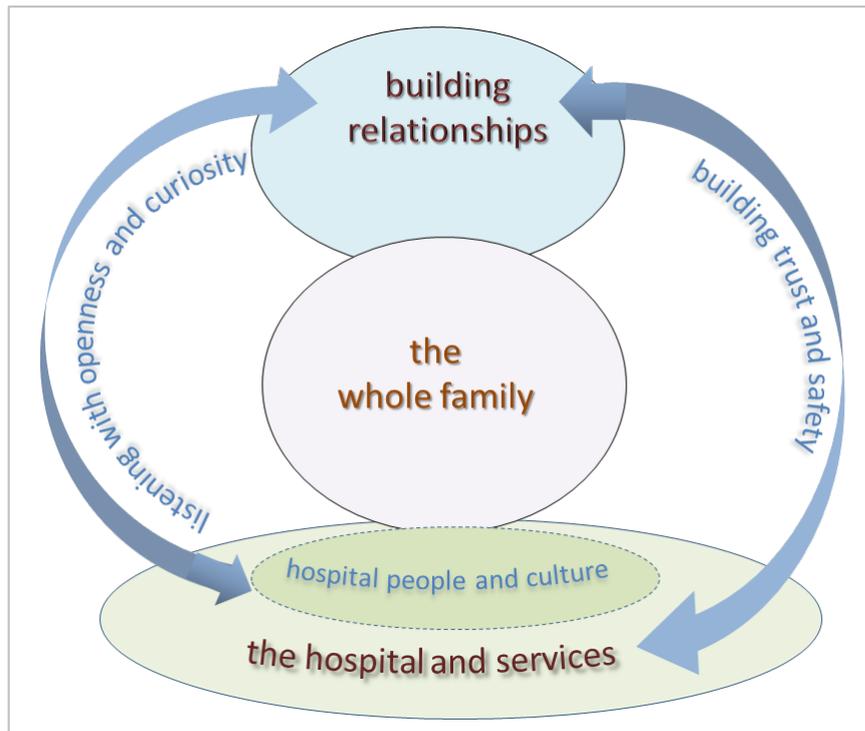


Figure 4.12
Emergent Conceptual Model

The first theme “*building relationships*” emerged from the data where an emphasis on the process of developing rapport was placed by PCGs and HCPs during one-on-one interviews and focus groups. Expressed feelings about feeling familiar and well known from the perspectives of the PCGs and HCPs make up this theme. Analysis of the transcripts identified two process themes within the first theme “*building relationships*”. These process themes were named “*listening with openness and curiosity*” and “*building trust and safety*” (see Figure 1). Both of these process themes were found to be fundamental to “*building relationships*” and served as functional bridges whereby relationships could develop, or not.

The first process theme, “*listening with openness and curiosity*” emerged from the characteristics identified in the expressed feelings and experiences of the PCGs about having their concerns heard and understood. Within this process theme, tension was identified between the experiences of PCGs about having their feelings heard and understood, and their need to maintain control as identified in their expressed desire for “*straight answers*” in order to “*get on with it*”. One interesting dynamic identified related to the need for PCGs to have their concerns heard and “*receive straight answers*” and an expectation that HCPs could meet this deep and possibly unanswerable need. Also identified was the expressed empathy and awareness by

HCPs for the long term trajectory of chronic or serious illness where reference to grief and loss was evident but remained unspoken. These expressed feelings by HCPs also distinguished a felt caution about bringing up some topics that PCGs may be not yet willing or able to contemplate.

The second process theme “*building trust and safety*” emerged and was found to be thematically linked to building interpersonal trust and safety through conversational dialogue. An expressed aim to develop an open and trusting relationship was identified where these issues could be addressed. However, caution, hesitancy, and protectiveness around pursuing enquiries was identified in the transcripts particularly PCGs and HCPs feelings and experiences about discussing issues perceived to be sensitive. A preference to address the immediate practical concerns as a way to engage and build trust and rapport was identified in the expressed feelings of HCPs.

The second theme “*the whole family*” emerged from an emphasis expressed by PCGs and HCPs about talking about family structure and dynamics. Analysis of the feelings and experiences expressed by HCPs highlighted consideration for a range of individuals outside the nuclear family who were involved in supporting the care of a child who was seriously or chronically ill. These members of the extended family social support networks were identified for inclusion in the “*family*”. In particular, the expressed views of HCPs with more than ten years of experience pointed to the role of grandparents who, from their perspectives, were found to be more involved in the day to day care of their grandchildren, in comparison to earlier in their professional experiences.

Shared hesitancy and reluctance in relation to discussing aspects of family functioning was also identified. Analysis of the expressed feelings of PCGs and HCPs showed that talking about family relationships, educational attainment, and parental occupation, were topics considered to be less comfortable to broach by PCGs and HCPs. Tension between a shared reluctance by HCPs regarding asking PCGs about their family relationships was met with a conflicting “*need to know*”. Similarly, hesitation expressed by most PCGs regarding talking about family relationships was found to be directed towards others considered to be less advantaged, rather than themselves. However, both PCGs and HCPs shared the view that talking about family relationships and aspects of family functioning became effortless when the PCGs felt “*well known*” by HCPs, and the HCPs felt trusted by PCGs. Thematic analysis found the third theme “*the whole family*” was also linked to the process themes “*listening with openness and*

curiosity” and *“building trust and safety”* that made it possible for the dynamics of *“the whole family”* to be expressed by PCGs and understood by HCPs, or not.

Finally, the third theme named the *“the hospital and services”* emerged from analysis of the transcripts. Within this theme the physical structure of the hospital and the services provided within it were identified as the environment in which PCGs and HCPs developed relationships with the whole family. For this reason the third theme evolved as a foundational unit that infiltrated into the first and second themes *“building relationships”* and *“the whole family”*. From this third theme *“the hospital and services”* a sub-theme emerged and was named *“hospital people and culture”*. Data pertaining to participants’ perspectives about the practices of HCPs in the hospital and the expectations brought to the environment by PCGs is included in this sub-theme. Also included are analysed perspectives and experiences, both helpful and unhelpful, relating to authority, and the philosophies, principles, and practices in the hospital. Differences in expectations about the roles and responsibilities of PCGs and HCPs were identified. Expressed feelings of appreciation and confidence shared by PCGs were also met with opposing feelings of disappointment and frustration. Feelings of cautious concern about being intrusive and shared helplessness about not being able to resolve issues by some HCPs were identified. The experience of uncertainty shared among PCGs about accessing information about their children in hospital were met with HCPs concerns about how information was articulated and understood.

Like the third theme, *“the hospital environment and services”*, the sub-theme *“hospital people and culture”* represented the environment in which relationships between PCGs and HCPs were initiated. For this reason the third theme and sub-theme were found to be directly linked to the *“the whole family”* through the first theme *“building relationships”*. As with the first and second themes *“building relationships”* and *“the whole family”*, the process themes named *“listening with openness and curiosity”* and *“building trust and safety”* were also found to be linked to the third theme *“the hospital and services”* and sub-theme *“hospital people and culture”*. Examination and re-examination of the data showed that initial relationships between *“the whole family”* and the *“hospital people and culture”* evolved into direct relationships between PCGs and families and the hospital institution itself. Trust and confidence that developed between the PCGs and hospital HCPs and people were found to extend beyond the individual HCPs to confidence, or otherwise, in the overall hospital environment and services. See Figure 1.

4.3.2.1 First theme: Building relationships

PCGs and HCPs were in agreement that talking together about the family was important when in hospital with their children or providing care in hospital. However, this was only possible when communication was conducted with a sense of genuine enquiry coupled with familiarity and safety for both the PCGs and HCPs. As indicated earlier, building relationships was found to be dependent on the two process themes “*listening with openness and curiosity*” and “*building trust and safety*” because they represented the means by which relationships could be built and also guided how these relationships developed. The resultant relationship with the hospital people and familiarity with the culture and practices resulted in confidence in the services, or otherwise. Analysis of the data showed that these relationships that were generated by the people and culture within the hospital occurred over time. Thematic analysis showed that the first theme “*building relationships*” with “*the whole family*” as the second theme, was found to be guided by the sub-theme “*the hospital people and culture*” towards a resultant relationship with “*the hospital environment and services*”. See Figure 1. Analysis of the data related to “*people and culture*” will be presented within the context of the two process themes starting with “*listening with openness and curiosity*”, and “*building trust and safety*” in the following subsection.

4.3.2.2 Process theme one: Listening with openness and curiosity

Further examination of excerpts about communicating together, building trust, and feeling understood by HCPs in the hospital environment showed that “*listening with openness and curiosity*” was one functional component that made “*building relationships*” possible or otherwise. For this reason it was named a process theme. All ten PCGs, were regular attenders to one of the participating tertiary hospitals, reported that they felt at ease when communicating with HCPs on their children’s ward or clinic area. However, this ease with HCPs was something that had developed over time and was not the case in the beginning when their children’s health “*journeys*” first began. Seven of the ten PCGs, reflected back to their earlier experiences with HCPs when their children were first admitted to hospital. Feelings of confusion, fear and bewilderment were identified in their expressed concerns of powerlessness about being left in the dark:

“Often I will ask questions, and they (HCPs) say ‘I don’t know’ or ‘maybe’... And I am going what does that mean? ... You are in the dark ... is he behaving this way because of the drugs, or is it him doing it....? Should we be concerned...?”

(Rose, PCG of an infant)

Similarly, a need to have concerns heard and understood, were identified in the expressed experiences within the transcripts of another participant whose older child had previously undergone numerous procedures.

“Knowing all the possibilities would help! Like, he didn’t eat after the second operation and he was so underweight and I had to ask the question, how long can he not eat for? This is ok? Or not ok?”

(Barb, PCG of an older child)

An identified sense of exclusion from the transcripts was further illustrated in another participant’s expressed view about feeling inconspicuous.

“I just prefer if they (doctors and nurses) talk to us and not just to each other around us ...”

(Joe and June, PCGs of a toddler)

Similarly, an additional protectiveness and need to maintain control was identified by the PCG of a toddler in the Intensive Care Unit.

“I have 100% trust in my intuitions and gut feelings and I like doctors and nurses to take note of that ...”

(Olive, PCG of a young child)

These experiences of not knowing, feeling excluded and inconspicuous illustrated a desperate need by PCGs to connect with people in the hospital environment in order to understand what was happening with their seriously ill children. This recognised need to be heard and understood also featured a welcome opportunity to build a connection by *“listening with openness and curiosity”*. Findings about how PCGs needs could be heard and understood are presented in the following paragraphs.

4.3.2.2.1 *Perspectives about having needs heard and understood*

Further examination of the transcripts identified a further need to feel heard and understood by PCGs in their responses. In one example, this was illustrated by the PCG of an infant who had spent most of his life in hospital with serious respiratory illness.

“It comes from all the chain, because this (child’s health) is a really, really, bad situation. I find it very annoying when people are telling me what I should be feeling or expecting”.

(Sara, PCG of an infant)

A contrasting example highlighted the impact of empathic listening and communication in the expressed experience of another PCG who was moved to tears when she related her felt appreciation for one nurse. This nurse had recently asked her for the first time what hand signs she needed to know in order to be able to communicate with her adolescent son who was deaf. The absence of any expressed expectation for earlier attention to this during many previous admissions to hospital was felt by the Candidate at the time.

A sense of solitariness and an expressed call for understanding, and support was highlighted in a single example shared by a PCG of a child with special needs who compared herself to others.

“If we want to access respite care we can’t because we both work, and our income threshold is above the limit which means we are cut off ... so the system is not built to help any working parent ... let alone a working mother”.

(Maggie, PCG of an older child)

During one interview, a PCG extended an invitation to her adolescent who was present at the time, to share what she thought was most important from her perspective. Without hesitation, she responded; *“Listening and understanding... yeah.”* (Eve, PCG of an adolescent).

While the need to be heard and understood was identified in the transcripts, prompt responses by HCPs to PCGs’ experiences of distress when they were expressed outwardly were identified. With this, the absence of any expectation by PCGs for

earlier support or attention from HCPs was noted by the author in their shared gratitude for the kind responses received at the height of their distress. *“The times when you have breakdowns they (the nurses) are beautiful”* (Barb, PCG of an older child). For another PCG, her need for attention was also heard when physically expressed: *“I kind of stand up and wave my arms”* (Sara, PCG of an infant). Likewise, the distress and despair experienced by another PCG was heard by responding HCPs when *“I was like a psycho screaming and crying”* (Annie, PCG of a young child).

While gratitude for the support received to their obvious distress, resistance and protectiveness was also identified in PCGs transcripts about going into too much detail with HCPs. A need for clarity and directness was expressed by PCGs so they could *“get on with it”* (Tom, PCG of an infant), (Sara, PCG of an infant), (Rose, PCG of a young child). With this however, frustration about receiving information considered unnecessary was also identified. This was exemplified by one participant who expressed frustration if information from HCPs about her child was *“unclear”* (Maggie, PCG of an adolescent), while the need to *“receive straight answers”* (Tom, PCG of an infant) was also identified. Further to this a ‘more black and white’ perspective was found to be related to the need to *“just get on with it”* rather than being told *“something that was difficult nicely, just to make it sound softer”* (Rose, PCG of a young child). A similar perspective was identified in the expressed views of another PCG that called for straight talking:

“When you’ve got sick kids ... you don’t have time for people to sugar coat things. So honesty... yeah absolutely.... honesty would be the number one thing for me ... yeah”.

(Tom, PCG of an infant)

Further to this a dilemma between staying in control and *“getting on with it”* and fear about being able to cope with the possibly overwhelming demands of parenting their seriously or chronically ill child was identified. Concern about feeling confused and burdened on hearing too much information was identified in the transcripts of another PCG. *“It is difficult when people maybe overcomplicate the answers”* (Rose, PCG of a young child).

4.3.2.2.2 *Shared concerns about meeting overwhelming needs*

An unspoken expectation was identified in the expressed need by PCGs for “*straight answers*”, whereby HCPs would and could provide answers to meet a deep and possibly unanswerable need. This need for straight answers was met by an expressed empathy by HCPs for the grief and loss that is anticipated along the trajectory of chronic or serious illness. This empathy for the anticipated grief and loss experienced by parents of children who are seriously or chronically ill was identified in the transcripts of HCPs who shared their experiences from many years of clinical experience:

“We have been nursing for a long time and it makes many of these aspects easier to talk about and if I reflect back as a junior nurse some of that I really would have struggled with”.

(FG.3: Nurse)

The enormity of the grief and loss experienced by families was identified in the transcript of a PCG who reflected back to her young child’s infancy.

“For us, we had this beautiful baby boy with an illness we never heard of. We did not imagine it could be possible, and no one could imagine what we were going through. You get that sense of going it alone ... you know? ... So many times”.

(Annie, PCG of a young child)

Sadness and grief were also evident in analysis of the expressed feelings of another PCG who shared a similar sense of loneliness and isolation.

“All of our friends don’t live the life we live anymore so even though they have got kids they ... don’t get it ...”

(Joe and June, PCGs of a toddler)

Grief and loss was also identified in another PCG’s protective need to maintain control in the face of overwhelming burden and uncertainty associated with her infant’s serious illness:

“We have travelled a long way to get here and it’s not easy to bring two kids ... as the older one is just one and the baby is five weeks old ... So when we are here we just want someone to give it to us straight ... this is what the issue is and let’s get on with it”.

(Tom, PCG of an infant)

Similarly, the expressed experiences of shock, loss, and overwhelm along with the need to preserve some control was evident in the analysis. In one example, despite the accumulation of a number of additional life stresses that coincided with her child’s admission to hospital, that included recently selling and moving the residential home, managing the unexpected downturn in her partner’s work, a stoic need to maintain some control was observed.

“There was lots going on. Again, we just dealt with it, in a way...”

(Sara, PCG of an infant)

The overwhelming nature of this experience which was not unique within the transcripts. Nonetheless, the enormity was acutely felt by the author who reflected and wondered at the time how nursing staff would be able to hold such need.

Similarly, hesitation was identified during analysis of protective perspectives by HCPs where the challenge of gauging enquiry into family issues was expressed.

“I think if you are going to ask if everything is OK at home, people are not going to know... Like if something is wrong... they are not going to know how deep their answer should be”.

(FG1, nurse)

The expressed views by HCPs revealed the enormity of unspoken grief and loss associated with a serious and often life-long diagnosis. A felt hesitation and caution about broaching some topics with PCGs before they were ready during relationship building, was identified. These shared views of HCPs included concerns that PCGs may feel unwilling or unable to contemplate talking about some family issues over others. Further analysis of the excerpts from HCPs revealed that this challenge of maintaining a balance between timing and capacity to address what may unfold when

discussing family issues was met with reluctance and hesitation. Ambiguity between the expressed view to listen with openness and expressed concerns about feeling overwhelmed and unable to cope were identified.

‘Sometimes by just asking that, it can open the flood gates. But you have to be ready...’

(FG3, nurse)

A similar sense of resistance was justified by a disparity of resources available to adequately meet the needs of PCGs.

“(Other named department) have better access to resources... and philanthropic sources ... if you put your hand up and say we need funded supportwhereas in (other named department) we don’t have that level of support”.

(Kim, allied health professional)

This identified sense of reluctance and justification about broaching some family issues was highlighted by another HCP. *“I think you have to be prepared if you’re going to ask questions and you have some solutions other than mainstream referrals to services that they already know. Our department doesn’t have a lot of support”* (Susie, a nurse).

Similarly protectiveness and constraint about meeting unspoken needs were identified in the analysis of expressed feelings by another HCP:

“Sometimes it is too difficult. It is easy to focus on what you know and what you are good at.”

(FG1, nurse)

The presence of reflective thinking was identified in the expressed feelings of some HCPs about the need for sensitivity and empathy.

“I think it is also about having empathy for our families. They feel no one else is going to understand the issues that they have

more than we are. While we may not be able to solve it, the fact that we can understand what they are telling us”.

(FG3, nurse)

4.3.2.2.3 Empathy and curiosity

A shared sense of curiosity and wondering by HCPs about what it might be like for PCGs was revealed in the transcripts where the empathy for an anticipated arduous road ahead was shared.

“We have a little girl at the moment going through chemotherapy and she looks fabulous and she is really engaging, a gorgeous little girl but I think, what that like for the parents is maybe not really knowing what the prognosis is and if she will make old bones”.

(Kim, allied health professional)

Empathically building rapport, particularly when a lengthy and potentially difficult trajectory was predicted, also emerged during thematic analysis in the following example from the expressed feelings of HCPs about connecting with PCGs under difficult circumstances.

“And ... find some little links whatever they may be, with the parents ... and the kids themselves. Sometimes it is something in common ... anything to get those gossans of thin threads of relationship... that will still be there when any of the tough bits happen, you know?”

(FG4, allied health professional)

An overall emphasis on the importance of listening to what may arise was identified in analysis of the transcripts and articulated in the expressed feelings of four nurses participating in FG3, namely “*Listening*”, “*I agree*”, “*Not just listening REALLY listening!*” and “*Non-judgemental and really listening*”.

Similarly, listening with gentle enquiry was recurrently identified in the transcripts of HCPs. This was found to occur naturally in conversation by HCPs. Examination and re-examination of the transcripts showed that this perspective was endorsed by HCPs

verbal and non-verbal affirmations during one-on-one interviews, and during focus groups. Multiple examples from the HCP transcripts was illustrated by one HCP who was of the view that she just “*chatted*” because it was about helping families to feel comfortable (FC2, nurse). For another it was similarly and naturally expressed; “*just finding out stuff... chitchatting!*” (FG3, a nurse). For another it was about building rapport: “*We plan to know them a long time... these families*” (FG3, nurse).

Equally, a reciprocal openness to “*chat*” was identified in the transcripts of PCGs shared experiences about spending long periods of time in their children’s hospital wards. This need to interrupt the tedium associated with feeling removed from normality and isolated from others was illustrated in an example from a PCG of a seriously ill infant:

“I got so bored sitting there, after a couple of days I was just talking to anyone who came near me!”

(Sara, PCG of an infant)

Reciprocated sensitivity and empathy by HCPs to avail of opportunities to listen with openness was illustrated in a further example.

“Listening.... Trying not to talk too much... giving them space and really pick up on the nonverbal communication and let them say what they want to say but...can’t say sometimes....”.

(Marg, doctor)

Avoiding the temptation to speak too much was reinforced in a further example: “*... and not finishing off the parents’ sentences... allowing them to finish.*” (FG2: a nurse). A felt helplessness shared by allied health professionals in FG4 illustrated both empathy and courage by another HCP when PCGs have received difficult news.

“They (PCGs) may have found something out and they are overwhelmed...and they are so sad... and we so want to help... but it comes down to just being... and... And I know that is all I can do is be, be there for them... and it is that, helplessness...”

(FG.4, allied health professional)

Analysis of the transcribed data identified that for PCGs listening with openness, and feeling heard and understood were essential ingredients to building relationships with HCPs in hospital. Similarly, for HCPs listening with openness and gentle enquiry was found to underpin how a relationship could be built, or not. While this occurred naturally for some HCPs while “*chatting*”, there were times when it was challenging. Tension between feeling heard and understood, and having their concerns addressed while maintaining some control was identified in PCGs transcripts. For HCPs, ambiguity was identified where the complexity of listening openly and gently enquiring was met with fear of being overwhelmed or feeling incapable of meeting the needs of the PCGs. Similarly an expressed need to maintain control by ensuring that conversations felt safe and comfortable was revealed in the transcripts of HCPs. Further to this, empathy and insight expressed by HCPs for actual and potential grief and loss associated with the trajectory of chronic and serious illness emerged from the transcripts of HCPs. For many HCPs, listening with openness and curiosity occurred naturally in a conversation or while “*chatting*” which served as the vehicle for relationship building to occur, or not.

The second process theme “*building trust and safety*” contains the findings of thematic analysis of PCG and HCP data pertaining to the expressed feelings and experiences about how feelings of trust and safety develop within a relationship in hospital. These findings will be presented in the following paragraphs.

4.3.2.3 Process theme two: Building trust and safety

A sense of belonging was identified in the expressed feelings of the ten PCG transcripts. This sense of belonging was found to include: feeling well known by their children’s HCPs; and feeling that as PCGs they also knew the HCPs who were caring for their children. One PCG referred to this as being a “*regular*”. This sense of familiarity identified in the transcripts was found to develop over time as a result of talking with the HCPs while they provided care for their children in hospital. One PCG it was easier to speak with the nurses because talking with them during long periods of time spent on the ward provided her with some relief, distraction, and understanding. How this occurred was highlighted by another PCG:

“Nurses are quite good... they seem to listen and I think that is the best thing. They nod, and not say very much, and listen, most definitely.”

(Annie, PCG of a young child)

Likewise, a similar perspective about feeling more comfortable over time was revealed in the transcript from another PCG in hospital with her toddler who was seriously ill.

“The nurses though, they always ask how we support, and how are we going, and it comes from a good place, so it is appreciated because it shows that they genuinely care.”

(Olive, PCG of a young child)

4.3.2.3.1 Feeling familiar

The experience of feeling familiar with HCPs and the hospital over time was found to develop further to a sense of belonging. Further analysis of the transcripts identified links between getting to know HCPs, feeling more familiar over time, and the development of a relationship.

“I think ... there is a bond not because of our situation but because we have been there so long”.

(Sara, PCG of an infant)

As familiarity developed, feelings of security and belonging in a relationship together were identified.

“Nothing has worried me about talking with the nurses ... yeah... they know us. We have become pretty good friends”.

(Joe and June, PCGs of a toddler)

On further examination a relationship between familiarity, security and belonging were identified in the expressed feelings of another PCG.

“We have been here for so long and we have a great relationship with the whole (ward name) family. I mean they are like our second family”.

(Olive, PCG of a young child)

Thematic analysis showed that the development of trust and safety in the relationships between PCGs and HCPs was not immediate but grew with time. Rather, examination of the transcripts showed that the development of trust and safety was found to develop naturally in conversation. This was captured in the experience of one PCG in a ward area of her adolescent.

“When you are isolated in here it is good to talk with somebody... when you come in here the nurses get to know you and it is good to have a bit of a gasbag because they are not your friends and they have nothing to do with family so what you speak about, you know it is not going to get back to anyone...”

(Helen, PCG of an adolescent).

This natural progression towards familiarity, while building safety and trust, was found to be associated with talking about general topics where commonalities were acknowledged by both the PCG and HCP.

“For some people it may be a planned thing... to ask questions. But I think it is not usually planned and it just happens and it is where the conversation leads”

(FG3: nurse)

The link between familiarity and feeling secure was illustrated during thematic analysis in a contrasting example from a single interview where both parents of a young child participated. Analysis of the shared dialogue, exemplified disparate experiences associated with familiarity when their child was admitted to a ward area that was not their specialist ward area where they had previously spent time. The parents are identified as Mum and Dad in the following quote:

June: “Yes ... everyone knows us on (Ward One name) and then when we went to (Ward Two name) ...”

Joe: “Yeah we were a bit put out, weren’t we...?”

Joe: “We were just’Whoa’... this is a bit foreign...!”

June: “We were used to people walking past saying hi (Mum name), Hi (Dad name), Hi (child name) ... but that took time....”

(PCGs of a toddler)

While the association between feeling familiarity and secure with the passing of time was identified earlier, this example illustrated how easily the feelings of security could unravel for PCGs. Further examination of the data revealed that receiving verbal greetings from HCPs did not necessarily equate to feeling welcome. Analysis of this expressed perspective in a single example gave insight into the impact of receiving a greeting that is delivered mechanically without a sense of genuine inquiry.

“Somebody might say ... how you are? And ... ‘fine thank you’... is an automated response... but that answer often suits us, because we don’t like seeing people cry or... add to their burden”.

(Gill, a consumer advocate)

4.3.2.3.2 Feeling safe to talk

Hesitancy and reluctance emerged from examination and re-examination of the transcripts. This hesitancy and reluctance was found to be associated with apprehension by HCPs about losing trust as a result of being intrusive. A sense of protectiveness was also identified based on expressed concerns about being unable to respond to, or provide for, the potential complexity of some families’ needs and circumstances.

This was exemplified in the experience of one HCP concerns about imposing and losing trust that influenced her approach about talking with families in hospital.

“Some of it (talking about family life) is just prying too much, and they are just going to be Not as open ... and they are going to close up and think we are prying too much into what’s going on”.

(FG1: nurse)

Defensive justification for a similar protective approach was identified in the transcripts of the same focus group by another nurse who felt that parents would share information if they wanted her to know *“If they want you to know they are going to volunteer it” (FG1: nurse).*

Correspondingly, examination of PCG transcripts showed that it was only possible to talk about family issues with a coexisting sense of trust, safety and feeling cared for. This shared perspective was captured in the expressed experience of one PCG, for whom trust and safety was guided by feeling cared for, or not.

“I ask something... and they (HCPs) say ‘Oh... I don’t know’... or ‘I forgot...!’ I don’t know if I can trust your judgement because you don’t seem to care”

(Helen, PCG of an adolescent)

Striking the balance between feeling safe to talk about issues that may be considered sensitive by PCGs, and concerns about the risk of not getting any information at all were also identified in the transcripts of HCPs. “If you go in with guns blazing then you will get nothing” (Susie, nurse). A tension between needing to know but being concerned about having the right to enquire was similarly expressed by another HCP: “Is that my remit to know these things...? I think absolutely it is but my resonance (my place) to ask that...?” (Tina, doctor). This dilemma was further uncovered when the degree of permission by PCGs, to venture into certain areas in conversation, was pondered by another HCP:

“I think there are other things you can’t just ask straight up... sometimes the parents bring it up where there is parental conflict about... disciplining children ... or you know separation, or violence so it is really important but some of that less structural stuff is hard to ask”.

(Marg, doctor)

4.3.2.3.3 Time and trust

However, building trust and safety over time was not always the case. The impact of experiencing the absence of belonging and trust and safety over time was revealed in the expressed resignation about talking about family issues exemplified by another PCG of an eight year old child:

“Well you get used to it. We have been doing this for the last 8 years, and they (HCPs) don’t actually ask... they just ask about medical history and that is pretty much it”.

(Maggie, PCG of an older child)

On further examination of the transcripts, anxiety and apprehension associated with a loss of trust and safety was identified in the expressed feelings of another PCG:

“It is like a cycle, because if you lose trust in the doctor then every time they want to give a treatment then you are challenging it because you don’t trust them ... and they have to keep struggling with us saying that (my child) needs this... and I don’t think he does... it becomes a battle ...because everything is... trust...”.

(Rose, PCG of a toddler)

Further to this, a link between listening and taking time with families’ and building safety and trust in a relationship was emphasised. This included the passing of time itself as well as the timing of a conversation. For one HCP the feeling safe to talk occurred when there was time to talk (*Cath, a nurse*). This shared view was emphasised by another HCP:

“I look at timing... if all they (PCGs) want to do is sleep, then I don’t think that is the time...I assess the situation and it is timing”.

(Liz, a nurse)

Examination of reflexive notes by the author demonstrated that the sense of confidence expressed about having rapport building conversations was more prevalent among the transcripts where HCPs had reported practising paediatric healthcare for many years.

4.3.2.3.4 Just in a conversation

Expressed openness and curiosity was identified in examination of the transcripts from HCPs who indicated they had been in professional practice over five years. Thematic analysis showed that for these HCPs a safe conversational environment was established naturally and without formal effort: *“You just have a conversation!” (FG3, nurse)* and

(FG2, nurse). Similarly, in one focus group of nurses, using an informal approach was found to be associated with the time of day or night these conversations occurred.

FG2, nurse: “Have you seen the way they (HCPs) do it on nights though...? It is dark in there ... You can’t just go in and start filling out paperwork... Generally, you go in there and you have a conversation and you get all the information you need and you go out and fill out the paperwork.

FG2, nurse: “It’s informal isn’t it...? Yeah ...”

Additionally, a sense of opportunity associated with using an informal approach was identified by another HCP. “Often it will come up.... (in conversation), and that is a great privilege” (FG4: allied health professional). The benefits of expressed empathy and reflective listening during these naturally arising conversations were also noted:

“And trying to be a bit reflective... saying... I think that was a shock... you know? Or that was hard to hear... or you seem cross about that... just trying to... bounce back to them a little bit what you have noticed so that they feel that you have a real understanding of their side of the story”.

(Marg, a doctor)

4.3.2.3.5 Summary

Thematic analysis of the data identified the importance of building rapport and safety in a conversation applied equally to both PCGs and HCPs. Analysis of the transcripts identified that listening with openness and curiosity were pre-cursors to building trust and safety between PCGs and HCPs. Expressed feelings of apprehension and anxiety were identified in the transcripts of PCGs about feeling heard, understood, and cared for, while concerns about being intrusive were identified in the transcripts of HCPs. Thematic analysis of the transcripts identified more confidence in the expressed experiences of HCPs who had practised in paediatric healthcare for many years whereby conversations between PCGs and HCPs occurred naturally. Examination of the expressed experiences also identified that feelings of trust and safety were built up over time.

4.3.2.4 Second theme: The whole family

This theme emerged from thematic analysis of the transcripts of PCGs and HCPs about feelings and experiences regarding talking about aspects of family structure and family life during conversations together. Analysis of participants' feelings and experiences related to talking about family life included their perspectives about the meaning of family and family functioning. These findings are presented in the following paragraphs.

4.3.2.4.1 *Feelings about the significance of family*

Emphasis was placed on “the whole family” equally by PCGs and HCPs throughout the transcripts. However, in four of the ten PCGs transcripts this emphasis was not understood during the early admissions to hospital when their children were first diagnosed. Confusion about the relevance of family was identified in the early reflections shared by these PCGs about initial hospitalisations when their children's health journeys first began. Expressed feelings of intrusion were shared. One PCG of an older child reflected:

“It was all very confusing because they didn't explain why they were asking these questions. ... It is a bit invasive. When he was first born, they (HCPs) would bombard us with questions, who lives at home? How many siblings? Do you work? Do you do this? It's like, who really cares? Does that really matter?”

(Maggie, PCG of an older child)

Despite the overall emphasis on family by PCGs and HCPs that was identified in the data, hesitancy and conflict about being intrusive were identified in HCP transcripts, while the need to ask questions was justified by others: *“There are a heap of different things that they (PCGs) could think... but ... that is nothing for us to be afraid of ... parents should not be concerned that you are asking those sorts of questions”* (Liz, a nurse). Another HCP differentiated between children and families sharing the perspective that those who were “in the system” felt more comfortable discussing family life and those who were not (Cath, a nurse). Further examination of the transcripts revealed reservation due to the risk of being invasive *“I think sometimes families are quite surprised that they are being asked (about family life). I think there is a relative privacy and other nurses don't ask that routinely...”* (Susie, nurse).

Within PCGs transcripts, the importance of considering the whole family was not appreciated during initial or earlier admissions to hospital.

“I just thought they should concentrate on him (son) getting better... Now I feel differently. I understand why it is important. His (son’s) team involves the whole family unit when they talk to us. It is not just about him”.

(Annie, PCG of a young child)

An expressed protectiveness where a need to appear able by PCGs also emerged from the transcripts. It was noted at the time that this protective perspective was fortified between both parents of a young child who participated in one interview. .

Joe: “I don’t think it is important (to talk about family life).

June: “No one really asked me, the social worker come and asked a few questions.... but I don’t know.... We cope really well and I think that shows so I think they don’t need to know all that much”.

(PCGs of a toddler)

Protectiveness and a need to appear able to manage was similarly identified as stigma where the significance of talking about family was projected towards others possibly considered to be less advantaged *“It is important for them (HCPs) to ask actually.... yeah. Not specifically for me but for other people ... yeah” (Barb, PCG of an older child)*. In keeping with the second process theme *“building trust and safety”*, for one PCG with an infant who was seriously ill and from a rural area, openness to talking about family life was found to be related to an understanding of the importance of family.

“I like it that they ask about our home environment and our relationships and my partner”.

(Eve, PCG of an adolescent)

Awareness by HCPs of the significance of including attention to the family when caring for children who were seriously or chronically ill in hospital was identified

throughout thematic analysis. This perspective was unanimously supported with verbal and non-verbal affirmations during interviews and focus groups when reference was made to the ultimate influence of family when children are seriously ill. *“If we don’t help the family ... we are not helping the child” (FG.4, allied health professional.)*

4.3.2.4.2 *Consideration for family structure*

Attention to “the whole family” in PCG and HCP transcripts was found to extend beyond the nuclear family: “Family is such a different structure nowadays. It is not just Mum and Dad; it is often grandparents and aunties ...and looking at the bigger picture” (FG.3, nurse).

This was reinforced throughout analysis of the HCP transcripts: *“Yeah... the whole family” (FG.2, nurse)*. Open consideration to family structure was also identified: *“Bearing in mind that every family is unique in themselves” (FG3, nurse)*. Additionally, the many different structures of “family” in addition to the nuclear family, such as the “*blended family*”, and the “*foster family*” (FG2, nurse), were also identified along with acknowledgement of the support provided by many extended family members when a child is seriously ill:

“Well to me it means having the family involved, predominantly, parents and also grandparents, wherever there is extended family and support”.

(Susie, nurse)

Further examination of the transcripts uncovered a shared understanding of fluidity that can be associated with family structure that can change over time:

“The family changes ... what might be the way in January this year it, may not be in June... just acknowledging that with them”.

(FG3, nurse)

Understanding the family structure was also found to be linked to planning effective care by HCPs. A view that understanding the family helped to maintain the balance

between agreement and compromise, especially when treatment goals and expectations were found to be different for PCGs and HCPs:

“The family is involved and we respect everything they say, however, we are still able to have a say as well, like a team...yes.... they are very much involved, not just directed”.

(FG.3, nurse)

The importance of the whole family also emerged in practical terms in relation to practice by HCPs: *“So we need to have appointments made around the family as best as possible...”* (Sue, a doctor). This was echoed in the expressed feelings within the transcripts of other HCPs. *“Decisions are what fits with the family... not the family fitting with all the professionals”* (FG, allied health professional). Emphasis on the family within the context of the hospital environment more generally also emerged from the transcripts:

“What we do needs to sit with the family and the family’s priorities, as opposed to systems and structures”.

(Marg, a doctor)

This emphasis on family in HCPs transcripts was met with a call for further attention to family identified within the transcripts of the PCGs.

“They need to focus more on that, because it is the whole full affair... the whole ripple effect on everything, and the whole extended family”.

(Annie, PCG of a young child)

A sense of hierarchy was uncovered during further examination of the transcripts about tailoring care to the needs of individual families by HCPs. Here, subtle reference was made to delivering a plan of care where a desire, however, unconsciously expressed, to ‘solve’ or ‘fix’ issues was identified:

“We cannot possibly do family centred care until we have spent the time to understand how the family manages”.

(FG.3, nurse)

This subtle observation within the transcripts suggested a positional or a functional inequality between PCGs and HCPs. This was emphasised in a more obvious example identified within the transcripts “*From what I can see, the nurse is often the glue that keeps it all together... that’s what I do anyway*” (Cath, a nurse). However unintended, this expressed perspective suggested some inequality where the nurse was portrayed as indispensable while the parents were not.

Overall, a shared perspective that having understanding of and appreciation for the uniqueness of the family structure of a child who is seriously ill in hospital was found to be essential to care giving. However, having an understanding of the relevance of talking about family structure was found to be not well understood in the early days by PCGs. Responses from PCGs included expressed protectiveness about talking about family issues among some PCGs and a desire to resolve issues suggested some hierarchical inequality in the expressed perspectives of HCPs. Findings from thematic analysis related to talking about family functioning are presented in the following paragraphs.

4.3.2.4.3 *Talking about family functioning*

A range of perspectives among participants about talking about aspects of family functioning were identified during thematic analysis. These perspectives were related to the emotional health of PCGs, their family relationships, and their expressed experiences about exposure to additional life stress. In keeping with findings presented in the first theme “*Building relationships*”, analysis of the transcripts identified that HCPs who were reported to have practised in paediatric healthcare for many years expressed more ease and welcome to discussing psychosocial issues with PCGs: “*Isn’t that what we do?*” (FG.3, nurse); “*We do it all the time!*” (FG.3, nurse), and further echoed in FG.2 by a senior HCP; “*It is so critically important to what we do*” (FG2, nurse).

An openness to whatever may be of concern to a family was identified as key when addressing the priorities for a family by HCPs who reported having more than five years of experience in paediatric healthcare: “...it may be the animals at home they worry about” (FG.2, nurse). As with findings within the second process theme “*Building safety and trust*”, examination of the transcripts showed that discussing

issues related to family life and routine arose naturally in conversation. Further to this they were found to stem from a practical need:

“I ask what supports they have at home, if Dad is at home or if Mum is at home, and how are they going to cope with the three other children”.

(FG2, nurse)

Similarly, this identified confidence among more experienced HCPs about talking about family life was found to have a practical basis.

“I would say that I am very comfortable talking with families about their resources ... and if they are struggling, what respite are you getting...? What happens when things go bad...?”

(Marg, doctor)

However, an opposing cautious perspective was identified in the transcribed data from nursing participants who practiced in a ward based setting for less than three years:

“I wouldn’t feel comfortable asking about family issues. If they tell you then... OK to go on with it but sometimes I just don’t feel comfortable doing that.”

(FG.1, nurse)

Additionally, uneasiness was identified in analysis of the transcripts.

“If it is a really complex social history, it can be a little awkward sometimes”.

(FG3, nurse)

At the time, the influence of unspoken fears about being able to hold the PCG’s burden noted in reflexive notes, were pondered as potential underpinnings to this hesitancy by HCPs. Further examination of the transcripts revealed expressed concerns about meeting what might emerge:

“Perhaps I am not quite brave enough, but I try to have that overall interest in what is happening for that parent or that caregiver that comes in, because maybe...you can get a social worker or someone else involved.”

(FG4, allied health professional)

Further to hesitancy, conflict was identified in the expressed feelings of a nurse during a ward based FG that was supported within the forum with verbal agreement and nods of affirmation.

“I don’t really feel comfortable... but I like to know! ...but I don’t want to be the one to say!”

(FG2, nurse)

A corresponding sense of protective justification was also noted. *“I feel they can ask whatever they feel is appropriate and we can choose whether or not to answer or share that information” (Rose, PCG of a toddler).*

In contrast feelings of ease about talking with families that developed over time for more experienced HCPs were identified in the transcripts:

“I have become much more comfortable as I have gotten older, and I don’t know if that is age, or life experience, or work experience, but I think and I hope that I have got better at it”.

(FG.4, allied health professional)

4.3.2.4.4 Perspectives about the relevance of family relationships

Of the ten PCGs, six were found to be of the opinion that asking about parental relationships was important for the child and family. For one PCG this was necessary for her child’s doctors and nurses to ask about “with so many broken relationships” (Barb, PCG of an older child). Among the PCGs who expressed views that talking about parental relationships with HCPs was important, the reason for this was identified in the expressed feelings of one PCG. *“It does help ...yes...because it does impact on the child ...yeah” (Eve, PCG of an adolescent).* Of the ten participating PCGs, five participants had never been asked about their relationships by HCPs when they were in hospital with their children.

A conflicting view was also exemplified in the transcript of the PCG of an older child who felt that asking about parental relationships could uncover warning signs but was concerned about initiating a series of events which could be problematic “...*Yeah, the snowball effect...*” (Olive, PCG of a young child).

Similar to the findings that made up the second process theme “building trust and safety”, protectiveness was expressed by PCGs. While the importance of talking about these issues in hospital was acknowledged, this importance was directed towards others.

“There would be other families where it would be needed to find out a bit about their background... many parents deal with things in different ways. There may be some who get angry or grumpy...”

(Joe, PCG of a toddler)

Further examination revealed stigma where expressed concerns were projected to others deemed to be less advantaged:

“Well I have a good family relationship so I have no issue with them (HCPs) asking. However, if I did have issues it could be”.

(Barb, PCG of an older child)

This was reinforced by another PCG: “We cope really well and I think that shows, so they don’t need to ask all that much” (June, PCG of a toddler).

Similar caution was expressed by HCPs about asking about family relationships, “*Yeah ... it is how you ask it*” (FG3, nurse). Further concern about encroaching on family relationships was shared by another HCP “*Um...marital relationships... that’s a murkier, trickier area for conversations... not the starting point*”. (FG4, allied health professional). This expressed hesitancy and unease was reinforced by a further HCP “*...but between the parents...no.... I wouldn’t go there...*” (Susie, nurse). While for another nurse, the hesitancy was justified “*... they might be thinking that I am just being a sticky beak...?*” (Cath, nurse).

Further examination revealed a shared despondency by HCPs that was met with responding justification for these concerns.

“Some families may feel...’I’m sick and tired of telling this story so many times, that I will just tell that bit of the story so I don’t have to worry about it, or so they don’t ask me questions’...”.

(FG.3, nurse)

This sense of justification was supported with verbal nods and affirmations in another FG when one participant shared that she did not ask questions about family life unless she felt the need was there “No I would never ask, unless I was really worried” (FG1, nurse).

Similarly justification about talking about family relationships despite feeling uncomfortable was endorsed by other HCPs during a focus group:

“Normally I wouldn’t... but where things are not adding up... if there were little yellow flags... little things that they didn’t seem to be coping with, or taking in information, or following through with things, or missing appointments, or getting muddled... that sort of thing”.

(FG4, allied health professional)

4.3.2.4.5 Summary

An overall emphasis was placed by PCGs and HCPs on the importance of the whole family. A shared agreement among participant transcripts for acknowledgement of the uniqueness of family and range of family structures emerged from examination of the data. Protectiveness shared by PCGs about the relevance of discussing aspects of family functioning, in particular the dyadic parental relationship was projected towards others they considered to be less advantaged than themselves. This was met with expressed reluctance by HCPs regarding talking about family issues with PCGS. Further examination of the transcripts revealed expressed justification for not talking about family relationships by HCPs. Finally, emphasis on rapport building was shared by PCGs and HCPs within the transcripts.

In the following subsection the findings from thematic analysis of the expressed feelings of participants about the physical and cultural environment of the hospital are presented.

4.3.2.5 Third theme: Feelings about being in the hospital environment

Thematic analysis of the transcripts identified and named “*the hospital environment and services*” as the third theme. The findings that make up this theme are presented in this section for clarity however, these findings relate to each of the first two main themes and process themes and will be presented accordingly in the Discussion Chapter. The third theme named “*the hospital environment and services*” emerged as the foundation on which building relationships with the whole family occurred.

PCGs experiences about their expectations when they bring their children to hospital, and their feelings of confidence or otherwise in the hospital environment and people, are outlined within this theme. This includes the feelings and perspectives of PCGs about feeling acknowledged as a parent, and HCPs perspectives about acknowledging and supporting parental skills. Finally the experiences and expectations of PCGs and HCPs about service provision and meeting the needs of children and families in their care are included in this theme. A sub-theme within this theme was identified and named “the people and culture”. This sub-theme emerged from the expressed feelings and experiences of PCGs about adjusting to hospital routine and communication between PCGs and HCPs related to associated practices and behaviours. Tension between PCGs and HCPs about roles and responsibilities are outlined in this sub-theme.

4.3.2.5.1 *Feelings about being in the hospital environment*

Feelings of familiarity, or otherwise, identified in the expressed experiences of PCGs pertained to both the physical and the cultural environment of the hospital. As outlined in the first theme, these feelings of familiarity developed over time as relationships between PCGs and HCPs were built. Analysis of data relating to the people and culture of the hospital were found to be linked to feelings of confidence or not by the PCGs that extended beyond the people and service to a sense of confidence in the physical establishment itself.

Appreciation by PCGs when HCPs extended a welcome to their children and themselves was revealed while an expectation for courtesy and acknowledgement was identified within the PCG transcripts: “*Just being polite... just to acknowledge me when they (HCPs) come in the room...*” (Sara, PCG of an infant). Dissimilarity between PCGs who came to the hospital regularly and those who presented for the

first time, or once only, was identified. These feelings of familiarity identified earlier within the theme “building relationships” by PCGs were also related to the physical environment of hospital wards. Feelings of familiarity were linked to being a regular attender by eight of the ten PCG transcripts. Comparisons were drawn between those who attended regularly or over a long time was not the same as other children and families who attended the hospital for a single admission only where the need to feel known and familiar was not the same.

“Coming in for tonsils or adenoids or something like that ... is different. But when you have a long term illness like us it is important for them (HCPs) to know as much as possible about us”.

(Annie, PCG of a young child)

Within this sense of familiarity, boundaries were also identified. *“We have become really close with some of the nurses, and you can tell the nurses are...like... trying not to cross their line” (Joe, PCG of a toddler).*

4.3.2.5.2 Feelings about discussing parental characteristics and skills in hospital

A range of views about paying attention to the skills and attributes of PCGs of children in hospital was identified in the transcripts. A range of perspectives about the educational attributes and skills PCGs acquired through employment or education were examined.

Six of the ten PCGs shared the view that their education attainment and occupations were relevant because both influenced how important healthcare information was delivered by HCPs. However, defensiveness related to being judged was also identified regarding discussing their own situation. A conflicting opinion by one PCG who felt her education and occupational background was very relevant to her child, however, when asked about this was found to be another matter:

“I don’t think it is relevant for them to ask me about my education. I think they should speak to everyone on a level playing field... absolutely”.

(Tom, PCG of an infant)

Concerns about inequity and stigma were identified about being asked about education and occupation that were projected towards others.

“I mean with me... we are quite well off so it doesn't bother me... it isn't like an embarrassing question”.

(Barb, PCG of an older child)

Of the ten participants, three PCGs had been asked about their educational or occupational attributes, while the remaining seven had not. Confusion was identified when one PCG reported she did not know why she had been asked about her education or occupation. In contrast, a preference for educational attainments to be acknowledged was identified in the resigned perspective of another PCG.

“I think if they (HCPs) knew my educational background they would talk to me differently... Often they treat me like an idiot ... but they never ask ... and it probably would be a good thing to ask...”

(Olive, PCG of young child)

In reflexive notes by the author the disparity in tension when PCGs shared their feelings about talking about working outside the home in comparison to education was noted. Participants displayed more relaxed body language when talking about work hours and work routine in comparison to talking about education. The relevance of PCG skills was highlighted in the following exemplar.

“Really relevant... at a number of levels, I guess.... Their ability to understand the complexity of their child's condition would be determined by their education”.

(Tina, doctor)

However, little importance was assigned to parental education among four nursing focus group where a need to consider additional skills and qualities was identified.

“You can't generalise, some people have ten kids and they cope really well and may not have a job or education, but they seem to link it together, and someone who has one child and

you know they have a lot of money... influence and good jobs and they don't cope as well".

(FG2, nurse)

This reference to self-efficacy was identified throughout the transcripts.

"...a teenage drop out might have great support systems at home, more than a family who has just moved here who are very well educated with no family support".

(FG1, nurse)

The impact of additional factors on PCGs capacity to manage emerged from further examination of the transcripts.

"It depends on their coping skills... if parents are very stressed or anxious, they do not take the information in so it doesn't matter how bright they are or where they sit on the spectrum. If they are not able to focus or hear the information or have someone there to support them... it doesn't matter".

(FG3, nurse)

A range of behavioural responses was also identified during analysis *"Some go home and google it and some go home and look into it and some don't want to know"* (FG2, a nurse). The shared compassion by HCPs for the vulnerability and loss of control experienced by PCGs was also evident in the expressed dialogue by HCPs. This expressed need by PCGs to be able to cope and remain in control was met with the experience of feeling overwhelmed for some PCGs who felt incapable despite managing professional careers and significant responsibilities in their work lives.

PCGs and HCPs shared similar views that parental education was not helpful. This view was supported by shared concerns by PCGs about feeling judged while reference to the influence of self-efficacy, social support and capacity to cope were identified in the shared expressed feeling within the HCP transcripts.

4.3.2.5.3 Experiences of family life stress when in hospital

A range of experiences with additional life stress emerged from the transcripts. These ranged from the experience of uncertainty and stress pertaining to hospitalisation to

overwhelming additional life stress. A tension between maintaining control and dealing with the often unexpected circumstances and additional life stresses were identified in the transcripts.

For one PCG, anguish and distress was apparent in her expressed experience of stress. As a recent migrant and new mother of an infant who was seriously ill in hospital since birth, she had moved house, renovated and was in the process of moving house again within a short period of time. Additionally, her partner's work opportunities were uncertain. Further examination identified that the anguish and distress she experienced was related to the uncertainty about her child's health which she reported "*was not part of the plan*". On reflection, the experience of felt empathy by the author at the time was met a sense of dismissal by the PCG who at the time discounted the relevance of the additional life stress in relation to moving country, house and job because "*that was always part of our plan*" (Sara, PCG of an infant).

Similarly, a shared experience of anguish and uncertainty was identified in the transcripts of another PCG in hospital with her infant who ran two businesses from a rural location. Again the enormity of being at the hospital away from home while also managing a toddler that was evident to the author at the time of the interview was minimised by the participant. The enormity of managing these responsibilities diminished in comparison to the expressed experience of anguish related to her infant's persisting serious physical symptoms without any clear diagnosis (Tom, PCG of an infant).

The impact of exposure to stress over a long period of time was also identified in the transcripts of PCGs who had been attending the hospital for many years. For one PCG, attending the hospital throughout her adolescent' life, also included managing her own life threatening health problem, separation from her partner, and recently providing palliative care for both her parents who died of serious illness at close intervals.

"I have said to the doctors, 'I'm losing my short term'. I reckon it is just trauma. I just can't remember day by day. I said to the doctors, 'write it down' because I can't remember what you told me to do when I walk out".

(Helen, PCG of an adolescent)

This overwhelming stress and anguish was felt by the candidate where acknowledgement for the impact of stress over a long period of time and its effect on memory and functioning and care giving was noted.

Overall, thematic analysis showed that feeling welcome, acknowledged, and familiar was important for PCGs who came to the hospital regularly. PCGs and HCPs agreed that it was not helpful to discuss parental education because some PCGs may feel judged while HCPs were of the view that reference to the influence of self-efficacy, social support and capacity to cope were more useful aspects of capacity to discuss.

Analysis of the transcripts pertaining to the sub-theme “The hospital people and culture” are presented in the following paragraphs.

4.3.2.5.4 The people and culture

The range of feelings expressed by participants in the transcripts about the HCPs and their functions and routine in the hospital were included in this sub-theme. Feelings of familiarity and belonging expressed by some PCGs were found to be met with some frustration and confusion by other PCGs. A similar range of experiences about the need for clarity were also identified. Equally, corresponding challenges and frustrations were identified in HCPs transcripts. These findings are presented under the following headings, experiences and perspectives about the hospital routine, and feelings about information in hospital.

4.3.2.5.4.1 Experiences and perspectives about the hospital routine

Just as PCGs became familiar with their children’s HCPs and ward areas over time, this familiarity also applied to the hospital routine. PCGs reported spending long periods of time in the hospital they quickly became familiar with the language, people, and practices within healthcare they never previously considered. This was exemplified by one PCG where familiarity was related having some control in the Intensive Care Unit.

“We spend so much time in hospital that we have picked up ‘the lingo’ here and I feel when we use ‘the lingo’ then they respond to us in a different way because they know that we know what is going on”.

(Rose, PCG of a toddler)

This attention to the language was appreciated by another PCG. *“They are very open and they tend to explain things in a language that we understand” (Tom, PCG of an infant)*. This combination of understanding the language and feeling well known was further reinforced *“Nothing has worried me about talking to the nurses... yeah they know us” Helen, PCG of an adolescent)*.

However, resignation and despondency were identified in an opposing view by one PCG who had attended the hospital since her child’s birth.

“We have been doing it for the last eight years so and they (HCPs) just ask about medical history and that is pretty much it”.

(Maggie, PCG of an older child)

This sense of weariness at the lack of enquiry was similarly identified by another PCG who told of her tiredness and bewilderment related to an invasive procedure on her child for which they both felt ill informed and ill prepared *“I think it would be wonderful if anyone just cared!” (Barb, PCG of an older child)*. A further loss of control associated with hospital routine was identified in the experience of another PCG related to the night time routine.

“And he had this fear ... in hospital he tries to stay awake and see who he has got (nurse). And if it is someone good, he will just roll over and say ‘Goodnight Mum’. If not he will be awake and he has the fear...”

(Annie, PCG of a young child)

4.3.2.5.4.2 Feelings about information sharing

The expressed anxiety and a loss of control by PCGs also extended to practices related to medical and clinical rounds when teams of HCPs particularly medical doctors visited patients in the ward areas. Experiences of exclusion and feeling inconspicuous were identified.

“So they kind of huddle around each other and have a little discussion... ‘Oh she is going well...’ and then walk out and you hear the tail end. We have had to go... ‘Hey, come back...!’”.

(Joe, PCG of a toddler)

Confusion was also identified about the roles and responsibilities of HCPs. A need for clarity was found to contribute to the struggle PCGs experienced when they felt confused, or unsure about information. For one PCG the need to be consistently included was identified in her call to have her maternal role acknowledged.

“I have 100 per cent trust in my intuitions and gut feelings. Some doctors and nurses will listen and take it on board while others ... are just not interested”.

(Rose, PCG of a toddler)

Correspondently, the unique roles of PCGs was shared by HCPs who reported many years of clinical practice in paediatric healthcare: *“You will not be able to facilitate a good conversation if you are underestimating them”* (Jane, nurse), and *“if you patronise them you will often lose them...”* (Cath, nurse).

The influence of roles and the perception of the health system by PCGs and families was illustrated in the perspective of another HCP:

“As a paediatric trainee, I would ask questions about family history and relationships and get a certain amount of fairly bland straight factual information. When I became the psychiatry registrar I felt I asked the same questions but I got completely different answers”.

(Marg, doctor)

A corresponding experience of stress and helplessness about not being asked relevant questions was notable in the expressed feelings of one PCG, who was supporting her adolescent with impending transition to the adult setting.

“You ask questions but you can’t get answers. That can be very frustrating especially when we have got other health issues and disability on top of that. So we are just waiting for information. It is a scary system!”

(Eve, PCG of an adolescent)

Six of the ten participants expressed the need for more clarity in information sharing. One PCG this meant “*not being kept in the dark*” (Tom, PCG of an infant). A preference for attention to detail was also identified in another PCG’s call for clarity

“I don’t like it when people are sloppy and just missing out details ... what exactly does that mean, you know...?”

(Rose, PCG of a toddler)

Examination of the transcripts showed that these feelings of frustration were shared by both PCGs and HCPs. A sense of vulnerability and anguish were exemplified in the experience of one PCG who felt she could not leave her child’s room.

“You know how you do your switchover? I reckon that is a big thing.... I have to say no, no! She is not allowed to do that... and they (HCPs) say ‘Aw...sorry’. With a kid with a tumour who is not allowed to get up for so many hours... This is important!”

(Helen, PCG of an adolescent)

Similarly, feelings of confinement and a need to keep HCPs accurately informed were equally identified in the expressed perspective of other PCGs “*Sometimes nurses aren’t told what is happening*” (Sara, PCG of an infant). Further frustrations about feeling ill informed were shared:

“They (HCPs) walk out and you have to ask the nurses, ‘what did they say?’. Generally they are very good but there has been a few times when they didn’t tell us stuff... and we have had to try and chase it up...”

(Barb, PCG of an older child)

This was met by expressed empathy by some HCPs who recognised the need to clarify important health information:

“The child might be going to theatre and they (doctors) explain it to them (parents) and then they walk out and you say did you understand any of that? And they look at you as if to say... no”.

(FG.2, nurse)

4.3.2.5.4.3 When communication is difficult

A further sense of helplessness among HCPs was identified within the transcripts about meeting the needs of PCGs who do not speak or understand the English language. *“With parents who speak English you can’t say, the doctor is coming so have your questions ready!” (FG.2, nurse).*

Further to this expressed difficulty about offering support that extended beyond medical information was empathically expressed by HCPs who wondered about the additional stresses PCGs who did not speak or understand English could be experiencing:

“I think when people are upset often it is difficult to express yourself well in a language that is not your first. I want to explain to them... ‘I might be able to help you...’ but I don’t want to be just another person ...”

(Jen, a consumer advocate)

A way of enhancing support for HCPs during difficult conversations was shared by one HCP where mentorship and reflection was promoted in practice.

“...making sure that the junior members of the team are with you... they can observe... they need to be there to see how lots of different people have those conversations because everyone does it a little differently and you have to work out what is going to work with your own communication style and you own biases...”

(Tina, doctor)

Varying coping responses were also considered in the reflections of some HCPs when PCGs frustrations had escalated to aggression.

“I still carry on and I say please don’t speak to me like that, I am just here to help”.

(FG1, nurse)

“I try and stay as calm as possible, be empathic and be on their side as much as possible”.

(FGI, nurse)

“It is really a personal thing anyway. If they are upset it is usually anger at the situation, they are in not angry at me...that’s how I see it”.

(FGI, nurse)

However, the experience of distress and anguish as a consequence of the expressed frustration or anger of PCGs was also identified.

“Certainly we have a number of really awful situations where parents get really angry and upset in front of their child and the child is crying and the parents are shouting... so yeah... that is challenging. I think we do it better but we have a long way to go”.

(Marg, doctor)

The range of responses from PCGs was also identified:

“With some families ... You have to know them quite well ... And other families it is quite easy... they are more open and happy to talk about these things”.

(Tina, doctor)

The need for HCPs to effectively pitch information by six of the ten PCGs that stemmed from spending time at their children’s bedsides and observing others was identified.

“You don’t get any privacy in these rooms. I look at people who are less educated than me or my partner and the same team talks to them... they can dumb it down”.

(Annie, PCG of a young child)

4.3.2.5.4.4 The impact of the hospital and services on communication

Thematic analysis identified that participating PCGs shared a sense of familiarity and ease in their children ward areas. Analysis of the transcripts identified that expressed openness by some PCGs was met with feelings of protectiveness by others. Stigma by PCGs was also projected towards other families' circumstances who were considered to be less advantaged. Additionally ambiguity was identified within the transcripts of HCPs with less years of experience in practice where expressed reluctance to ask about family issues was met with a desire to know this information. The enormity of the burden carried by some PCGs was met with expressed empathy and helplessness among the HCPs about meeting the often overwhelming needs of PCGs.

A shared emphasis on feeling welcome and familiar in the hospital environment and with each other was identified in the transcripts of PCGs and HCPs. These feelings of familiarity were found to be met with a loss of control by PCGs and feelings of exclusion and confusion related to aspects of the hospital routine. Additionally feelings of frustration and helplessness were identified within the transcripts by PCGs about being kept informed. Additionally, feelings of helplessness and frustration were also identified in thematic analysis about responding to the needs of PCGs who did not understand or speak the English language.

4.3.3 Summary

In this chapter, the findings from thematic analysis using the six steps of thematic analysis by Braun and Clarke (2006) were presented. Analysis of the interview and focus group transcripts identified three major themes "*building relationships*", "*the whole family*" and "*the hospital and services*". Building relationships with the whole family in the context of the hospital services was found to be dependent on two process themes named "*listening with openness and curiosity*" and "*building trust and safety*".

A need for PCGs to maintain control, identified in their expressed desire for "*straight answers*", was associated with shared despondency when these needs were unheard or not understood. This corresponded with expressed hesitation by HCPs about meeting the unspoken enormity of the needs of PCGs while also being aware of the often difficult trajectory ahead. Becoming familiar and feeling at ease with HCPs over time was found to be related to whether trust was built in a relationship or not. Expressed

feelings of ease and belonging within relationships between PCGs and HCPs were linked trust and feeling cared for by HCPs. Emphasis on the value of “*having a chat*” was identified within the transcripts of PCGs and HCPs.

Expressed hesitancy was identified within the transcripts of PCG and HCPs about discussing family functioning and family relationships. Stigma was identified where PCGs concerns were projected towards others they considered to be less advantaged. Similarly, ambiguity in the expressed hesitancy of HCPs about broaching these issues with families was met with a conflicting “*need to know*”. Feelings of familiarity were also found to be related to the hospital environment and included participants’ feelings about being welcomed and in the hospital. Tension was identified about the relevance of asking about PCGs levels of educational attainment and occupation. The overwhelming enormity of the impact of additional life stress was identified in expressed experiences of PCGs. For some PCGs, especially those with younger infants, major life stresses were ‘glossed over’ in an effort to maintain control. This was in contrast to the PCG of an adolescent where concerns about short term memory and coping were attributed to her experience of accumulative stress over many years. Findings from thematic analysis showed that building trust and safety with the whole family was dependent on listening with openness and curiosity. Finally, safety and trust that is established and grown, or otherwise, was found to extend beyond the relationship between PCGs and HCPs as individuals to the hospital environment itself and the services within it.

In the following chapter the integrated findings from survey and thematic analyses are summarised, and discussed in detail in relations to the extant literature. Following this the emergent family psychosocial framework is presented and implications for practice and research are discussed.

5. Discussion

5.1 Introduction

In this chapter, the results of this study will be synthesised and discussed in detail in relation to the extant literature and the emergent conceptual model is finalised. A summary of the main findings will be presented beginning with the reported response rates and sociodemographic of the PCG and HCP samples and a synthesis of the attitudinal survey results and thematic analysis will follow. An illustration of the emergent conceptual model will guide discussion of the findings in more detail. Following this, the main findings will be placed in the context of extant literature and discussed in some detail. The summary of the new understandings will precede the presentation of the finalised emergent model where comparisons will be drawn between this model and the original framework. Subsequently, the practice and research implications for the finalised conceptual model for family psychosocial assessment will be outlined. Finally, the strengths and limitations of the study will be discussed and conclusions drawn.

5.2 Summary of main findings

Response rates for the PCG and HCP surveys and socio-demographic characteristics are presented before a synthesis of the main findings for both quantitative and qualitative aspects of the study.

5.3 Response rates and socio-demographic characteristics

The overall response rate for PCGs was 55 per cent. Most PCGs were female and spoke English at home, and all participants reported they were the parents of the children who were seriously ill. Fifty-one per cent held a university degree. This is in keeping with the level of advantage often reflected in survey samples where participants are those who speak English and have had some formal education (Regber et al., 2013). Using areas of residence as an indication of sociodemographic advantage or disadvantage established by the Australian Bureau of Statistics, the PCG sample was normally distributed (ABS, 2014). Children's ages ranged from two months to 18 years. The median age was six years. The most common serious illnesses were neurological, developmental, and respiratory conditions. Children with heart disease or chronic infection each accounted for 10 per cent, while endocrine disorders, childhood cancer, renal disease, and severe allergies were reported in lesser

proportions. Similarly, an overall response rate of 65 per cent was recorded from participating HCPs. Most participants were female with a high per cent being nurses (82%), while allied health professionals made up the larger part of the remaining 12 per cent along with medical doctors, chaplains and parent advocates. Most of those in the sample (63%) had more than five years' experience in paediatric healthcare. It is a common finding that HCPs who choose this area of specialty often remain working in it for some time (Mahon, 2014, Twigg & McCullough, 2014).

5.4 Synthesis of attitudinal survey findings and thematic analysis

Statistical analysis of survey data provided information about participants' attitudes regarding talking about psychosocial issues. Survey analysis also identified levels of importance assigned to psychosocial components that were to be considered for inclusion, or otherwise if determined not important, in the final framework... Thematic analysis of interview and focus group data provided much deeper insight regarding participants' perspectives about discussing psychosocial issues, and how these attitudes influenced their subsequent experiences.

Overall mean scores for PCGs using the *PATPSI*, and for HCPs using the *Physician's Belief Scale* scores, showed participants' attitudes regarding talking about psychosocial issues were positive and there were few differences associated with the social, demographic or professional characteristics of participants. These positive attitudes were reflected evenly across the subscale scores included in each of the instruments. However, thematic analysis revealed hesitancy and reluctance to talk about psychosocial issues. While most PCGs said that they felt comfortable talking about psychosocial issues at the time of the interviews, this was not the case in the beginning when their child was first diagnosed with a serious illness. Rather, this was found to occur over time, as trust was built and PCGs felt accepted by HCPs. For HCPs reluctance about imposing on PCGs by talking about personal issues, before trust was built, was identified.

With regard to the components of proposed psychosocial framework in the surveys, both PCGs and HCPs agreed that PCG emotional health and self-confidence were important and acceptable to discuss. However, the majority of PCGs and HCPs equally indicated that PCG educational attainment and occupation were not important or appropriate issues for discussion. As might be expected, PCGs and HCGs who

reported the most positive attitudes regarding talking about psychosocial issues were more positive about the components of the proposed framework. Insights from thematic analysis also revealed that psychological issues, maternal self-confidence and emotional well-being were considered to be easier to discuss. This perspective was in contrast to levels of education or occupation that were perceived to be ranked in terms of hierarchy. Stigma was also identified in the transcripts of PCGs while concern about being judgemental was expressed by HCPs.

The positive psychosocial attitudes of PCGs and HCPs, and the differences in the levels of importance assigned to the psychosocial components included in the surveys were found to be congruent with the named themes in the emergent conceptual model from thematic analysis. For this reason, the emergent conceptual model will guide discussion in this subsection. It is presented again here with a brief outline of the findings related to each theme and the relationships between them. See Figure 5.1.

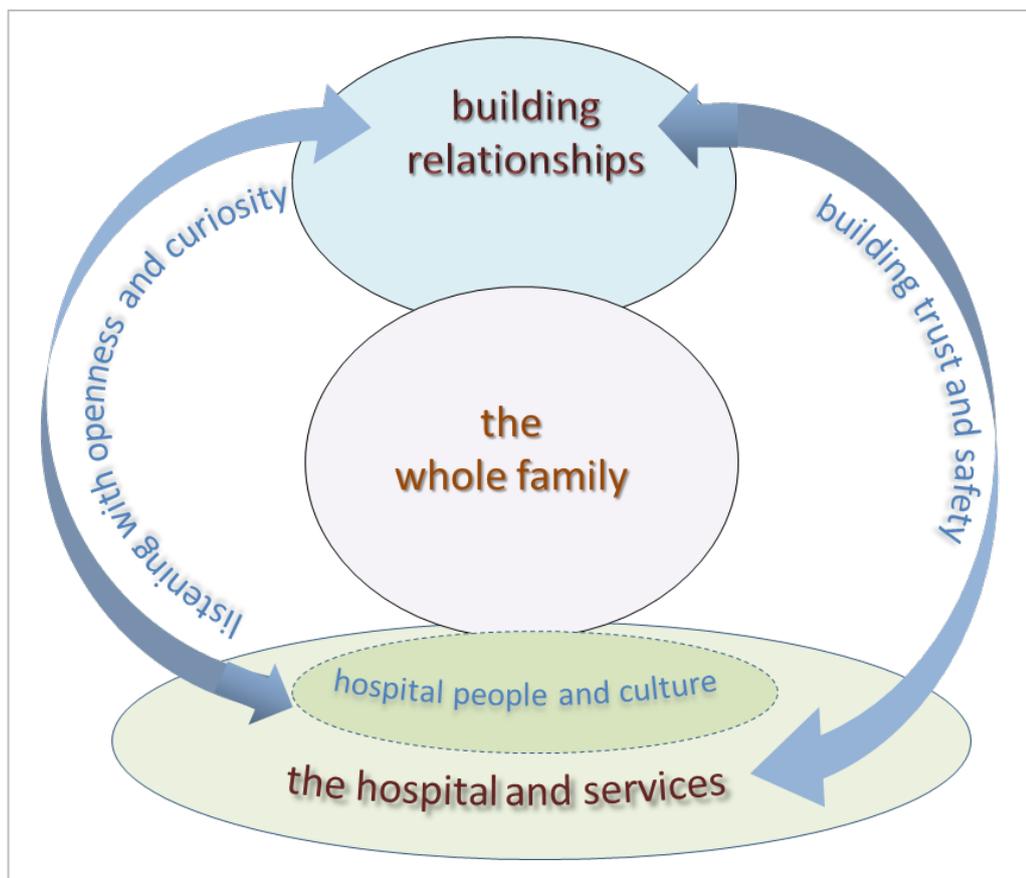


Figure 5.1

Emergent model from thematic analysis of one on one interview and focus group data and consistent with survey findings from PCGs and HCPs

Similarities and tensions identified during thematic analysis of one-on-one interview and focus group data provided deeper insights into the overall positive attitudes reported in survey analysis. The first main theme named “*building relationships*” contained an expressed willingness by PCGs and HCPs to talk about family issues. However, the willingness was found to be constrained by reluctance to broach issues considered to be sensitive. As outlined in the results section of this thesis, the first main theme was found to be indispensably connected to two process themes named “*listening with openness and curiosity*” and “*building trust and safety*”. Further examination showed that a desire to feel heard and understood was needed by PCGs in order to build trust and safety before talking about psychosocial issues. For HCPs, their expressed hesitancy and reluctance was found about their concerns about imposing on PCGs, before they felt families were ready to share this information.

The second main theme named “*the whole family*” emerged from unanimous emphasis by PCGs and HCPs that caring for the child involved every member of the family. The positive attitudes from survey findings were in keeping with the expressed willingness to talk about family structure and functioning. Tensions were identified in thematic analysis by PCGs as a need to be heard and understood, and a balance of power; PCGs, at times, felt dismissed and excluded from the hospital routine and communication. On the other hand, those HCPs with more years in practice were able to discuss psychosocial issues with ease and confidence compared to HCPs with less experience.

The final theme emerged from these tensions and was named “*the hospital and services*” with a sub-theme “*hospital people and culture*”. The findings from this main theme are located throughout the following sections because they remain intrinsically connected to “*building relationships*” and “*the whole family*” through the two process themes; “*listening with openness and curiosity*” and “*building trust and safety*”.

5.5 Discussion of findings in relation to extant literature

In this sub-section the integrated findings will be discussed in the context of the extant literature. The first theme was “*building relationships*”, the second theme was “*the whole family*”, and the third theme was the “*hospital and services*”. This subsection is organised under headings that represent the first main theme “*building relationships*”, the two process themes “*listening with openness and curiosity*” and “*building trust and safety*”, and the second theme “*the whole family*”. There is no

independent heading for the third theme “*the hospital and services*” and its sub-theme “*hospital people and culture*”. The theme “*the hospital and services*” represents the physical and cultural environment from which the first two themes emerged. Therefore, these findings are represented under the thematic headings in the following sub-sections.

5.5.1 Building relationships

Findings related to the first main theme named “*building relationships*” are discussed in the following paragraphs.

5.5.1.1 Participants’ attitudes about talking about psychosocial issues

The positive attitudes expressed by PCGs and HCPs indicated their shared perspectives that talking about psychosocial issues was important. These positive attitudes also supported a willingness to engage with each other. This is in keeping with findings from a review of primary care research where attention to psychosocial issues was considered essential to the emotional health and capacity to cope among individuals and families managing health problems (Mitchell et al., 2011). The positive attitudes of PCGs were not influenced by gender, level of education, or place of residence indicating that talking about family issues in hospital was considered to be important. There is some evidence that gender and socioeconomic disadvantage are barriers to engaging in psychological and supportive healthcare services (Cuesta-Briand, Sagers, & McManus, 2014; Ojeda & Bergstresser, 2008). However, in a meta-analysis of eight key studies from the US, UK, Africa and Asia, parents’ values and beliefs and previous engagement in healthcare were found to be more influential to health seeking attitudes than their sociodemographic characteristics (Sayal, 2006). Similarly, stigma, parents’ attitudes towards healthcare professionals, and previous engagement in healthcare services were found to be important influencing factors in survey analysis from the US (Turner, 2012).

The PCGs in this sample had some experience with health services. Many had been attending the hospital and HCPs for many years with their seriously or chronically ill children and felt they knew the HCPs well. Similarly, there is evidence that when people, including those in disadvantaged sociodemographic groups, have positive experiences with healthcare service providers, they tend to display more positive attitudes to talking about psychosocial issues as well as improved outcomes (Warr,

Mann, & Kelaher, 2013). Further to this, relationship building was found to be key to facilitating engagement in healthcare services for disadvantaged populations in a systematic review of 24 quantitative articles from the US, Canada, Africa and Asia, (Cyril, Smith, Possamai-Inesedy, & Renzaho, 2015).

With regard to HCPs, the finding that those with more than five years' experience in paediatric healthcare had more positive attitudes is notable. This finding concurs with two previously published studies, one undertaken in Europe (Blöndal et al., 2014) and the other in Australia (Gill, Leslie, Grech, & Latour, 2013). Firstly, a quasi-experimental study, the examination of nurses attitudes showed that those with the least years of experience shared the least supportive attitudes and reported that communication with families was more burdensome (Blöndal et al., 2014). In the second study, inconsistencies about providing social and emotional support to families were identified in thematic analysis of the perspectives of nurses doing post-graduate education in a critical care setting (Gill et al., 2013). The reasons why HCPs with relatively little experience show the least interest in talking about psychosocial issues has been explained in previous research. An integrative review about the skills and attributes of nurses in the UK, found that less experienced nurses were focused on clinical skills and tended to minimise attention to psychosocial care (Currie & Watterson, 2009). This review aligns well with Benner's theoretical continuum of skill acquisition; from novice to expert, where the development of nursing confidence and proficiency in practice occurs over time and with support (Benner, 2012). For example, in this study a number of HCPs with many years' of experience stated that talking with PCGs about family issues occurred naturally for them while "*chatting*". This was in stark contrast to the concern expressed by some less experienced HCPs that talking about family issues could "*open a can of worms*". Coincidentally, "*opening a can of worms*" is a term used by Bell (2013, p. 412), an instigator of the IBM of Family Assessment, when discussing limitations associated with relationship building in family-focused nursing.

While many PCGs and HCPs responded that they were open to discussing psychosocial issues, an underlying hesitancy and reluctance was identified in the thematic analysis indicating that building a trusting relationship together is complex. In the following subsection the factors that were found to influence relationship building are discussed.

5.5.1.2 Factors that influence relationship building

When prompted to talk in more depth about their psychosocial attitudes during interviews and focus groups, PCGs and HCPs identified a number of factors that influenced relationship building. These included: the need and desire of PCGs to focus attention on their seriously ill children and their need to feel heard and understood. Also included were PCGs' experiences about maintaining control while for HCPs concerns were about imposing on sensitive issues.

With regard to the desire to focus attention on the child, many PCGs' said that they felt overwhelmed when their children were first diagnosed, when their initial experience with the hospital system, "*their journey*", first began. High levels of anxiety and distress experienced by PCGs made it difficult for them to understand their situation and / or relate to others. PCGs used a variety of coping mechanisms, both adaptive and non-adaptive. Many were in denial, some were angry, and others felt that they were disassociated from reality. For them, at this time it was considered to be totally inappropriate to talk about family issues. These responses were not surprising, because strong emotional reactions are stimulated by the amygdala in response to threat or fear (Ingram, Steidtmann, & Bistricky, 2008). Such emotional reactions can dominate brain activity and interrupt information processing making and decision making (Taylor & Sebastian-Galles, 2007). Such interrupted brain activity has been illustrated using neuroimaging whereby activation in the frontal, pre-frontal, occipital and occipito-temporal cortices of the brain was necessary for effective information processing to occur (Schyns, Gosselin, & Smith, 2009).

Non-adaptive patterns of communication, such as aggression or avoidance have also been linked to reduced information processing in a meta-analysis of 56 studies from the US (Schrodt, 2008). The impact of relational and environmental factors on stress is also supported in the Adaptive Calibration Model of Stress developed by Marco Del Giudice (2011), whose scholarly work focuses on responsivity and adaptive mechanisms. As detailed in the review of the literature, stress hormones are 'filtered' or 'amplified' in response to stressful stimuli (Del Giudice et al., 2011). For PCGs in this study, their focus was on their child alone and communication with HCPs did not extend beyond their concerns for their children's physical condition during their early presentations to the hospital. In a similar way, a meta-analysis of studies from the US, UK, Europe and Australia found that psychosocial issues were rarely considered by

patients and families during times of acute care , because attention was focused primarily on stabilisation and reducing physical symptoms (Dilworth et al., 2014).

In a different way, attention to their physical signs of distress was included in the shared reflections by PCGs' of their early experiences in hospital when their children's serious illnesses were first diagnosed. HCPs shared reluctance to impose on PCGs by discussing issues they perceived as personal, and their prompt responses to external signs of distress are discussed in the following paragraphs.

5.5.1.2.1 A time and place to talk

In terms of selecting the best time to talk about psychosocial issues, the reflections and experiences of PCGs and HCPs indicated that the first presentation to hospital was not the time. The shared experiences of PCGs showed that sole attention was on their children's condition while HCPs were found to be 'tuned in' to physical signs. This was identified in the shared reflections by PCGs who recounted their early experiences of distress at the time of their children's early admissions to hospital. Expressed physical signs included breaking down in tears, waving arms in distress, and "*shouting and screaming*". While prompt responses by HCPs at the time were reported, the absence of any earlier enquiry by HCPs was notable. Equally notable, was the absence of any anticipation by PCGs for earlier attention to their pending distress. The need for more attention to recognising psychosocial issues and the benefits of supporting nurses in their response has been recently highlighted (Tallon, Kendall & Newall, 2015). This void was observed in their shared gratitude to HCPs who promptly responded to their obvious distress which was expressed without expectation and was perceived as additional.

This lack of expectation by PCGs for support is not an isolated finding. Similar perspectives from a nationwide longitudinal study conducted in Germany that examined the quality of life of over 1500 parents of children with chronic illness found that the needs of their children took precedence over their own (Vonneilich, Ludecke, & Kofahl, 2016). This focus on their seriously ill children without expectation for early support was found to be associated with a need to cope and have some control. This need to maintain some control and '*get on with it*' was evident in the early expressed experiences by PCGs. In keeping with this, stoic perspectives and a need to cope were found to make seeking help for psychosocial issues unfeasible among 129 patients and family members, in a multisite Australian study that used survey data to identify

barriers to psychosocial assessment (Bradford & Rickwood, 2014). On the other hand, evaluations of the application of short therapeutic conversations based in FSN have resulted in improved emotional and cognitive adjustment by patients and their families during initial assessment in acute care settings (Bell, 2013) and acute mental health settings (Sveinbjarnardottir, Svavarsdottir, & Wright, 2012). Further to this, an integrative review of the family nursing research has also shown that family nursing interventions implemented in world-wide studies across the life course have resulted in improved understanding, emotional well-being, and improved behavioural responses in patients and families during early presentations with chronic illness (Östlund & Persson, 2014).

For most HCPs, discussing psychosocial issues at the time of the first presentation to the hospital was “*not the time or the place*”. However, contradictory views were identified with their expressed and concurrent “*need to know*”. Difficulties related to talking about psychosocial issues have been the focus of some research. For example, the opinion that patients and families did not want to talk about psychosocial issues in hospital was shared by 80 per cent of HCPs ($n = 600$) surveyed in a UK study (Gosselin et al., 2011). Further research indicated that concerns about ‘imposing’ were found to be related to not having time to support potential issues that could arise. In a Swedish cross sectional study insufficient time and a lack of resources were identified as barriers to discussing psychosocial factors among 548 HCPs working in cancer care (Fagerlind, Kettis, Glimelius, & Ring, 2013). Further to this, a lack of confidence and skills were identified in thematic analysis of 53 interviews with district nurses in the UK who recognised emotional distress in their patients however, were found to avoid the issue by focusing their attention on clinical care (Griffiths, Ewing, & Rogers, 2010). Further to this, reservation associated with talking about psychosocial issues was illustrated in a phenomenological study of 19 nurses in a palliative care setting, who also identified their patients’ emotional feelings of distress or sadness, however, felt in conflict between this and being part of the curative culture where a focus on treatment was maintained (Leung et al., 2012). This focus on physical signs resonates with dominance of a biomedical approach even in the palliative setting where the research was conducted. This was further hat was emphasised in an integrative review of published findings related to psychosocial assessment (Zabora & MacMurray, 2012).

Further prompting during interviews and focus groups showed that many HCPs felt it was inappropriate to talk about psychosocial issues before a trusting relationship was established. This perspective was mirrored in published findings, where feeling safe and secure in the hospital culture and environment was linked to trust and safety in a qualitative study of 13 PCGs from the Netherlands (Wassenaar, van Den Boogaard, van Der Hooft, Pickkers, & Schoonhoven, 2015). Conversely, an integrative review of published findings from the US, illustrated that it was not possible to achieve a relational environment if parents felt they could not talk to HCPs, or have their questions answered (Johnson, 2008). In a similar way, the development of trust and safety was found to be obstructed for PCGs in this study, who felt their questions were left unanswered. Here their subsequent experiences of uncertainty resulted in a loss of trust because of their perceived views that HCPs “*did not care*”. In keeping with this, phenomenological examination of parents’ experiences following their children’s serious injury, showed that they often have strong negative responses when they feel misunderstood or are confused (Rosignano, Savage, Grant, & Philipsen, 2013).

5.5.1.2.2 *Familiarity with the hospital environment*

PCGs described how their feelings of isolation and confusion during early admissions to hospital were replaced with a sense of familiarity and belonging over time. The contrast between PCGs’ early reflections when they felt alone, confused and afraid, and their current positions where they felt comfortable, familiar and “*part of the hospital family*” was apparent. Insight into how this occurred emerged in the relational examples from the perspectives of HCPs. In particular the use of reflective listening by more experienced HCPs was illustrated in their expressed ease related to talking about psychosocial issues with PCGs and families. These HCPs were found to obtain relevant information about a child’s family life while “*chitchatting*”. In the same way, information was shared while “*chatting*” in a qualitative study from the UK, referred to earlier by Griffiths et al. (2010). For other HCPs it was about identifying commonalities with PCGs and families that could be used later “*when any of the tough bits happen*”. This too was noted in an examination of research findings from the UK where empathic curiosity was found to enhance meaningful relationship building and confidence in practice among HCPs and caregivers when caring for the elderly (McEvoy & Plant, 2014). The expressed empathy and understanding by HCPs in this study for the potentially difficult trajectories ahead that may not yet be apparent to the PCGs was also

observed. These qualities of empathy, reflective listening, and connecting with others are also supported and promoted in the work of nursing theorists such as Peplau's Nursing Theory of Interpersonal Relations where nursing is defined as a therapeutic relationship between individuals to influence positive change (Peplau, 1997). Furthermore, Peplau's work was considered to be motivated towards FSN where sensitive communication between nurses and families occurred that focused on the interplay between illness and health outcomes are promoted (Wright & Leahey, 1990).

The need for PCGs to maintain some control emerged from further examination of their early feelings of isolation and confusion and the process of feeling more familiar with time. This need for, and loss of, control in the unfamiliar hospital environment is discussed in the following paragraphs.

5.5.1.2.3 *The balance of power*

Experiences of powerlessness about feeling compelled to trust HCPs without knowing them were identified in interviews and focus groups. The need for PCGs to maintain some control in the face of their child's serious illness was identified in their expressed need for "*straight answers*" so they could "*get on with it*". This need for PCGs to maintain control is not unique. Empowerment is advocated in healthcare; however research shows that this is not always the case in practice. A lack of clarity in roles, guidelines, and embedded hierarchical practices were found to hinder relationship building and empowerment in a concept synthesis from the UK related to the care of children with chronic illness (Smith, 2015).

The impact of hierarchical practices perceived by PCGs within the hospital setting and culture were identified as exclusion and the need to exert some control. The exclusion of PCGs from healthcare team discussions in the hospital ward environment described as "*the huddle*" was evident in their shared frustrations to be included. In a similar way, hierarchical perspectives were highlighted by Coyne and Cowley (2007) in a European study of grounded theory design where nurses assumed that parents' would participate in their children's care in hospital, but did not relate to them as partners because the boundaries of care rested with them. Further to this, examination of parental emotional and decisional needs during major corrective surgery showed that they are vulnerable to unequal power relationships with their children's healthcare teams (Nelson, 2012).

For PCGs, their experiences of adjusting to the hospital environment included learning and using “*the lingo*”. Further prompting revealed this as a way PCGs asserted some control in terms of being included and feeling able to ask questions of their children’s HCPs. Likewise, examination of the perspectives of parents of seriously ill children in Canada found that maintaining equality was challenging and that parents of children who were seriously ill often felt frustrated and dissatisfied (Legrow, Hodnett, Stremler, McKeever, & Cohen, 2014). A need for equality was further identified by PCGs who shared the view that communication needed to be on an “*even playing field*”, when at times, this was not the case. Supporting this, differences between patients and HCPs about how problems were perceived in the management of a chronic illness, found that HCPs expectations that patients would follow their advice were barriers to equality in relationship building in a Norwegian qualitative study (Zoffmann & Kirkevold, 2012).

In keeping with equality, survey and thematic analysis showed that PCGs and HCPs shared the view that initiating discussion about some psychosocial issues included in the original framework were perceived as potentially hierarchical and judgemental. Analysis of surveys, interviews, and focus groups showed that these psychosocial issues were considered to be unhelpful and inappropriate. These survey findings and deeper insights from analysis of the experiences of PCGs and HCPs, related to adapting to the hospital environment and culture, will be discussed in the following paragraphs.

5.5.1.2.4 *Feeling judged*

PCG and HCPs unanimously agreed that the maternal educational attainment and the occupation of parents were both unimportant and inappropriate for inclusion in discussion in hospital. These findings are contrary to research evidence where maternal education and parental occupation have been identified as social determinants of child health and developmental outcomes (Victorino & Gauthier, 2009; Zubrick, 2000). Despite over 90 per cent of PCGs reporting positive attitudes regarding talking about family issues, stigma was projected towards others in less advantageous circumstances than themselves. These concerns, similarly reflected in analysis of the transcripts. This is in keeping with findings from a qualitative study of 20 in depth interviews with disadvantaged sole parents from an Australian city who felt judged during interactions with HCPs in a primary healthcare setting (Winkworth, McArthur, Layton, Thomson, & Wilson, 2010).

Concerns about PCGs feeling judged were also shared among HCPs. Shared agreement that maternal education and parental occupation were influential to child health outcomes, was met with the converse view that talking about these issues was considered unhelpful. Rather than education attainment, an understanding for self-efficacy was identified in the experiential comparisons drawn by HCPs. Reflections from experience were shared where some PCGs managed well despite having an incomplete education, while others with professional jobs, access to money and support often struggled to manage. Stemming from social cognitive theory, self-efficacy theory proposes that physical psychological and social motivators influence an individuals' capacity to exert some control on their circumstances (Bandura, 2012). Supporting this, research evidence shows that self-efficacy has been used as a measure of parental capacity. For example, previous research by the author that originally focused on measuring levels of maternal knowledge and understanding was found to be more a measure of the impact of psychosocial issues on maternal confidence in their caregiving (Tallon, Kendall, et al., 2015a). Further to this, in a cross sectional multi-centred prospective study of 550 mothers in Hong Kong found that self-efficacy was associated with greater psychosocial adaptation (Hui Choi et al., 2012). Furthermore, self-efficacy was found to be associated with reduced parental stress in a prospective European study that followed 120 mothers during their pregnancies and following birth (Bolten, Fink, & Stadler, 2012). Similarly, the development of maternal self-efficacy was found to support psychological functioning in mothers following pre-term birth in a phenomenological study in the UK (Swanson et al., 2012). Further to this, the benefits of avoiding hierarchical imbalances while talking about parental skills were highlighted in the examination of 59 healthcare staff and parent perspectives about factors that impacted on relationship building in a specialist neonatal environment in the UK (Jenkins, 2009).

The emphasis placed on self-efficacy by more experience HCPs were in keeping with the high levels of importance assigned to maternal emotional wellbeing and self-confidence by PCGs and HCPs in this study. In the following subsection, the findings related to maternal emotional health and self-confidence are discussed in relation to the extant literature. These findings relate to the two process themes "*listening with openness and curiosity*" and "*building trust and safety*".

5.5.2 Listening with openness and curiosity to build trust

As outlined in the summary of the main findings earlier in this chapter, the two process themes named “*listening with openness and curiosity*” and “*building trust and safety*” were found to be essential to building relationships. This was supported by the high levels of importance assigned to the psychosocial factors; maternal emotional health, and self-confidence, reported in the surveys and emphasised during interviews and focus groups. Because the two process themes, “*listening with openness and curiosity*” and “*building trust and safety*” were found to be essential to building relationships, discussion of the findings in this subsection include experiences related to how conversations about family issues are initiated.

5.5.2.1 How are you feeling? ... How are you doing?

The importance assigned to talking about maternal emotional health and maternal self-confidence shared by over 90 per cent of PCGs and HCPs was not new. Allocating priority to the psychological health of mothers has been the focus of much research examining the impact of maternal caregiving on child health and developmental outcomes. In studies examining maternal responsiveness, maternal post-partum depression was found to have a negative impact on family functioning, in addition to effects on the maternal child bond (Field, Diego, & Hernandez-Reif, 2009; Fletcher, Vimpani, Russell, & Sibbritt, 2008). A persisting insecure state of mind in mothers regarding attachment one year after the birth of their child, has also been linked to ongoing depression that can have an intergenerational impact (McMahon, Trapolini, & Barnett, 2008). Such findings, that stem from pioneering research by Bowlby (1958), continue to illustrate the influence attachment has on cognitive and emotional development. While this is important to the child, it remains relevant to the PCGs, as experiences of attachment impact an individual’s mental health and capacity to relate to others across the life course (Gumley et al., 2014). Further, emotional regulation has been identified as a mediator between attachment and depression in a systematic review of international literature conducted in the UK, by Malik and colleagues (2015). Openness to talking about emotional health and self-confidence was shared by PCGs who also expressed interest in talking with HCPs, especially the nurses. For most PCGs relational interactions were welcomed during long periods sitting by their children’s bedsides, while others’ expressed curiosity: “*I say hello, and I ask them (the nurses) how they are*”. In the same way, attention to the emotional well-being of PCGs

was reflected in the expressed experiences of HCPs, where enquiring about maternal emotional health was considered to be both important and appropriate. Furthermore, it was considered easy to do by HCPs who asked “*how are you feeling?*” The value of enquiring about emotional well-being is well-evidenced. The meaningfulness of empathic gestures such as saying hello or holding a patient’s hand, have been highlighted in the perspectives shared by patients in a qualitative study from the UK (Smith, 2014).

Application of skills in genuine enquiry and reflective listening, and promoted in partnership models such as the Family Advisor Model developed for paediatric practice in the UK by Davis and colleagues (2002), have resulted in improved coping and decision making by parents of sick children. Also in nursing practice, skills of therapeutic communication are embedded in models of care from FSN that are applied internationally, and support improved emotional health and confidence in caregiving (Bell, 2009; Wright & Leahey, 2012). In keeping with this, an integrative review by Östlund and Person, 2014 supported improved self-efficacy in patients, PCGs and families, where empowerment was promoted through a reciprocal relationship between families and HCPs. More locally, relational strategies were welcomed by 111 mothers who showed improved emotional wellbeing and caregiving as a result of a home visiting programme in Australia (Rossiter, Fowler, McMahon, & Kowalenko, 2012). Further to this, most frequent interventions by nurses in a home visiting programme for vulnerable families in a disadvantaged area in Sydney, Australia were found to be responses to maternal emotional needs (Stubbs & Achat, 2012). The value of inter-relational attention to emotional wellbeing and capacity to manage is also endorsed by Wright (2015) who was instrumental in the implementation of the CFAM and the IBM, and suggests that therapeutic conversations between nurses and families, with attention to reflective listening, can contribute to healing.

5.5.2.2 Allowing additional worries to surface

In addition to maternal emotional health and self-confidence, positive attitudes about discussing additional life stresses indicated a shared openness by PCGs and HCPs. However, while over 90 per cent of PCGs and HCPs considered talking about exposure to additional family life stress to be important, differences between the levels of importance assigned by participants were noted. HCPs were found to be more likely to rate additional family life stress as very important compared to only 36 per cent of

PCGs ($p = .001$). This difference correlates with the expressed need to maintain control and “*get on with it*” where the needs of PCGs were overlooked in favour of their children’s needs. The differences could also be representative of an understanding by HCPs for the damaging impact stress has on long term health trajectories, particularly as a result of exposure to accumulative stress or allostatic load (Beckie & Groer, 2012; Danese & McEwen, 2012). An example of the adaptive role the brain plays in responding to stress through plasticity is highlighted in an integrative review that draws the attention of nurses to the implications prolonged exposure to stress in childhood plays on their life trajectories (Nelson et al., 2014).

For children with serious or chronic illness, the understanding that the impact of stress can be more pronounced has been the focus of some research. A longitudinal study of the health outcomes for young adults who grew up with chronic illness showed an increased risk of emotional and behavioural problems and reduced cognitive ability (Maslow et al., 2011). Findings from the Ontario Child Health Study of 3294 children aged between four and sixteen years of age where higher risks of mental health problems were similarly identified among children with chronic illness and disability in comparison to their healthy counterparts (Cadman et al., 1987). In addition to this, a meta-analysis of international findings conducted in the US found that higher levels of parenting stress and dysfunction were identified among families with children who were seriously or chronically ill, in comparison to healthy children (Cousino & Hazen, 2013). Exposure to additional life stress was found to reduce caregiving capacity and confidence among 95 PCGs in a longitudinal study that examined predictors to caregiving stress associated with having a child with cancer in Europe (Sulkers et al., 2014).

When prompted to talk about their worries, PCGs expressed a shared ease about talking about worries when they felt known by HCPs in hospital. However, appreciation for the impact of stress on PCGs emotional wellbeing was not reflected in their shared experiences. Rather, examples from the data showed that the enormity of the stress experience expressed was often minimised. For example, the need to survive was noted, where experiences of life stress included: being a migrant, having no access to family support, recent multiple residential moves, uncertain employment, and financial strain, which were dismissed with “*we just got on with it*”. Similarly, an integrative review of 37 quantitative and qualitative international studies conducted in

China found that over 50 per cent of parents of children with Autism Spectrum Disorders used a more practical problem focused coping approach in favour of emotional focused coping to manage their stress (Lai & Oei, 2014). These dismissive perspectives towards the experience of life stress are in keeping with the evidence by Vonneilich and colleagues (2016) presented earlier, where parents of children who are seriously or chronically ill placed their children's needs over their own. It is not to say that the reduced attention to life stressors experienced by PCGs in this study necessarily equated to them feeling more resilient. Research findings suggest the contrary. For example, a meta-analysis of international findings showed that greater levels of parenting stress have been found to be associated with poorer psychosocial adjustment in both PCGs and children with chronic illness (Cousino & Hazen, 2013). Furthermore, examination of the impact of stress on maternal confidence in caregiving found that higher levels of anxiety and lower levels of social support were related to lower levels of confidence in caregiving among 91 mothers surveyed at the time of their children's major surgery in Australia (Tallon, Kendall, et al., 2015a). These findings further support the benefits of using gentle enquiry by HCPs to encourage PCGs to share their worries even if perceived as unimportant, where the potential effects could be explored in therapeutic communication.

Research evidence supports the drawing on relational qualities as a well-recognised medium through which PCGs can be supported and encouraged in the care of their seriously ill children (Spiers, Parker, Gridley, & Atkin, 2011). Even when communication can be challenging, where spoken English is not well understood, the application of strength-based approaches have been found to support cultural sensitivity in non-English speaking parents. Using a culturally sensitive strength-based framework resulted in increased engagement and confidence in PCGs of children who are chronically ill (Haley, 2009). The importance of using a strength based approach, that went beyond partnership building, was identified in a qualitative study that explored children's, parents and health professionals perspectives across two tertiary hospitals in the UK (Coyne & Cowley, 2007). Initiatives from FSN have also provided ways to measure improved adaptation and increased confidence using nursing interventions. In one example using linked data that yielded a sample of over 18,000 surveys across the US, the application of therapeutic strength based conversations was found to improve parental adaptation in paediatric settings (Guerrero, Chen, Inkelas,

Rodriguez, & Ortega, 2010). In a further example, also in the US, application of therapeutic communication and relationship building was instrumental in the development of a rural model for the prevention of diabetes across eleven counties (Johnson, 2015).

Strength based conversations guided by nursing models of care from FSN, such as the CFAM and IBM outlined in the review of the literature, have also resulted in improved outcomes for patients and families particularly in Canada and the US (Bell, 201; Deatruck et al., 2006; Knafl et al., 2013; Leslye King, 2002). Likewise these interventional approaches provide an evidenced based conduit to talk about psychosocial issues with PCGs. Evidenced based knowledge and understanding of the benefits of these interventional approaches could see the application of gentle enquiry about emotional health and self-confidence and reflective listening to practice with increased confidence. Following on from that, and in keeping with the emergent conceptual model, attention can be focused on the whole family as emphasised by PCGs and HCPs in survey and thematic analysis. Findings related to “*the whole family*” and family functioning will be discussed in the following paragraphs.

5.5.3 The ‘whole family’ in hospital

As outlined in the summary of the main findings earlier in this chapter, the second named theme “*the whole family*” emerged from the emphasis placed on family by PCGs and HCPs. In this subsection, the findings related to talking about family and family functioning are discussed in relation to the extant literature. This includes how ‘family’ is emphasised in the context of the hospital environment. Finally, evidenced based literature related to the provision of family-focused care is highlighted. Inconsistencies are identified, and opportunities to promote “*the whole family*” in practice, using the finalised family psychosocial framework are encouraged.

5.5.3.1 Family structure and relationships

PCGs and HCPs shared positive attitudes regarding talking about family structure, family relationships, and access to support from friends and family. In the same way as maternal emotional well-being and self-confidence, talking about family structure and access to social support was considered by participants to be easy to discuss. On the other hand, talking about relationships between PCGs and their partners was less favoured.

In relation to family structure and access to social support, over 90 per cent of PCGs and HCPs assigned importance to family structure, relationships and social support. For PCGs, the impact on family life of having a child with serious or chronic illness was emphasised with reference to the “... *the whole ripple effect*”. In relation to physical, emotional, cognitive, and social outcomes for children, longitudinal research has shown that the resources and skills within the family are far more influential in promoting successful outcomes than community influences (Elder, 1998). More specifically the review of longitudinal studies of children in the US through the Great Depression and into adulthood that supported this view, recognised life course as a theory whereby historical contexts in combination with the social patterns and relationships that children were born into influenced all aspects of their development throughout life (Elder, Johnson, & Crosnoe, 2003). This reference to the impact of changes that occur through relationships known as social capital which was introduced to social theory by James Coleman (1988) highlights how the financial, physical, and human capital of parents influences child health and developmental outcomes through relationships and trustworthiness. Further supporting the impact of the “*ripple effect*” of family and with reference to child and maternal health, is the systems approach recommended by Cheng and Solomon (2014) using a life-course model to healthcare as a longitudinal approach to address the impact of family psychological and social influences on child health outcomes.

Attention to family structure by HCPs in this study emphasised the importance of social capital by including all aspects of family, and in particular the extended family such as the grandparents. The benefits of being supported emotionally and practically by extended family members has been endorsed with the application of models of care that incorporate extended family for children and families in the UK (Spiers, Parker, Gridley, & Atkin, 2011). Also in the UK, the Avon Longitudinal Study of Parents and Children highlighted the significant role grandparents played in the care of children regardless of their health (Fergusson, Maughan, & Golding, 2008). Further to this, the benefits of having access to extended family support when a child is seriously or chronically ill was also reinforced in examination of the experiences of mothers of seriously ill children attending a public hospital in Brazil (de Amorim Silva et al., 2016). Global mobility has seen increasing numbers of families with little access to family support because they live far away from family support networks (Root &

Humphrey, 2014). Migrant families without access to family support, unsupported single parent families, or families affected by poverty or violence have been found to be additionally vulnerable in a review of childhood health disparities by Jack P. Shonkoff and colleagues (2009). These findings have informed policy makers and HCPs to include consideration for the impact of life stress and financial burden on families of children who are chronically ill in the US (Shattuck, 2008).

The issue of disharmony within families, especially between PCGs and their partners was identified in thematic analysis. The quality of the dyadic relationship and social capital in the family, for example, where parents can provide each other with emotional and practical support during hospitalisation is associated with improved coping (Wiener et al., 2014). Such access to social capital or otherwise has been associated with reduced physical, cognitive and emotional health outcomes in children using the Maternal Social Support Index (MSSI) developed by Pascoe (1988) in the US. For HCPs a shared reluctance to impose where family relationships were considered tense were met with a conflicting need to know, but not wanting to ask. In a research synthesis of 59 peer-reviewed quantitative papers from NZ, for some parents of children in hospital the presence of extended family was found to be a source of stress, particularly when difficulties in family relationships were experienced (Foster, 2016). The impact of family disharmony and dysfunction was illustrated in a review of 55 qualitative studies by Deatrck and Knafl (2003), where families' responses to illness were identified as "*thriving*", "*enduring*", "*struggling*" or "*floundering*". Families who were identified as "*thriving*" were found to demonstrate higher social competence in comparison to those who were not "*thriving*" (Deatrck & Knafl, 2003). Furthermore, wide adaptation of the Family Measurement Model that followed, further supported placing emphasis on family structure and functioning by HCPs in practice (Knafl et al., 2011).

5.5.3.2 Support outside the home

Support outside the home was also identified as an important psychosocial factor by PCGs and HCPs. The importance of family engagement in the community was emphasised by almost 90 per cent of PCGs and HCPs in analysis of survey findings. Likewise, ease related to talking about family engagement in local community activities was expressed by PCGs and HCPs. This finding is in keeping with research focusing on family support where the benefits of connecting with others was

emphasised. For example, initiation of parenting programmes has shown increased knowledge and confidence in parenting practices resulting in improved child attendance at health and education facilities (Bunting, 2004; Haswell-Elkins et al., 2009). Similarly, the positive effects of joining a parent support groups and engaging in supportive activities in their communities has been found to improve health outcomes for mothers and their babies in a qualitative study of 18 mothers in Australia (Mills et al., 2013). Shared agreement and expressed ease by PCGs and HCPs about talking about community engagement further supports inclusion of this psychosocial component in the finalised framework.

More experienced HCPs shared reflections showing that enquiring about family issues with PCGs was more difficult earlier in their careers. The ease and confidence identified in the data had come with time and with practice. Openness to talking about the family's access to support was identified during thematic analysis of data from PCGs and HCPs. In this study, talking about family and social support was found to be appropriate and easy to discuss. This is also in keeping with the philosophies of family nursing and FCC, detailed in the review of the literature, that support the notion that a child's serious or chronic illness is considered to be a family affair (Bell, 2013; Coyne et al., 2011).

Talking about parental occupation was found to be unfavourable among PCGs and HCPs, whereas talking about maternal confidence or emotional health was considered both important and easy. Likewise for HCPs openness to talking about work hours in the context of managing family life and care provision was supported. Similarly, rather than emphasising occupation, research findings identified associations between family functioning and child behaviour as a result of the impact of parental shift work (Dockery et al., 2009). Further evidence from a quantitative Australian study highlighted the impact of long parental work hours on children with a higher incidence of behavioural problems found among boys with fathers' who worked long hours, in comparison to girls (Johnson et al., 2013). These findings remain relevant to the family psychosocial assessment framework central to this study because talking about work hours and family routine were found to be acceptable to discuss, and more likely to give relevant insight into family functioning.

5.5.3.3 Emphasis on “the whole family” in practice

The positive attitudes reported by PCGs and HCPs related to talking about psychosocial issues, and the importance assigned to most psychosocial components suggest that talking about psychosocial issues is considered both acceptable and feasible. The unequivocal emphasis on family by PCGs and HCPs in this study, is in keeping with the agreed philosophy that underpins FCC where care of the child is provided in the context of the whole family (Shields et al., 2013). Despite this, there remains little evidence that FCC has been successfully implemented in contemporary healthcare (Shields, 2011; Tallon, Kendall, et al., 2015b; Bell 2013) and rationales for why family centred care implementation has been unsuccessful have been suggested by Bell (2013) . Further to this hierarchical approaches were found to persist in an examination of patient and family perspectives about FCC (Coyne et al., 2011; Shields, 2010; Smith et al., 2015).

On the other hand, attention to the care of families through therapeutic communication and healing conversations is well supported in published literature. As discussed earlier, undertaking strength based conversations guided by nursing models of care from FSN, such as the CFAM and IBM, have resulted in improved outcomes for patients and families particularly in Canada and the US (Bell, 2015; Deatrack, 2006; Knafl, 2013; Leslye King, 2002). Similar European examples show that therapeutic conversations focusing on family support and functioning have resulted in statistically significant higher levels of perceived support (Sveinbjarnardottir et al., 2012).

Research findings from US, Canada, Europe and Australia support a family nursing approach where the implementation of FSN initiatives have been found to support improved health outcomes for individuals and families (Duhamel, 2010; Moules et al., 2012; Östlund & Persson, 2014; Tomlinson et al., 2012). This approach is distinct from FCC where care is organised and provided for a child in the context of family. In family nursing, the family is related to as a system that includes all family members’ and focuses on their interactions with each other in the context of health and illness. This is achieved within a reciprocal nurse-family relationship that is generated through therapeutic conversation (Bell, 2009). The essential need to focus on the whole family identified in this study sits well in the context of the family nursing. So too does the first theme “*building relationships*” and the two process relational themes “*listening with openness and curiosity*” and “*building trust and safety*” that emerged from

thematic analysis as essential to relating together. Furthermore, the emergent theme “*the whole family*”, remains central to the finalised psychosocial assessment framework, emerged from “*the hospital and services*” where promoting a non-hierarchical approach is essential. Equally a FSN approach, where a non-judgemental reciprocal relationship is promoted sits well as an underpinning theoretical base for the family psychosocial assessment framework central to this study. The findings from this study also support the acquisition of nursing skills and confidence proposed by Patricia Benner in 1984, where support, practice and mentorship facilitate the translation of knowledge from novice to expert in clinical practice (Da Silva, Ferreira, & Apostolidis, 2016).

In light of the findings of this formative evaluation and an in-depth examination of extant literature, the assessment framework that was initially proposed to guide this project has significant limitations. This formative evaluation provides some evidence that psychosocial assessment is much more likely to be implemented appropriately if the focus is on the acquisition of skills in implementing a relational framework rather than the use of psychosocial screening instruments. The emergent family psychosocial assessment framework provides a structure for the application of systems theory knowledge and therapeutic communication to facilitate the recognition of psychosocial issues in the families of children who are seriously or chronically ill. Before the presentation of the framework and a brief outline of implications for practice and research, the following section identifies some strengths and limitations of this study.

5.6 Limitations of this study

This study has a number of limitations that must be taken into account when translating the findings into policy and practice. Firstly, PCGs who completed a survey or participated in one-on-one interviews comprised a fairly homogenous group of people who spoke English as their first language, were Caucasian, and were brought-up in the broadly Judeo-Christian tradition. Little or no cultural diversity was represented within the sample because PCGs from culturally and linguistically diverse (CALD), ethnic, religious, or indigenous backgrounds were not specifically recruited. In the healthcare facilities that were chosen for data collection, people of diverse ethnicity and culture are in attendance, however, they are much less likely than other to participate in research. This situation is common in Australia and other similar Western countries (Ganann, R, 2013). It is possible that the attention given to the

psychosocial care of families in this study may be seen as unnecessary, or even offensive, by people from diverse ethnic and religious groups. This means that the sample that was obtained for the quantitative part of the study was biased and the findings cannot be generalised to populations other than those with similar ethnic and cultural characteristics. The administration of the PCG and HCP surveys to people in other ethnic and cultural groups is one of the suggestions for future research that is made in a following section.

While the homogeneity of the sample is a limitation of the quantitative part of the study, it is a strength of the qualitative part. This is because gaining a deeper understanding of people's experiences is best achieved with people who have similar ethnic, cultural and socio-demographic characteristics (Creswell, 2013). While the sample was appropriate for the intended purpose of developing a psychosocial assessment model, further qualitative research will be required to explore and test the assumptions of model in more diverse ethnic and cultural population groups. Again, this is one of the suggestions for future research that is made in a following section.

Secondly, it is possible that PCG survey and interview participants were self-selected from the higher end of the socioeconomic spectrum. It is usual in research of this type for people who have lower levels of education and income to choose not to participate (Lim, Immerwahr, Lee, & Harris, 2013). The analysis of PCG data indicated that the sample population resided in geographical locations with levels of advantage or disadvantage that that would be expected in the Australian population as a whole. However, the finding that over 50 per cent of PCGs held a university degree did place the sample in the higher socioeconomic category. This may be an issue because there is some evidence to suggest that those with higher levels of education are likely to have greater health literacy (Matsuyama, Wilson-Genderson, Kuhn, Moghanaki, Vachhani, & Paasche-Orlow, 2011). While degree of health literacy is not necessarily reflected in health behaviours, further research is required to examine the possible influence of lower levels of educational attainment, and other social disadvantage, on the psychosocial attitudes and perspectives of affected PCGs. This is another suggestion for future research.

Thirdly, the PCG sample comprised only 10 per cent males. This proportion may not reflect the true population figure given that 19 per cent of one parent families in Australia are headed by men (ABS, 2013). Similarly, the HCP sample was largely

female with only 10 per cent males. Eighty- two per cent of the sample consisted of nurses of whom only three per cent were male. This is less than expected given that 10 per cent of nurses in Australia are men (ABS, 2009). Having said that, the proportion of males working the paediatric healthcare settings may be lower. Of the four per cent of HCPs sample who were medical doctors, half were male. This is likely to reflect the true proportion, because even though 66 per cent of all medical doctors in Australia are men, women are more highly represented in paediatric medical practice (ABS, 2010). Whether or not the ratio of male to female PCGs and HCPs in the sample has influenced the findings is open to conjecture. In the experience of the Candidate, there are exceptionally caring and compassionate men and women caring for their children and working in paediatric healthcare settings.

Lastly, while justified within the methodology chapter of this thesis, the sampling method used was limited to convenience and purposive sampling. While random sampling is considered gold standard, this was neither practical nor appropriate within the scope of this study. The Candidate is well known by HCPs at the research setting in WA and while every effort was made to minimise bias by inviting recruitment through members of the Steering Committee, it was possible that HCPs knowledge of the Candidate may have influenced their decision to participation. Similarly, online survey participation for HCPs in VIC, through invitation by a member of the supervisory team based there, may have been similarly affected. Despite the expectation of the Candidate and her supervisor of a reasonable response, both were surprised by the numbers of HCPs who completed the online survey. Following discussion, it was agreed that this was most likely due to their interest in the topic rather than their association with the researchers. Furthermore, recruitment of PCGs in Victoria was limited as the Candidate is not based there. It is possible that a larger PCG survey sample could have been achieved if the Candidate had spent more time there.

5.7 Emergent family psychosocial assessment framework

The emergent conceptual model from analysis of data illustrated earlier in this chapter represents connectivity of data analysis to the theoretical aspects of the family psychosocial assessment framework. Supported by the theoretical underpinnings outlined in this thesis, the conceptual model provides a means for how family psychosocial assessment can be approached. Effectively, the emergent conceptual model from thematic analysis in combination with the theoretical underpinnings has

the potential to be operationalised in practice as a skills-based practice framework for family psychosocial assessment.

As outlined earlier, the positive attitudes reported by PCGs and HCPs in survey data indicated their readiness and willingness to talk about psychosocial issues, however, thematic analysis revealed hesitancy and reluctance to talk about psychosocial issues. Discussion of the findings in relation to the extant literature has provided further insight and identified possibilities in relation to the implementation of the final family psychosocial assessment framework that has emerged from analysis of survey, interview and focus group data.

Findings from this study show that the positive attitudes of PCGs and HCPs towards talking about psychosocial issues did not mean that all participants were comfortable or confident about doing so in practice. This gap between attitudes and behaviours is similar to other circumstances where positive intentions do not necessarily equate with positive behaviours. For example, evidenced based findings related to lifestyle choices such as diet and exercise show that individuals' healthy attitudes do not consistently equate to healthy behaviours (Farrow & Fox, 2011; Pescud & Pettigrew, 2010). Despite the reported positive attitudes and expressed willingness to discuss psychosocial issues with families in this study, other factors were identified that prevented PCGs and HCPs from translating these positive attitudes to behaviour and practice.

One factor relating to talking about psychosocial issues was the need to establish and develop trust and safety. This was identified in the emergent disparity between expressed feelings of overwhelm and isolation by PCGs who reflected on initial hospitalisations with their children, in comparison to their current feelings of familiarity and belonging. Further to this, a balance in power that prevented PCGs from feeling heard and understood was identified. This is in keeping with research findings where a loss of control is associated with poorer health behaviours and increased morbidity (Bergerot et al., 2013). Furthermore, thematic analysis showed that when PCGs felt their concerns were left unanswered or minimised, any existing feelings of trust were replaced by feelings that HCPs "*did not care*". Not surprisingly, the expressed experience of feeling dismissed was identified as obstructive to "*building trust and safety*". Further to this, the need to be heard and understood as the parents of their children, and to be included by HCPs in their children's ward environments, was identified as essential. The process theme that emerged from

thematic analysis named “*listening with openness and curiosity*” was not only deemed to be essential to the second process theme “*building trust and safety*”, it provided a means of harnessing this trust and safety. “*Listening with openness and curiosity*” could potentially operationalise how trust and safety develop from the perspectives of both PCGs and HCPS. Additionally, these process themes provide an appropriate conversational environment in which to explore psychosocial issues that are acceptable and welcomed by PCGs.

Thematic analysis showed that the main factor preventing the translation of positive psychosocial attitudes into behaviours by HCPs was related to confidence and skill acquisition, rather than any perceived lack of care. Examination of the gap between the attitudes and behaviours of HCPs identified in this study showed that the reluctance and hesitancy conveyed by HCPs with fewer years of experience was replaced by an expressed confidence and ease in those with more experience in practice. Limitations in the capacity for early career HCPs to develop proficiency in new clinical skills while simultaneously providing psychosocial support is well illustrated in nursing theory and research (Benner, 2012). This identified disparity provides an opportunity to support the effective translation of the positive psychosocial attitudes reported in this study into corresponding positive behaviours through formal skill-based educational activities and mentorship. The major emergent themes from thematic analysis could be applied, where qualities and attributes that foster effective therapeutic communication could be distinguished, shadowed, and embedded in practice. The inclusion of reflective practice and debriefing activities could further reinforce confidence in acquisition of skills in therapeutic communication (Moules et al., 2012). Furthermore leadership skills could be fostered through mentorship and example learning whereby effective skills in communication could be naturally acquired during every day clinical practice.

Further to this, the emergent family psychosocial assessment framework could provide a comprehensive foundation to support capacity building because it is based on systems theory knowledge and evidence. In keeping with acquisition of skills by Benner (2012), it is well understood that HCPs relationships towards knowledge changes with time and practice, especially among nurses, as they develop more proficiency in practice (Gardner, 2013). Findings in this study that support the implementation of relevant systems theory in practice, underpin the final family

psychosocial assessment framework. Furthermore, evidenced-based knowledge and understanding of child development and family wellbeing could be shared with caregivers using therapeutic communication and a strength-based approach. This notion is supported by the findings from action research where examination of patients and nurses' experiences identified the direct relationships between giving compassionate care and improved job satisfaction (Adamson, 2013).

The application of "*listening with openness and curiosity*" as a way to "*build trust and safety*" is also in keeping with using a strength-based approach advocated in family nursing interventions where equality and empowerment are fostered (Mooney-Doyle, Deatrack, & Horowitz, 2015). Fostering equality between PCGs and HCPs could see the balance of power identified in the data more evenly maintained. In a similar way, the importance of acquiring appropriate knowledge and skills together with feeling accepted was found to enable parents to be better able to cope (Kane, Wood, & Barlow, 2007).

The findings embedded in the emergent conceptual model indicate that the promotion of family psychosocial assessment could be achieved more successfully through skills-based educational and mentorship programmes than a new family psychosocial assessment instrument. Given that both PCGs and HCPs often struggle to communicate effectively about psychological and social issues, it is recommended that skills-based programmes in communicating about psychosocial issues be developed for both groups. While it may be feasible to hold workshops with the PCGs of seriously and chronically ill children, they are likely to be extremely challenging to initiate. Therefore, as a first step, the key recommendation of this study is that an inter-professional learning package be created in collaboration with stakeholders to enhance HCP skills in family psychosocial assessment and support. It is anticipated that skilled HCPs will provide future support and advocacy for PCG programmes to be implemented. A tentative skills-based practice framework for HCPs is outlined in the following sub-section.

5.7.1 A skills-based practice intervention for family psychosocial assessment

The implementation of a skills-based practice intervention will involve further collaboration with PCGs and HCGs in the development of an effective inter-professional education programme based on findings from this formative evaluation. The emergent

conceptual model and theoretical underpinnings will guide the generation of learning modules to include the relevant theoretical concepts, practice models of care to guide psychosocial enquiry, appropriate algorithms to recognise and respond to psychosocial strain, workshop materials addressing relationship building, and the development of a leadership through mentorship programme. It is envisaged that the education programme will include approximately five learning modules containing relevant theoretical knowledge and a practical skills-based components in readiness for implementation to practice in paediatric settings. The development of the skills-based practice intervention will be achieved in three phases: The writing of learning materials, the evaluation of the materials by stakeholders, and a pilot study.

5.7.1.1 Writing of the learning materials

Learning modules will be developed to cover the following topics: attention to psychosocial issues and care, relationship building, appropriate response strategies, and mentorship incentives to cover all aspects of the skills-based practice intervention.

Module 1: Psychosocial issues and health will be addressed in this learning module. Here evidenced based findings illustrating the impact psychosocial issues have on the long-term health and developmental trajectories of children who are seriously or chronically ill and their families will be summarised. Psychosocial determinants of health, particularly maternal emotional health, maternal self-confidence, family structure and relationships, social support and engagement in the community will be emphasised.

Module 2: Talking about family issues in practice will be the focus of this learning module. With an understanding of evidenced based psychosocial components and theoretical concepts from module one, building relationships with the whole family in the context of complex care and associated stress, will be addressed. This will include attention to relationship building, therapeutic communication, building trust and safety, and the influence of organisational culture.

Module 3: This learning module will focus on psychosocial assessment and the triage of families into appropriate pathways of psychosocial support. For some families, this process will lead to interventions implemented by nurses alone, while for others it will mean referral to additional support services offered by other members of the healthcare team.

Module 4: This module will involve teaching specific skills in communicating with family members about psychosocial issues. Using a number of techniques including role plays, reflective listening, and the use of verbal and non-verbal cues, participants will learn how to effectively build safe and trusting relationships and discuss family psychosocial issues in a mutually respectful and positive manner. Participants will be given ample opportunities to practice these skills in simulated “real-life” situations developed from case-studies.

Module 5: This module will consolidate knowledge and understanding of theory and practice in psychosocial assessment and participants will be encouraged to be mentors and pursue leadership roles in the settings in which they work. This module will draw on the understanding of the importance of the hospital people and culture that is a key component of the conceptual model, in the successful implementation of the emergent psychosocial assessment framework.

The collaborative process will include analysis of the stakeholders’ perspectives about learning modes, how materials should be presented, the type of language used, and appropriate pre-reading and learning packages. These perspectives will shape the presentation and delivery of these modules, for example, online delivery, pre-reading followed by a quiz, or face to face workshop interaction.

5.7.1.2 Evaluation of the learning materials

Following development of the learning modules these will be subject to review by stakeholders for readability, content accuracy and validity, and incorporation of a range of learning styles.

5.7.1.3 Piloting of the skills-based practice programme

Following evaluation by expert stakeholders, a pilot study will be conducted in a participating ward or department of the paediatric healthcare facility where the programme has been introduced. Pre and post testing will be conducted with HCPs to establish perspectives about levels of knowledge and confidence before and after undertaking the learning modules. Perspectives about incorporating this knowledge and understanding into practice will also be examined.

It will be important that a collaborative approach be maintained throughout the development and implementation of the skills-based practice intervention where regular communication with stakeholders takes place. In this way amendments can be

made to the educational modules prior to adaptation to a wider range of paediatric healthcare settings. It is anticipated that these learning modules will form the foundation for the implementation of a skills-based family psychosocial assessment intervention to practice in paediatric healthcare settings.

5.7.2 Implications for research and nursing knowledge

The ethnic and cultural homogeneity of participants has been identified as a limitation of the study. Furthermore, the higher level of education attained by many PCGs and the fact that most PCGs and HCPs were women, were also flagged as potential problematic. Therefore, a great deal more data collection will be required with both PCGs and HCPs who are representative of a range of ethnic and cultural groups, socioeconomic groups, as well as sexually and gender diverse groups. As with the current study, the key to further research will be the collaborative process. For the Candidate, the prospect of working with people from a wide range of diverse backgrounds is both daunting and exciting. It is important to stress again here that the psychosocial assessment framework discussed in previous sub-sections is emerging, it is by no means final. It is very likely that significant modification will be required to transform it into a framework that can be implemented universally.

As outlined in the methodology chapter of this thesis, in health promotion practice formative evaluation is the first step in four phases of research that are intended to produce health interventions that are efficacious and sustainable (Stetler, et al., 2006). Having undertaken a formative evaluation in order to ascertain the degree to which a proposed intervention suits and is feasible for the intended population group, the next step is to undertake process evaluation, followed by impact evaluation and outcome evaluation. With regard to implementation of the skills-based practice intervention outlined in the previous sub-section, process evaluation will involve the collection of information about the acceptability to participants of the practical aspects, such as recruitment of participants, the mode of delivery (face-to-face or online), the time and place of delivery if face-to-face, the availability of the online learning package if online, and the amount of time taken to complete the modules. Impact evaluation, as suggested previously, will involve the measurement of the knowledge and understanding, and attitudes and values, of HCPs about psychosocial assessment before and after their completion of the intervention. Finally, outcome evaluation will involve one or more quasi-experimental or randomised controlled trials in which the

psychosocial assessment skills of HCPs who have completed the skills-based intervention will be compared with those who have not completed it.

The skill-based practice intervention for HCPs outlined previously is just one of a number of interventions that might evolve from the emerging practice framework. Briefly, it might be feasible in some settings to implement a skill-based intervention for PCGs and other family members. This intervention would focus on the experience of families in caring for a seriously or chronically ill child and highlight the positive aspects of the situation as well as the challenges for individuals and the family as a whole. Content might include information about the importance of appropriate care in order to maximise the child's health and developmental outcomes as well as communication and advocacy skills to empower family members to partner effectively with HCPs in the hospital environment. It almost goes without saying that this intervention would be developed in close collaboration with PCGs, families, and consumer advocates. Once developed, this intervention would be subjected to process, impact, and outcome evaluations.

It is anticipated that further theoretical and research work that will evolve from the emergent psychosocial assessment framework will generate research findings that contribute to the body of nursing knowledge regarding FCC and FSN. There is potential for the emergent family psychosocial assessment framework to be embedded in healthcare curriculum where education in the theoretical and practical components can be simultaneously components in tertiary Sim Suite settings using role play. The current drive to involve consumers could be further stimulated with the involvement of motivated individuals and families willing to share their consumer experience in the healthcare setting by engaging in the educational activities of healthcare providers.

Not only would this contribute to the education of healthcare providers but also create partnerships with the potential to build transformational partnerships in healthcare.

The Candidate is optimistic that future nursing practice will be transformed through a focus on people and families rather than the diagnosis and treatment of disease. In a world where most serious and chronic illnesses are incurable, appropriate care and favourable psychosocial conditions are key to optimal health and developmental outcomes for all people. By truly embracing FCC and FSN, the nursing profession has

a great opportunity to separate itself from medicine, so that nurses everywhere are able to practice as independent health professionals.

The dissemination of findings will be critical to stimulate interest and dialogue among HCPs and consumer groups through publications and platform presentations in a range of clinical, academic, professional, and public forums. While Australia is a large country, it is somewhat geographically isolated. The development of collaborative research relationships with healthcare colleagues and experts in the field internationally are critical for the pursuit of improved health and developmental outcomes for all vulnerable groups, individuals, and families.

5.8 Conclusion

For many children and families, living with serious or chronic illness is a life-long experience. Rather than cure, the emphasis is on quality care to support optimal health and developmental outcomes. An alternative model of healthcare that goes beyond medical diagnosis and treatment, has come to the forefront of public consciousness in recent years. This approach is reflected in the healthcare systems of Western countries, where chronic health conditions are common and people are advised, through health promotion activities, to take control of their own, and their family's health, by making appropriate lifestyle choices and participating in primary healthcare activities, such as check-ups and screening. There is an increasing recognition by many healthcare professionals, supported by a great deal of research evidence, that psychological and social factors play a significant role in poor health and developmental outcomes. Complex causal pathways to many diseases involve the experience of significant life-stress as a major contributor. Cystic fibrosis is an example of one disease experienced by children and young people, where the principal cause is a series of genetic polymorphisms, but the outcomes in terms of morbidity and mortality are very much determined by the psychosocial functioning and caregiving activities of the family.

FSN has made a great contribution to knowledge, understanding, and practice where the application of FSN models of care has resulted in improved health and developmental outcomes in individuals and families as well as increased satisfaction among the HCPs who care for them. However, FSN has yet to be disseminated broadly and applied universally within the nursing community such that all qualified registered nurses use it as their preferred framework for practice. A great strength of FSN is that

it is grounded in systems theory and that systems theory is now widely accepted as the most appropriate way to understand factors that influence human health and development. This interdisciplinary approach which focuses on individuals within families, their communities, and wider socio-political influences is the basis of holistic care which has been talked about for many years.

This thesis has touched on many of these issues. The synthesis of research evidence highlighting the biological, relational, and environmental influences on children, and how exposure to persistent stress becomes biologically embedded has provided a great learning journey. A greater appreciation of the inherent influence that psychosocial factors have on the health and developmental outcomes of children, in particular those who are seriously or chronically ill, has strengthened this enquiry. The highlight for the Candidate has been her growing awareness of the value of collaborating with stakeholders. The enthusiastic support received, and knowledge shared, with parents, consumer support staff, and clinicians that mirrored their experiential understanding of the impact of psychosocial distress and the desire to support families, cannot be underestimated. This collaborative process has guided the development and realisation of this research enquiry where the findings show that, rather than finalising an assessment instrument for psychosocial assessment, attending to the psychological and social care of the family should be more about building trusting relationships where conversations about family issues can occur.

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APPENDICES

A. Illness categories

Table A.1
A serious or chronic illness is defined as one lasting
or estimated to last more than six months (ABS, 2009).

Category	Conditions included in this category
Airway and Asthma	Asthma Bronchiolitis Bronchiectasis Chronic lung disease of prematurity Cystic Fibrosis
Autoimmune disease	Juvenile arthritis Rheumatic fever Kawasaki disease Henoch-Schonlein Purpura Lupus Lyme disease Vasculitis Spondyloarthropathies
Allergy	Anaphylaxis
Behavioural	ADHD Asperger's Anorexia nervosa
Burns	Burns requiring hospitalisation, skin treatment and follow up
Cancer and Haematology	Sickle cell anaemia Thalassemia Coagulopathy disease such as Haemophilia Leukaemia Neoplasm requiring oncology intervention
Developmental	Cerebral palsy Autism Gross developmental delay Spina bifida
Endocrinology and Diabetes	Diabetes Hyperinsulinism
Gastroenterology, Hepatology and Nutrition	GI motility disorders Coeliac disease Inflammatory bowel disease such as Chron's disease Alagille syndrome Biliary atresia Liver disease Liver transplant

Category	Conditions included in this category
Genetics and metabolic disease	Inborn errors of metabolism e.g.; PKU /MCAD Mitochondrial disorders Lysosomal storage disorders Connective tissue disorder e.g.; Marfan syndrome, osteogenesis imperfect Williams syndrome 22q11.2 deletion Down syndrome Turner syndrome
Heart disease	Congenital heart disease Acquired heart disease Rheumatic heart disease Giant aneurysm r/t Kawasaki disease Pulmonary hypertension Cardiomyopathy
Infectious diseases	AIDS Meningitis – bacterial or viral Pertussis
Neurological function	Epilepsy Neuromuscular myopathy Multiple sclerosis Stroke Friedreich's Ataxia Hydrocephalus Surgery to the brain or spine
Renal function	Glomerular nephritis Nephrotic syndrome Polycystic kidneys Renal failure Peritoneal or haemodialysis
Trauma and Injury	Burns Head Injury – rehabilitation Spinal injury Immersion

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B. PCG Survey Information Sheet



QUESTIONNAIRE

PRIMARY CARE GIVER INFORMATION SHEET

Study Title: Development of a psychosocial assessment tool for families of children who are seriously or chronically ill in hospital.

Research Team: Mary Tallon, Dr Garth Kendall, Dr Lynn Priddis

You are invited to participate in a research project that is being conducted in conjunction with Curtin University at three Australian tertiary children's hospitals. The participating hospitals are Princess Margaret Hospital for Children in Perth, WA, The Royal Children's Hospital in Melbourne, VIC, and The Royal Children's Hospital in Brisbane, QLD.

This research has the approval of the Curtin University Human Ethics Committee and Ethics Committee in each of the three named hospitals.

The aim of this research is to learn about parents' and health professionals' points of view about discussing family issues. It is anticipated that the study findings will contribute toward the development of an assessment tool that will assist staff to identify problems promptly so that appropriate support can be offered.

As a participant you will be asked to complete a questionnaire, either by hand or on line. The questionnaire will ask some questions about your feelings about being asked (as a parent) or, asking (as a health care provider), questions about family qualities and circumstances.

Your participation in this project will remain confidential. The information you share will be identified only by a study number. All research information will be stored in locked filing cabinets and accessed only by the researcher and supervisors named above.

If you are interested in answering questions in more detail please contact the researcher on M.Tallon@curtin.edu.au or by calling 0401 306 061 about participating in a focus group or one on one interview.

The researcher will be available by phone or email to answer any questions you may have about this research. Alternatively if you have any concerns you may contact the Principal Supervisor Dr Garth Kendall on (08) 9266 2191.

In the event of any questions or concerns of an ethical nature in relation to the intentions of this study you are welcome to contact the Secretary of the Human Research Ethics Committee, Curtin University on (08) 9226 2784.

Researcher:	Mary Tallon
Email:	M.Tallon@curtin.edu.au
Mobile contact:	0401 306 061

C. PCG Survey Consent Form



QUESTIONNAIRE

PRIMARY CARE GIVER CONSENT FORM

Study Title: Development of a psychosocial assessment tool for families of children who are seriously or chronically ill in hospital.

Research Team: Mary Tallon, Dr Garth Kendall, Dr Lynn Priddis

I have been given clear written information and understand the intentions of this study.

I have taken the time to consider participation in this study.

I have had the opportunity to ask questions and had them answered to my satisfaction.

I understand that in the event of this work being published, as a participant, I will not in be in any way identifiable.

I understand I may withdraw from the study at any time without consequence, effect or access to routine health care.

I know that I can contact the Principal Supervisor Dr. Garth Kendall on (08) 9266 2191 if I have questions or concerns.

I am also aware that in the event of my having any complaints regarding this study, I can contact Dr Garth Kendall on (08) 9266 2191 on a confidential basis. My concerns will be drawn to the attention of the Ethics Committees who are monitoring this study. I am aware that Curtin University Human Ethics Committee and the Ethics Committees at Princess Margaret Hospital for Children in Perth, WA, The Royal Children's Hospital in Melbourne, VIC, and The Royal Children's Hospital in Brisbane, QLD, have given approval for this research to be conducted.

Participant Statement

..... (Print full name)

understand the intentions of the study and know that I have the opportunity to ask questions at any time.

I agree to complete a questionnaire and / or participate in a focus group and / or one on one interview.

I understand that my participation in this study is voluntary and I can withdraw at any time without any consequences to position or my child's access health care and services.

Signature Participant

Signature Researcher

D. PCG Survey



Talking about your family when your child is in hospital

Family Questionnaire

Curtin University

Hospital name here

The purpose of this questionnaire is to obtain information about your feelings regarding nurses and doctors asking you about your family when your child is in hospital.

Remember ALL answers are confidential

Thank you very much, we appreciate the time you will spend completing this questionnaire.

Please return the questionnaire using stamped addressed envelope attached.

If you have any questions please contact the researcher on:

Phone: [0401 306 061](tel:0401306061)

Email: M.Tallon@curtin.edu.au

Please respond as completely, honestly, and accurately as you can. If you are uncomfortable about a question or unsure of an answer, please leave it blank.

Completion Instructions

Please shade the circle that corresponds to your answer
or
Write your response in the space provided

PART A: ABOUT YOUR CHILD

A1. What is your child's age? years and / or months
--------------------------------------	-----------------------------------

	Male	Female
A2. What is your child's gender?	<input type="radio"/>	<input type="radio"/>

A3. From the groups below, please select the condition that best describes your child's main health problem (the one for which they are currently hospitalised).

ALLERGY	Anaphylaxis	<input type="radio"/>	HEART DISEASE	Congenital heart disease	<input type="radio"/>
AUTOIMMUNE	Juvenile arthritis	<input type="radio"/>		Cardiomyopathy	<input type="radio"/>
	Lupus	<input type="radio"/>		Pulmonary hypertension	<input type="radio"/>
	Kawasaki disease	<input type="radio"/>		Aneurysm r/t Kawasaki	<input type="radio"/>
BEHAVIOURAL	ADHD	<input type="radio"/>	INFECTION	Meningitis	<input type="radio"/>
	Asperger's	<input type="radio"/>		Pneumonia	<input type="radio"/>
CANCER and HAEMATOLOGY	Oncology treatment for cancer	<input type="radio"/>		Septicaemia	<input type="radio"/>
	Haemophilia	<input type="radio"/>		Bacterial endocarditis	<input type="radio"/>
	Sickle cell anaemia	<input type="radio"/>	NEUROLOGICAL	Epilepsy	<input type="radio"/>
	Thalassemia	<input type="radio"/>		Stroke	<input type="radio"/>
DEVELOPMENTAL	Autistic spectrum disorder	<input type="radio"/>		Neuromuscular myopathy	<input type="radio"/>
	Cerebral palsy	<input type="radio"/>		Surgery to brain or spine	<input type="radio"/>
	Developmental delay	<input type="radio"/>		Freidreich's ataxia	<input type="radio"/>
	Spina bifida	<input type="radio"/>		Hydrocephalus	<input type="radio"/>
ENDOCRINE	Diabetes	<input type="radio"/>	RENAL	Glomerular nephritis	<input type="radio"/>
	Hyperinsulinism	<input type="radio"/>		Nephrotic syndrome	<input type="radio"/>
GASTRIC TRACT	Allagille syndrome	<input type="radio"/>		Polycystic kidneys	<input type="radio"/>
	Biliary atresia	<input type="radio"/>		Renal failure	<input type="radio"/>
	Chron's disease	<input type="radio"/>		Renal dialysis	<input type="radio"/>
	Coeliac disease	<input type="radio"/>		Renal transplant	<input type="radio"/>
	Feeding or swallowing disorder	<input type="radio"/>	RESPIRATORY	Asthma	<input type="radio"/>
	Liver disease	<input type="radio"/>		Chronic lung disease	<input type="radio"/>
	Liver transplant	<input type="radio"/>		Cystic fibrosis	<input type="radio"/>
GENETICS and METABOLIC disease	Inborn error of metabolism e.g; PKU / MCAD	<input type="radio"/>	TRAUMA/ INJURY	Burns	<input type="radio"/>
	Mitochondrial disorder	<input type="radio"/>		Head injury	<input type="radio"/>
	Down syndrome	<input type="radio"/>		Immersion	<input type="radio"/>
	22q11.2 deletion	<input type="radio"/>		Spinal injury	<input type="radio"/>
	Marfan syndrome	<input type="radio"/>	OTHER HEALTH PROBLEM (not listed)		
	Osteogenesis	<input type="radio"/>		
	Williams syndrome	<input type="radio"/>		
	Turner syndrome	<input type="radio"/>		

PART B: YOUR FEELINGS ABOUT TALKING TO HEALTH PROFESSIONALS ABOUT YOUR FAMILY

B1. The statements below are about how individuals might feel about seeking and accepting help with family problems (such as, worries about support; relationships; stressful events; money; or emotional well-being) from doctors, nurses, and other health professionals during their child's stay in hospital.

Remember your responses are strictly confidential. Please rate your agreement / disagreement with the following statements.

There are no right or wrong answers – just say what you think would be true for you.

Strongly disagree Disagree Neither agree nor disagree Agree Strongly agree	1	2	3	4	5
If we were having problems at home that were impacting on my child I would get professional help if I wanted to	<input type="radio"/>				
I would want to get professional help if I was worried about issues at home	<input type="radio"/>				
To avoid worrying about my problems, doing other activities helps	<input type="radio"/>				
I would not want hospital staff to know we are having problems at home	<input type="radio"/>				
Problems at home do not affect my child's health and are separate	<input type="radio"/>				
Important people in my life would think less of me if I needed professional help to manage problems at home	<input type="radio"/>				
Problems and worries at home tend to work out by themselves	<input type="radio"/>				
I expect to be asked about our family life at home when my child is admitted to hospital	<input type="radio"/>				
There could be things that if they happened in my family, I would not want to discuss with anyone	<input type="radio"/>				
There is something admirable about people who cope with their problems without seeking professional help	<input type="radio"/>				
It would be relatively easy for me to access professional help for family problems if I needed it	<input type="radio"/>				
I do not feel comfortable discussing any problems at home with staff who are caring for my child in hospital because I would worry about what they might think	<input type="radio"/>				
If I needed professional help for problems at home I would be confident that health professionals caring for my child would help	<input type="radio"/>				
If I needed help with problems at home I would feel it should be 'kept secret'	<input type="radio"/>				
Seeking professional help for problems at home is a sign of weakness	<input type="radio"/>				

B2. When your child is in hospital, how important do you think it is to your child's recovery for doctors and nurses to ask you questions about your family situation?
Please mark a level of importance for questions about each of the following family circumstances

	Not at all important	A little important	Moderately important	Very Important
Your education	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your emotional well-being	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your self-confidence in your child's care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your occupation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Who lives at home	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Money worries	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family relationships	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Additional life-stresses in the family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your access to social support (friends and family)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your community / neighbourhood activities (such as toy library, playgroup, swimming lessons etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Yes	No	N/A
B3. Have you ever sought professional help for a family problem?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
B4. If you answered yes, were you satisfied with the level of help you received?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

PART C: ABOUT YOU

	Male	Female
C1. What is your gender?	<input type="radio"/>	<input type="radio"/>

	Yes	No
C2. Were you born in Australia?	<input type="radio"/>	<input type="radio"/>
If No , in which country were you born?		

	Yes	No
C3. Do you mostly speak English at home?	<input type="radio"/>	<input type="radio"/>
If No , what language do you mostly speak?		

C4. What is your postcode?

C5. Which of these categories best describes your highest schooling / education?	
Didn't complete High School	<input type="radio"/>
Completed High School (Leaving Certificate)	<input type="radio"/>
Completed High School (TEE or equivalent)	<input type="radio"/>
Apprenticeship/TAFE diploma	<input type="radio"/>
University Degree	<input type="radio"/>
Other, not included above (please specify)

Thank you very much, we appreciate the time you have spent completing this questionnaire

If you have any questions please contact the researcher on:
Phone: [0401 306 061](tel:0401306061)
Email: M.Tallon@curtin.edu.au

Please return the questionnaire using stamped addressed envelope attached.

E. HCP Survey Information Sheet



QUESTIONNAIRE

HEALTH CARE PROFESSIONAL INFORMATION SHEET

Study Title: Development of a psychosocial assessment tool for families of children who are seriously or chronically ill in hospital.

Research Team: Mary Tallon, Dr Garth Kendall, Dr Lynn Priddis

You are invited to participate in a research project that is being conducted in conjunction with Curtin University at three Australian tertiary children's hospitals. The participating hospitals are Princess Margaret Hospital for Children in Perth, WA, The Royal Children's Hospital in Melbourne, VIC, and The Royal Children's Hospital in Brisbane, QLD.

This research has the approval of the Curtin University Human Ethics Committee and Ethics Committee in each of the three named hospitals.

The aim of this research is to learn about parents' and health professionals' points of view about discussing family issues. It is anticipated that the study findings will contribute toward the development of an assessment tool that will assist staff to identify problems promptly so that appropriate support can be offered.

As a participant you will be asked to complete a questionnaire, either by hand or on line. The questionnaire will ask some questions about your feelings about being asked (as a parent) or, asking (as a health care provider), questions about family qualities and circumstances.

Your participation in this project will remain confidential. The information you share will be identified only by a study number. All research information will be stored in locked filing cabinets and accessed only by the researcher and supervisors named above.

If you are interested in answering questions in more detail please contact the researcher on M.Tallon@curtin.edu.au or by calling 0401 306 061 about participating in a focus group or one on one interview.

The researcher will be available by phone or email to answer any questions you may have about this research. Alternatively if you have any concerns you may contact the Principal Supervisor Dr Garth Kendall on (08) 9266 2191.

In the event of any questions or concerns of an ethical nature in relation to the intentions of this study you are welcome to contact the Secretary of the Human Research Ethics Committee, Curtin University on (08) 9226 2784.

Researcher:	Mary Tallon
Email:	M.Tallon@curtin.edu.au
Mobile contact:	0401 306 061

F. HCP Survey Consent Form



QUESTIONNAIRE

HEALTH CARE PROFESSIONAL CONSENT FORM

Study Title: Development of a psychosocial assessment tool for families of children who are seriously or chronically ill in hospital.

Research Team: Mary Tallon, Dr Garth Kendall, Dr Lynn Priddis

I have been given clear written information and understand the intentions of this study.

I have taken the time to consider participation in this study.

I have had the opportunity to ask questions and had them answered to my satisfaction.

I understand that in the event of this work being published, as a participant, I will not in be in any way identifiable.

I understand I may withdraw from the study at any time without consequence, effect or access to routine health care.

I know that I can contact the Principal Supervisor Dr. Garth Kendall on (08) 9266 2191 if I have questions or concerns.

I am also aware that in the event of my having any complaints regarding this study, I can contact Dr Garth Kendall on (08) 9266 2191 on a confidential basis. My concerns will be drawn to the attention of the Ethics Committees who are monitoring this study. I am aware that Curtin University Human Ethics Committee and the Ethics Committees at Princess Margaret Hospital for Children in Perth, WA, The Royal Children's Hospital in Melbourne, VIC, and The Royal Children's Hospital in Brisbane, QLD, have given approval for this research to be conducted.

Participant Statement

I..... (Print full name)

understand the intentions of the study and know that I have the opportunity to ask questions at any time.

I agree to complete a questionnaire and / or participate in a focus group and / or one on one interview.

I understand that my participation in this study is voluntary and I can withdraw at any time without any consequences to position or my child's access health care and services.

Signature Participant

Signature Researcher

Date

G. HCP Survey



Family Psychosocial Assessment

Questionnaire for health care professionals

Curtin University

Hospital name here

The purpose of this questionnaire is to obtain information about your feelings about family psychosocial assessment when caring for children who are seriously or chronically ill.

Remember ALL answers are confidential

Thank you very much, we appreciate the time you will spend completing this questionnaire.

Please return the questionnaire using stamped addressed envelope attached.

If you have any questions please contact the researcher on:

Phone: [0401 306 061](tel:0401306061)

Email: M.Tallon@curtin.edu.au

Please respond as completely, honestly and accurately as you can.

Completion Instructions

Please shade the circle that corresponds to your answer

Or

Write your response in the space provided

PART A : ABOUT FAMILY PSYCHOSOCIAL ASSESSMENT

A1. The statements below are about how health care staff might feel about initiating or pursuing discussion with parents about family psychosocial issues.
Remember your responses are strictly confidential. Please rate your agreement / disagreement with the following statements.
There are no right or wrong answers – just say what you think would be true for you. There are no right or wrong answers – just say what you think would be true for you.

Strongly disagree Disagree Neither agree nor disagree Agree Strongly agree	1	2	3	4	5
I feel I am intruding if I ask parents about psychosocial issues	<input type="radio"/>				
Evaluating and treating psychosocial problems will cause me to be more overburdened than I already am	<input type="radio"/>				
Parents do not want me to ask about psychosocial issues	<input type="radio"/>				
I can investigate psychosocial issues without losing my efficiency	<input type="radio"/>				
I focus on the physical signs not psychosocial problems	<input type="radio"/>				
If I address psychosocial issues I may lose the parent's trust	<input type="radio"/>				
There is so much to consider when assessing patients that I do not consider psychosocial issues	<input type="radio"/>				
I feel guilty probing the psychosocial issues of families in my care	<input type="radio"/>				
It is difficult to deal with psychosocial problems if I have many of these problems myself	<input type="radio"/>				
I am too pressed for time to routinely assess for psychosocial issues	<input type="radio"/>				
My own psychosocial issues do not interfere with my ability to address psychosocial problems	<input type="radio"/>				
Parents feel questions about psychosocial issues are irrelevant	<input type="radio"/>				
The stresses we all feel do not significantly influence disease	<input type="radio"/>				
Parents will become more dependent on me if I open up psychosocial issues	<input type="radio"/>				
Consideration of psychosocial issues will require more effort than I have to give	<input type="radio"/>				
Exploring psychosocial issues with families often causes me pain	<input type="radio"/>				
I must consider physical and psychosocial problems concurrently	<input type="radio"/>				
Parents will reject the idea of me addressing their psychosocial concerns	<input type="radio"/>				



	0-2 years	2-5 years	5-10 years	> 10 years
B3. How many years have you worked in this role	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	0-2 years	2-5 years	5-10 years	> 10 years
B4. How many years have you worked in this role in paediatric health care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Thank you very much, we appreciate the time you have spent completing this questionnaire

Please place it in the envelope provided for return via internal mail. Outgoing mail trays can be located at the ward, outpatient, or hospital enquiry desk. Thank you.

If you have any concerns please contact the researcher on:

Phone: 0401 306 061

Email: M.Tallon@curtin.edu.au

H. PCG Interview Information Sheet



ONE ON ONE INTERVIEW

PRIMARY CARE GIVER INFORMATION SHEET

Study Title: Development of a psychosocial assessment tool for families of children who are seriously or chronically ill in hospital.

Research Team: Mary Tallon, Dr Garth Kendall, Dr Lynn Priddis

You are invited to participate in a research project that is being conducted in conjunction with Curtin University at three Australian tertiary children's hospitals. The participating hospitals are Princess Margaret Hospital for Children in Perth, WA, The Royal Children's Hospital in Melbourne, VIC, and The Royal Children's Hospital in Brisbane, QLD.

This research has the approval of the Curtin University Human Ethics Committee and Ethics Committee in each of the three named hospitals.

The aim of this research is to learn about parents' and health professionals' points of view about discussing family issues. It is anticipated that the study findings will contribute toward the development of an assessment tool that will be helpful for families by assisting staff to identify problems promptly so that appropriate support can be offered.

As a participant you will be asked a series of questions asking what you think about talking about family issues when your child is in hospital.

Your participation in this project will remain confidential. Your name and the information you share will be identified only by a study number. All research information will be stored in locked filing cabinets and accessed only by the researcher and supervisors named above.

The researcher will be available by phone or email to answer any questions you may have about this research. Alternatively if you have any concerns you may contact the Principal Supervisor Dr Garth Kendall on (08) 9266 2191.

In the event of any questions or concerns of an ethical nature in relation to the intentions of this study you are welcome to contact the Secretary of the Human Research Ethics Committee, Curtin University on (08) 9226 2784.

Researcher:	Mary Tallon
Email:	M.Tallon@curtin.edu.au
Mobile contact:	0401 306 061

I. PCG Interview Consent Form



ONE ON ONE INTERVIEW

PRIMARY CARE GIVER CONSENT FORM

Study Title: Development of a psychosocial assessment tool for families of children who are seriously or chronically ill in hospital.

Research Team: Mary Tallon, Dr Garth Kendall, Dr Lynn Priddis

I have been given clear written information and understand the intentions of this study.

I have taken the time to consider participation in this study.

I have had the opportunity to ask questions and had them answered to my satisfaction.

I understand that in the event of this work being published, as a participant, I will not be in any way identifiable.

I understand I may withdraw from the study at any time without consequence, effect or access to routine health care.

I know that I can contact the Principal Supervisor Dr. Garth Kendall on (08) 9266 2191 if I have questions or concerns.

I am also aware that in the event of my having any complaints regarding this study, I can contact Dr Garth Kendall on (08) 9266 2191 on a confidential basis. My concerns will be drawn to the attention of the Ethics Committees who are monitoring this study. I am aware that Curtin University Human Ethics Committee and the Ethics Committees at Princess Margaret Hospital for Children in Perth, WA, The Royal Children's Hospital in Melbourne, VIC, and The Royal Children's Hospital in Brisbane, QLD, have given approval for this research to be conducted.

Participant Statement

I..... (Print full name)

understand the intentions of the study and know that I have the opportunity to ask questions at any time.

I agree to complete a questionnaire and / or participate in a focus group and / or one on one interview.

I understand that my participation in this study is voluntary and I can withdraw at any time without any consequences to position or my child's access health care and services.

Signature Participant

Signature Researcher

Date

J. PCG Interview Guide and Schedule



PRIMARY CARE GIVER ONE ON ONE INTERVIEW: GUIDE AND SCHEDULE

Introduction

My name is Mary Tallon and I'm conducting research with the families of children who are seriously or chronically ill and the health professionals who care for them. The focus of this research is to learn about parents' and health professionals' points of view about discussing family issues.

Today's interview is scheduled for one hour. The purpose of this interview is to get your point of view about talking about family issues.

Before I begin I would like to ask you to complete a consent form. It is important that you are fully informed about the study: its purpose, your right to have questions answered to your satisfaction, and your right to confidentiality.

I will now read through the information sheet that you have been given. Read information sheet. Do you have any questions? Please feel free to ask, no questions are silly. Answer questions.

It is my role to keep the discussion focused on the topic and I may need to move the conversation along. I will encourage you to express your point of view fully. There are no right or wrong answers; just answer as honestly as you can. Tell me what you really think and feel not what you think I would like to hear.

I would like to reiterate that you can be assured of complete confidentiality – your name will not be attached to any report or publications. And finally, if you do not wish to sign the consent form you are welcome to withdraw from participating in this research now. In the event of you feeling uncomfortable with any questions at any time please feel free not to answer or withdraw your participation at any time without any consequence effect or access to health care.

Shall we begin?



8. How do you feel about nurses asking questions about family issues as part of a routine assessment on your child's admission to hospital?

8.1. Would you be happy to provide information your background including your education, occupation, physical and emotional health, relationships, and exposure to stress?

9. Is there anything you would like to add?

This brings the questions to an end.

Thank you very much for your participation in this interview. Your point of view is very important to us and your participation is very much appreciated.

K. HCP Focus Group/Interview Information Sheet



FOCUS GROUP / ONE ON ONE INTERVIEW HEALTH CARE PROFESSIONAL INFORMATION SHEET

Study Title: Development of a psychosocial assessment tool for families of children who are seriously or chronically ill in hospital.

Research Team: Mary Tallon, Dr Garth Kendall, Dr Lynn Priddis

You are invited to participate in a research project that is being conducted in conjunction with Curtin University at three Australian tertiary children's hospitals. The participating hospitals are Princess Margaret Hospital for Children in Perth, WA, The Royal Children's Hospital in Melbourne, VIC, and The Royal Children's Hospital in Brisbane, QLD.

This research has the approval of the Curtin University Human Ethics Committee and Ethics Committee in each of the three named hospitals.

The aim of this research is to learn about health care professionals' and parents' points of view about discussing family issues in hospital. It is anticipated that the study findings will contribute toward the development of an assessment tool that will assist staff to identify family problems promptly so that appropriate support can be offered.

As a participant you will be asked a series of questions asking what you think about talking about psychosocial issues with parents of the children you are caring for in hospital.

Your participation in this project will remain confidential. Any names used and the information you share will be identified only by a study number. All research information will be stored in locked filing cabinets and accessed only by the researcher and supervisors named above.

If you are interested in answering questions in more detail please contact the researcher on M.Tallon@curtin.edu.au or by calling 0401 306 061 about participating in a focus group or one on one interview.

The researcher will be available by phone or email to answer any questions you may have about this research. Alternatively if you have any concerns you may contact the Principal Supervisor Dr Garth Kendall on (08) 9266 2191.

In the event of any questions or concerns of an ethical nature in relation to the intentions of this study you are welcome to contact the Secretary of the Human Research Ethics Committee, Curtin University on (08) 9226 2784.

Researcher:	Mary Tallon
Email:	M.Tallon@curtin.edu.au
Mobile contact:	0401 306 061

L. HCP Focus Group/Interview Consent Form



FOCUS GROUP / ONE ON ONE INTERVIEW HEALTH CARE PROFESSIONAL CONSENT FORM

Study Title: Development of a psychosocial assessment tool for families of children who are seriously or chronically ill in hospital.

Research Team: Mary Tallon, Dr Garth Kendall, Dr Lynn Priddis

I have been given clear written information and understand the intentions of this study.

I have taken the time to consider participation in this study.

I have had the opportunity to ask questions and had them answered to my satisfaction.

I understand that in the event of this work being published, as a participant, I will not in be in any way identifiable.

I understand I may withdraw from the study at any time without consequence, effect or access to routine health care.

I know that I can contact the Principal Supervisor Dr. Garth Kendall on (08) 9266 2191 if I have questions or concerns.

I am also aware that in the event of my having any complaints regarding this study, I can contact Dr Garth Kendall on (08) 9266 2191 on a confidential basis. My concerns will be drawn to the attention of the Ethics Committees who are monitoring this study. I am aware that Curtin University Human Ethics Committee and the Ethics Committees at Princess Margaret Hospital for Children in Perth, WA, The Royal Children's Hospital in Melbourne, VIC, and The Royal Children's Hospital in Brisbane, QLD, have given approval for this research to be conducted.

Participant Statement

I..... (Print full name)

understand the intentions of the study and know that I have the opportunity to ask questions at any time.

I agree to complete a questionnaire and / or participate in a focus group and / or one on one interview.

I understand that my participation in this study is voluntary and I can withdraw at any time without any consequences to position or my child's access health care and services.

Signature Participant

Signature Researcher

Date

M. HCP Focus Group/Interview Moderator Guide



HEALTH CARE PROVIDER FOCUS GROUP AND ONE ON ONE INTERVIEW: MODERATOR GUIDE AND SCHEDULE

Introduction

My name is Mary Tallon and I'm conducting research with the families of children who are seriously or chronically ill and the health professionals who care for them. The focus of this research is to learn about parents' and health professionals' points of view about discussing family issues in hospital.

Today's discussion is scheduled for 45 minutes. The purpose of this focus group is to get your point of view about talking about family issues with the parents of children you care for in hospital.

Before we begin I would like to ask you to complete a consent form. It is important that you are fully informed about the study: its purpose, your right to have questions answered to your satisfaction, and your right to confidentiality.

I will now read through the information sheet that you have been given. *Read information sheet.* Do you have any questions? Please feel free to ask, no questions are silly. *Answer questions.*

It is my role to keep the discussion focused on the topic and I may need to move the conversation along so we can cover all the items and hear from everyone here today. I will encourage you to express your point of view, while at the same time respecting the views of others.

I would like to reiterate that you can be assured of complete confidentiality - no names will be attached to any report or publications. There are no right or wrong answers; just answer as honestly as you can. Tell me what you really think and feel not what you think I would like to hear. And finally, if you do not wish to sign the consent form you are welcome to withdraw from the group before the discussion begins. If anyone is feeling uncomfortable with anything that we talk about at any time please feel free to leave or sit quietly and not comment.



4. Is there anything you would like to add?

This brings the questions to an end.

Thank you very much for your participation in this focus group. Your points of view are very much appreciated.

If you would like to participate in a one on one interview please let me know either today or by taking a business card and contacting me within the next week.

N. Levels of importance allocated by participating PCGs to components of proposed psychosocial assessment framework

Table N.1
Levels of importance allocated by PCGs by gender.

Psychosocial component	Female		Male	
	n	%	n	%
Your education				
Very important	35	27	2	15
Of some importance	59	46	9	70
Of little or no importance	34	27	2	15
Your occupation				
Very important	14	11	2	16
Of some importance	80	63	8	61
Of little or no importance	33	26	3	23
Your emotional health				
Very important	91	72	11	85
Of some importance	35	27	2	15
Of little or no importance	1	1	0	0
Your self- confidence				
Very important	102	80	10	77
Of some importance	23	18	3	23
Of little or no importance	2	2	0	0
Family structure				
Very important	63	50	4	31
Of some importance	57	45	8	46
Of little or no importance	5	5	1	8
Family relationships				
Very important	64	50	7	54
Of some importance	59	46	5	39
Of little or no importance	5	4	1	8
Life stress				
Very important	45	36	6	46
Of some importance	79	62	5	39
Of little or no importance	3	2	2	15
Financial strain				
Very important	28	22	1	8
Of some importance	78	61	11	84
Of little or no importance	22	17	1	8
Social support				
Very important	72	56	5	39
Of some importance	56	44	8	62
Of little or no importance	0	0	0	0
Your engagement in community activities				
Very important	28	22	2	15
Of some importance	85	66	9	69
Of little or no importance	15	12	2	15

Statistically significant difference ¹Chi square p-value < .05, ²FET p-value < .017 (n = 350).

Table N.2
Levels of importance allocated by PCGs by state.

Psychosocial component	WA		VIC	
	n	%	n	%
Your education				
Very important	29	26	6	20
Of some importance	51	46	17	57
Of little or no importance	31	28	7	23
Your occupation				
Very important	14	13	2	7
Of some importance	68	62	20	67
Of little or no importance	28	26	8	27
Your emotional health				
Very important	80	73	22	73
Of some importance	29	27	8	27
Of little or no importance	1	1	0	0
Your self- confidence				
Very important	90	82	22	73
Of some importance	18	16	8	27
Of little or no importance	2	2	0	0
Family structure				
Very important	57	53	10	33
Of some importance	45	41	20	67
Of little or no importance	7	6	0	0
Family relationships				
Very important	64	50	7	54
Of some importance	59	46	5	39
Of little or no importance	5	4	1	8
Life stress				
Very important	37	34	14	47
Of some importance	69	63	15	50
Of little or no importance	3	3	1	3
Financial strain				
Very important	20	18	2	7
Of some importance	70	63	19	63
Of little or no importance	21	19	1	30
Social support				
Very important	50	45	11	37
Of some importance	61	55	19	63
Of little or no importance	0	0	0	0
Your engagement in the community				
Very important	24	22	6	20
Of some importance	70	63	24	80
Of little or no importance	17	15	0	0

Statistically significant difference ¹Chi square p-value < .05, ²FET p-value < .017 (n = 350)

Table N.3
Levels of importance allocated by PCGs by education attainment.

Psychosocial component	High school incomplete		Completed Year 12		Trade or Diploma		University Degree	
	n	%	n	%	n	%	n	%
Your education								
Very important	8	42	9	34	9	22	11	20
Of some importance	7	37	12	44	20	49	29	54
Little importance	4	21	6	22	12	29	14	26
Your occupation								
Very important	3	16	6	22	10	25	14	26
Of some importance	10	52	15	56	27	68	36	68
Little importance	6	32	6	22	3	7	4	6
Your motional health								
Very important	12	63	21	78	32	80	37	68
Of some importance	7	37	6	22	7	18	17	32
Little importance	0	0	0	0	3	1	0	0
Your self- confidence								
Very important	17	89	23	85	31	78	41	76
Of some importance	2	11	3	11	8	20	13	24
Little importance	0	0	1	4	1	2	0	0
Family structure								
Very important	10	53	19	70	20	49	18	33
Of some importance	7	37	7	26	19	46	35	65
Little importance	2	10	1	4	2	5	1	2
Family relationships								
Very important	10	53	19	70	20	49	22	41
Of some importance	7	37	7	26	19	46	31	57
Little importance	2	10	1	4	2	5	1	2
Life stress								
Very important	7	37	27	30	16	40	20	37
Of some importance	11	58	18	66	22	55	33	61
Little importance	1	5	1	4	2	5	1	2
Financial strain								
Very important	5	26	8	30	7	17	9	17
Of some importance	9	47	14	52	26	62	40	74
Little importance	5	26	5	18	8	19	5	9
Social support								
Very important	11	58	19	70	21	52	29	54
Of some importance	8	42	8	30	20	49	25	46
Little importance	0	0	0	0	0	0	0	0
Your engagement in the community								
Very important	5	26	7	26	8	20	10	19
Of some importance	11	58	15	56	28	68	40	74
Little importance	3	16	5	18	5	12	4	7

Statistically significant difference ¹Chi square p-value < .05, ²FET p-value < .017 (n = 350)

O. Level of importance allocated by participating HCPs to components of proposed psychosocial assessment framework

Table O.1
Levels of importance allocated by HCPs by gender.

Psychosocial component	Female		Male	
	n	%	n	%
Maternal education				
Very important	54	17	4	15
Of some importance	84	26	7	27
Of little or no importance	185	57	15	58
Parental occupation				
Very important	17	5	2	7
Of some importance	107	33	6	23
Of little or no importance	200	62	18	69
Emotional health				
Very important	251	78	17	65
Of some importance	64	20	7	27
Of little or no importance	9	3	2	7
Self- confidence				
Very important	261	81	20	76
Of some importance	60	19	3	12
Of little or no importance	3	1	3 ²	12
Family structure				
Very important	179	55	8	31
Of some importance	118	37	15	58
Of little or no importance	27	8	3	11
Family relationships				
Very important	216	67	13	50
Of some importance	94	29	11	42
Of little or no importance	14	4	2	8
Life stress				
Very important	217	67	10	39
Of some importance	99	31	14	54
Of little or no importance	7	2	3 ¹	8
Financial strain				
Very important	143	44	9	35
Of some importance	154	48	13	50
Of little or no importance	26	8	4	15
Social support				
Very important	263	82	15	58
Of some importance	56	17	11	42
Of little or no importance	4	1	0 ²	0
Engagement in community activities				
Very important	146	45	9	35
Of some importance	137	42	12	46
Of little or no importance	41	13	5	19

Statistically significant difference ¹Chi square p-value < .05, ²FET p-value < .017 (n = 350)

Table O.2
Levels of importance allocated by HCPs by state.

Psychosocial component	WA		VIC	
	n	%	n	%
Maternal education				
Very important	22	18	36	16
Of some importance	33	28	58	25
Of little or no importance	64	54	136	59
Parental occupation				
Very important	9	8	10	4
Of some importance	41	34	72	32
Of little or no importance	70	58	148	64
Emotional health				
Very important	84	70	184	80
Of some importance	29	24	42	18
Of little or no importance	7 ¹	6	4	2
Self- confidence				
Very important	86	72	195	85
Of some importance	29	24	34	14
Of little or no importance	5 ²	4	1	1
Family structure				
Very important	56	47	131	57
Of some importance	53	44	80	35
Of little or no importance	11	9	19	8
Family relationships				
Very important	76	63	153	67
Of some importance	33	28	72	31
Of little or no importance	11 ¹	9	5	2
Life stress				
Very important	71	59	156	68
Of some importance	43	36	71	31
Of little or no importance	6	5	3	1
Financial strain				
Very important	45	45	107	47
Of some importance	61	51	106	46
Of little or no importance	14	12	16	7
Social support				
Very important	83	69	195	85
Of some importance	34	28	33	14
Of little or no importance	3 ²	2	1	1
Engagement in community activities				
Very important	9	38	109	47
Of some importance	50	42	99	43
Of little or no importance	24 ¹	20	22	10

Statistically significant difference ¹Chi square p-value < .05, ²FET p-value < .017 (n = 350)

Table O.3
Levels of importance allocated by HCPs by professional role.

Characteristic	Nurses		Doctors		Psych/Social workers		Other allied health	
	n	%	n	%	n	%	n	%
Education								
Very important	53	19	1	6	1	10	3	9
Moderately important	73	26	5	29	2	20	9	27
Not at all or a little important	156	55	11	65	7	70	22	64
Occupation								
Very important	16	5	2	12	1	10	0	0
Moderately important	86	30	7	41	5	50	18	44
Not at all or a little important	188	65	8	47	4	40	19	56
Emotional health								
Very important	224	78	12	71	9	100	20	64
Moderately important	58	20	4	29	0	0	4	13
Not at all or a little important	7	2	0	0	0	0	7	23
Self confidence								
Very important	183	82	8	76	9	100	20	59
Moderately important	49	17	3	18	0	0	11	32
Not at all or a little important	2	1	1	6	0 ²	0	3 ²	9
Family structure								
Very important	150	54	8	47	8	80	15	44
Moderately important	107	37	8	47	2	20	16	47
Not at all or a little important	26	9	1	6	0	0	3	9
Family relationships								
Very important	185	66	11	65	8	80	17	59
Moderately important	84	29	6	35	2	20	12	35
Not at all or a little important	14	5	0	0	0	0	2	6
Life stress								
Very important	185	65	8	47	8	80	2	6
Moderately important	91	32	9	53	2	20	10	32
Not at all or a little important	7	2	0	0	0	0	19	62
Money								
Very important	126	45	8	47	7	78	9	26
Moderately important	130	46	9	53	2	22	21	62
Not at all or a little important	26	9	0	0	0	0	4	12
Social support								
Very important	232	82	12	71	8	80	22	65
Moderately important	48	17	5	29	2	20	11	32
Not at all or a little important	3	1	0	0	0	0	1	3
Community engagement								
Very important	125	44	5	29	7	70	14	47
Moderately important	121	43	9	53	3	30	12	38
Not at all or a little important	37	13	3	18	0	0	5	14

Statistically significant difference ¹Chi square p-value < .05, ²FET p-value < .017 (n = 350)

Table O.4
Levels of importance allocated by HCPs by years in paediatric practice.

Characteristic	0-2 years		>2-5 years		>5-10 years		>10 years	
	n	%	n	%	n	%	n	%
Education								
Very important	12	23	18	24	11	16	16	10
Moderately important	12	23	18	24	16	24	45	29
Not at all or a little important	27	54	39	52	41	60	93	60
Occupation								
Very important	5	9	4	5	2	3	8	5
Moderately important	17	33	20	27	22	32	53	34
Not at all or a little important	30	58	51	68	44	65	93	61
Emotional health								
Very important	42	81	55	73	52	76	119	77
Moderately important	9	17	18	24	11	16	32	21
Not at all or a little important	1	2	2	3	5	7	3	2
Self confidence								
Very important	43	83	59	78	57	84	122	79
Moderately important	9	13	14	19	10	15	3	10
Not at all or a little important	1	2	2	2	1	1	2	1
Family structure								
Very important	29	56	37	49	33	48	88	57
Moderately important	20	38	33	44	30	44	50	32
Not at all or a little important	3	6	7	7	5	7	16	10
Family relationships								
Very important	36	65	49	65	41	60	103	67
Moderately important	13	30	22	35	25	37	44	28
Not at all or a little important	3	5	4	0	2	3	7	5
Life stress								
Very important	30	58	49	65	39	57	109	67
Moderately important	19	36	24	32	27	40	43	28
Not at all or a little important	3	6	2	3	2	3	2	1
Money								
Very important	22	42	33	44	7	37	72	47
Moderately important	24	46	38	51	20	54	68	44
Not at all or a little important	6	12	4	5	4	9	13	8
Social support								
Very important	38	73	59	78	58	85	123	80
Moderately important	14	27	15	20	8	12	29	19
Not at all or a little important	1	0	1	1	2	3	1	1
Community engagement								
Very important	17	33	23	31	36	53	79	51
Moderately important	26	50	37	49	26	38	60	39
Not at all or a little important	9	17	15	20	6	9	15 ¹	10

Statistically significant difference ¹Chi square p-value < .05, ²FET p-value < .017 (n = 350)