Family-centred care

for children with

Chronic respiratory disease:

A New Zealand Perspective

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Abstract

Introduction

Family-centred care (FCC) is proposed as best-practice within paediatrics facilitating positive outcomes for parents, children, health professionals and facilities. However, issues exist around the consistent implementation and definition of this philosophy of care. It is proposed that limited research, education, evaluation and understanding regarding the practical application attribute to this. Accordingly, the focus of this thesis was to assess the factors that impact on family-centred care for parents of children with a chronic respiratory disease.

Method

A two stage embedded mixed method approach was undertaken. Stage One involved a national benchmark survey of four paediatric facilities within New Zealand, and aimed to provide a national overview, and internationally benchmark, the integration of FCC within New Zealand's paediatric facilities. Stage Two utilised both quantitative and qualitative methodologies. The influence of coping, anxiety, depression and parental needs on parent's ability to participate in the care of their hospitalised child was explored through three tools the Coping Health Inventory for Parents, Hospital Anxiety and Depression Scale and the Needs of Parents Questionnaire. The qualitative stage of the study explored parental self-efficacy, coping and social support for parents managing their child's chronic respiratory disease.

Results

A total of eighty two nurses across the four centres completed the survey on family-centred care. New Zealand was found to be at a beginning stage in terms of the integration of family-centred care and behind international facilities within the United States, Canada and Italy.

A total of fifty one parents completed the three questionnaires. Overall parents were not experiencing symptoms of anxiety and depression and coped with their child's hospitalisation and chronic respiratory condition. Aspects of service delivery that were deemed important for parents to be able to cope, centred on child access, discharge and care. The aspect of service delivery that parents considered to be lacking was related to continual access to their child.

Twenty three parents were interviewed about managing their child's respiratory condition. Parents identified that the management of their child's chronic disease impacted on family life and their own self-management.. Parents felt an overwhelming sense of being on their own with the responsibility of their child's chronic disease; this was shaped by the level of predictability of the disease process.

Discussion

The study suggests that how effectively information is shared between nurses and parents and the degree to which health professionals value parental knowledge and expertise impact on parental participation and engagement with primary health services. While the level of parental responsibility experienced by parents managing their child's disease and lack of organisational support can negatively influence parental participation and thus FCC. There is evidence that a dichotomy exists within New Zealand between the nurse's perception of

family-centred care practice and parents' experiences. Findings also suggest when parent's knowledge and expertise are not respected or information needs are not appropriately met, parents feel isolated, less confident and disengage from the health service, thus impacting on their sense of responsibility and participation in their child's care. Moreover, a lack of organisational and health professional support around FCC implementation suggests the need to improve the integration of FCC within facilities and the education of health professionals in New Zealand. These findings are important as they suggest that parents of children with chronic respiratory diseases, health professionals and organisations within New Zealand are not experiencing the full benefit of a philosophy of care that can enhance outcomes and experiences

While these findings provide new knowledge on how well paediatric facilities in New Zealand support the concepts of FCC, it is the discovery of overwhelming responsibility experienced by the primary caregiver and reduced self-efficacy amongst fathers that is an original contribution to knowledge and provides the potential for future work.

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A bend in the road is not the end of the road... unless you fail to make the turn. ~Author Unknown

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Introduction and Background

The involvement of parents and family in the care of their hospitalised child has been strongly advocated and viewed as best practice (Espezel & Canam, 2003; Polly, 2004; Ygge & Arnetz, 2004). The foundation for family-centred care (FCC) practice within paediatric services is grounded in the belief that health professionals should treat families with dignity and respect, and the child's emotional and developmental needs are best met when families are given choices regarding involvement in, and provision of, services and planning of care (Dunst, Trivette, & Hamby, 2007; Shields, Pratt, Davies & Hunter, 2009). It is proposed that FCC can improve patient and family outcomes, enhance patient and family satisfaction, build on child and family strengths, boost professional fulfilment, reduce health care costs and lead to a more effective use of health care resources (Neff et al., 2003; Shields et al., 2009). Furthermore, it is claimed that FCC can encourage self-resolve, competence in decision–making, self-efficacy and additional improvements in intrapersonal and interpersonal behaviour characteristics (Shelton, Jeppson, & Johnson, 1987).

Although FCC is promoted as best practice within paediatrics by leaders and policy makers, issues still exist around a clear conceptual definition and consistent implementation of this philosophy (Franck & Callery, 2004; Ponte et al., 2003). Empirical evidence suggests these issues are related to the dearth of research into the practical application of FCC concepts along with evaluation of care delivery models and health care outcomes (Ahmann & Johnson, 2000; Bruce et al., 2002; Smith & Coleman, 2010). One major gap in the research is the significance of FCC in the treatment of chronic disease. Accordingly this thesis examines the relationship between FCC and chronic respiratory disease, not only from the perspective of families, but also from an organisational perspective nationally and internationally.

For this study the researcher drew on a definition from the Institute for Family–Centered Care's (2009) of FCC as

> *an innovative approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care patients, families, and providers. Patient-and family-centered-care applies to patients of all ages, and it may be practiced in any health care setting. Institute For Family-Centered-Care, (p.1)*

The remainder of this chapter provides the background to the prevalence and impact of disease, and specifically paediatric chronic respiratory disease, on individuals, families and economies, and explores the historical integration of FCC in the New Zealand paediatric health service. The chapter concludes with an outline of the thesis.

Impact on families of a child with chronic disease

The experience of a chronic disease poses many challenges for the child, their family/guardians and health professionals (Abbott, Cairns, & Davies, 2008; Bachman & Comeau, 2010; Dobbie & Mellor, 2008; Hovey, 2005). Children living with a chronic disease face many issues, such as disruption to education, increased hospitalisations for acute episodes and exacerbation of their chronic disease, all of which can contribute to poor psychological outcomes and possible social isolation (Abbott et al., 2008; Anthony, Gil, & Schanberg, 2003; Balling & McCubbin, 2001; Chernoff, Ireys, DeVet, & Kim, 2002; Schmidt, Petersen, & Bullinger, 2003). Parents describe the stress of dealing with time pressures, long term treatments and concerns over their child's health and future prognosis while also experiencing feelings of loss, social isolation and stigma (Abbott et al., 2008; Anthony et al., 2003: Fawcett, Baggaley, Wu, Whyte, & Martinson, 2005; Matuszewski & Clarke, 2003). Health professionals face challenges supporting families due to the complex issues that must be addressed when a child has a chronic disease (Dobbie & Mellor, 2008).

Many families have described difficulties due to the strains involved in managing their child's chronic disease. Many parents have never been shown how to manage the disease, handle their family's resources or cope with this type of situation (Williams et al., 1999). Children living with chronic diseases often require an abnormally large share of family resources, resulting in siblings feeling ignored and in some situations neglected, creating pressure for parents endeavouring to organise resources to manage the chronic disease (Yantzi, Rosenberg, Burke, & Harrison, 2001). Although parents of a child with a chronic disease may experience high levels of distress and impaired quality of life, research suggests that a greater participation by the family in care planning and management is beneficial because it will enhance their child's health outcomes (Boman, Viksten, Kogner, & Samuelsson, 2004; Goldbeck, 2006; NHC, 2007).

Chronic disease in a child can have a huge financial impact on the family as the parents' capacity to work is often limited. Families of children with chronic conditions have described higher out-of–pocket expenses and decreased maternal employment compared to other families (Lukemeyer, Meyers, & Smeeding, 2000). For a number of households the financial impact of insufficient health care coverage is a major challenge. Families have to make difficult choices regarding how they use their limited income, while making considerable sacrifices in other areas to guarantee satisfactory care for their child. In some circumstances, the means to pay for treatment is just not there, so a child potentially misses out on the appropriate care, resulting in adverse outcomes in their health, development and ability to function (Bachman & Comeau, 2010).

New Zealand people with chronic diseases have consistently reported problems with the price of health care and other related costs for their life and that of their family (NHC, 2007). The costs borne by the family incorporate direct costs such as visits to general practitioners and other health professionals

or specialists, medication, and aids and modifications: there are also indirect costs such as loss or reduction in income and lowered involvement in work and society, along with the physical and emotional toll on the family of managing the child's health (NHC, 2007; World Health Organization, 2002).

Chronic respiratory disease

The World Health Organisation (WHO) (2008) describes a chronic disease as one of long duration and generally slow progression. A fuller definition is given by the Council for Children and Adolescents with Chronic Health Conditions (CCACHC):

> *Any biologically-based condition; A condition lasting an extended period of time (three months or longer); A condition that brings about significant changes in the life of the child and family; A condition that requires more medical care from primary care and specialty providers than typically required by well child and acute illness visits (Council for Children and Adolescents with Chronic Health Conditions, 2011, p.3)*

The cost of chronic disease to each country encompasses direct costs (subsidising providers, pharmaceuticals, providing income support), underlying costs (capital and equipment), and indirect costs (reduced employment or social productivity) (NHC, 2007). Due to escalating financial and social costs within the health sector and society worldwide there is an increasing need to address chronic diseases (World Health Organization, 2006). These costs have prompted an international resolve to address this huge threat to health care sectors and societies (NHC, 2007).

Recognising the high prevalence of chronic disease, the WHO (2005) has described chronic diseases as the "health care challenge of this century" (cited in NHC, 2007, p. 1), and estimates that Canada and the UK will make a

loss of $8.5 billion and $32.8 billion respectively between 2005 and 2015 because of lost labour from deaths due to heart disease, stroke and diabetes (WHO, 2006). Similar social and health sector costs exist within New Zealand, where chronic diseases are responsible for greater than 80% of all deaths, account for up to 60% of the hospital workload and use up to 70% of the public sector health funds (NHC, 2007; Ryall, 2007). Therefore, individuals with chronic diseases use a wider range of health services more regularly while their disease creates barriers to independence and contributing to the workforce and society.

Amongst children, asthma is the most common chronic disease and is defined by frequent bouts of breathlessness and wheezing that fluctuate in severity and occurrence from person to person (Chiang, Huang, & Chao, 2005; Sales, Fivush, & Teague, 2008; Sterling & Peterson, 2003). Although asthma occurs in both developed and developing countries and has a relatively low fatality rate, 255,000 people died from asthma in 2005, and over 80% of these deaths were in low and lower-middle income countries (WHO, 2006). The WHO (2009) suggests that asthma is regularly under–diagnosed and under-treated, placing a significant burden on individuals and families, often triggering sleeplessness, daytime fatigue and school and work absenteeism, potentially restricting the affected individuals for a lifetime.

Compared to other countries in the Organisation for Economic Co-operation and Development (OECD), New Zealand has one of the highest documented prevalence rates of asthma in the world (Hodges, Maskill, Coulson, Christie, & Quigley, 1998). During the years 2002-2006, 22,869 paediatric admissions were related to asthma, accounting for 32.7% of all lower respiratory admissions in New Zealand (Craig, Jackson, & Yeo Han, 2007). As in other countries, the prevalence of childhood asthma in New Zealand has increased over the last twenty to thirty years, though hospital admissions have gradually declined (Craig et al., 2007; Hodges, et al., 1998). Throughout the period 2002-

2006, hospital admissions for asthma within New Zealand were highest for male children under five years of age who were of non-European descent living in the most deprived areas (Craig et al., 2007). Asthma admissions in New Zealand in this period were also marked by regional variations, ranging from 3.1 per 1,000 to as high as 7.6 per 1,000 (Craig et al., 2007).

Cystic fibrosis (CF) is the most common inherited chronic lung disease in children and young adults (Bartholomew et al., 1997; Gjengedal, Rustoen, Wahl, & Hanestad, 2003; Hodgekinson & Lester, 2002; Lomas & Fowler, 2012; Wong & Heriot, 2008). It affects approximately 70,000 people worldwide and is estimated to affect one in 3,000-3,500 babies born in New Zealand. At present there are more than 500 children and adults diagnosed with this condition in New Zealand (Cystic Fibrosis Association of New Zealand, 2011). This life-threatening progressive disease is caused by the mutation of a gene that disturbs the transportation of salt and water across cell membranes, resulting in the build up of thick mucus that blocks organs such as the lungs and pancreas, resulting in constant infections, dietary malabsorption and infertility (Gjengedal et al., 2003; Lomas & Fowler, 2012; Wong & Heriot, 2008). No cure is yet available; however, advances in diagnosis and management over the last three decades have increased the life expectancy for children with CF from six months in 1959 to approximately 37.4 years at present (Hodgekinson & Lester, 2002; Lomas & Fowler, 2012; Wong & Heriot, 2008). Improved life expectancy for these children is dependent on parental efficacy related to medical care access, physiotherapy and close monitoring for respiratory infection (Bartholomew, et al., 1997; Hodgekinson & Lester, 2002; Ziere & Hadjiliadis, 2011).

The need for a family-centred care approach to chronic disease

Due to the high medical costs and poor outcomes associated with chronic disease, it is considered essential that public health systems respond in order to maintain their viability. International and national literature suggests a better coordinated, family-centred and proactive health system for those with chronic disease is needed in order to better align their needs with what is offered by the

health system (NHC, 2007). It is therefore proposed that by developing evidence-based models, measures and plans for cost-effective interventions, and by adjusting health systems to respond to the need for effective management of chronic disease, health care for people with non-communicable diseases can be strengthened (WHO, 2008). Thus numerous countries throughout the world have been prompted to produce, test and assess new models of care, acknowledging the importance of making chronic disease a priority for strategic action (NHC, 2007). Despite international evidence that finds people with chronic diseases have an improved healthcare experience and better outcomes under these new models of care, like the Wagner Chronic Care Model, Innovative Care for Chronic Conditions and Kaiser Permanente, New Zealand has been slow to integrate them into practice (Bodenheimer, Wagner, & Grumbach, 2002; NHC, 2007).Thus, in 2007, the National Advisory Committee in New Zealand called for a comprehensive and focused research approach to address the needs of people with chronic conditions in order to improve effectiveness and efficiency of services.

Research by the NHC in New Zealand has identified that while living with the effects of a chronic condition enables patients and their families, whānau and carers to become proficient about identifying their needs, they feel that health professionals do not communicate well. It was further identified that the family/whānau need to be involved, and individuals' needs and culture should be recognised, while better links between mental and physical health need to be established (NHC, 2007). Therefore in 2007 a national policy was rolled out that was designed to support strategies to decrease chronic disease prevalence and improve care for people with chronic diseases. It was proposed that by involving family /whānau in appraising, care planning and managing their relative's care, inequalities could be reduced, access to health care could increase and outcomes could improve (NHC, 2007). However, in order to achieve this better long-term care, New Zealand needs to move to a new way of working in partnership with communities, individuals, organisations and

family/whānau. Thus research into the best way to support family/whānau needs to be undertaken (NHC, 2007).

A change of government in 2008 has resulted in a new health care initiative coined *Better, Sooner, More Convenient* (Ryall, 2007). One of the goals of this policy is to develop a high-quality patient-centred health system that cares about the wellbeing of New Zealanders (Ryall, 2007). A key principle is that patients should be at the centre of all health services; they should be in control of their own care and be able to make informed choices (Ryall, 2007). The present National government is working towards personalised healthcare with a patient-centred health system, where individuals are active partners with health professionals in the management of their own treatment and care (Ryall, 2007).

The integration of FCC into the New Zealand paediatric service

New Zealand has been somewhat of a pioneer with the integration of family involvement into the hospital system. Prior to 1942, children undergoing surgery to correct congenital deformities in New Zealand were nursed by their mother either at home or at another location in order to minimise the risk of cross-infection (Pickerill & Pickerill, 1945). In 1942 two plastic surgeons, Dr H.P. Pickerill & Dr C. Pickerill, from Wellington, recognised that the conditions in some of these homes were far from ideal, and these children still had a 25% chance of being cross-infected by other family members (Pickerill & Pickerill, 1945). This prompted them to solicit support from the New Zealand Health Department to develop a twelve bedded hospital. The Pickerills showed that cross infection rates did not increase when mothers were introduced into the hospital system to take on the care of their child. They discovered that by keeping the mother and child together there was an improvement in drug therapy, with children requiring less sedation and in a number of cases none at all. The Pickerills maintained that a mother and her baby were a biological entity and therefore needed to be treated as such in order to get the best results. With the Pickerills' research occurring some 14 years before the Platt Report was

published, these innovations were met with scepticism by the international medical and nursing professions, as it was thought that children were better off not having over-emotional parents present in the hospital (Shields & Nixon, 1998).

Historically, paediatric services in New Zealand were purchased from the government as part of general medicine and surgical services, and only became a speciality when paediatric surgical and medical services were purchased separately from adult services (Paediatric Society of New Zealand, 1997). The speciality of paediatrics developed in an ad hoc manner from the 1940s and was regarded by clinicians and funders at the time as unsustainable, prompting a national review of paediatric speciality services in 1997 titled *Through the Eyes of a Child* (Paediatric Society of New Zealand, 2002). This review generated nine key principles, the first of which was to be "child and family focused" (Paediatric Society of New Zealand, 1997). The following year, the New Zealand policy document *Child Health Strategy* (1998, p,vii) made its second key principle that child health and disability support services should be focused on the child/tamariki and their family/whānau." This document, produced under the auspices of the Minister of Health, Hon. Bill English, was intended to reflect the paediatric community's views on how to improve health outcomes for children/tamariki and their family/whānau, and became a key directive for the next decade. It has since been acknowledged that both New Zealand and the United Kingdom have led the way in developing national standards designed to achieve child-centred hospital services that concentrate on providing "excellent" and safe medical care and social support along with "excellent" and safe physical environments (Hill, Pawsey, Cutler, Holt, & Goldfield, 2011).

In 2002, due to concerns by some about the lack of clear acceptable national standards for children and adolescents receiving healthcare, The paediatric society of New Zealand, a multidisciplinary organisation of child health professionals from throughout New Zealand, drafted a set of thirteen

standards and audit tools for all healthcare settings including general practitioner services (Paediatric Society of New Zealand, 2002). Standard three within this document, *New Zealand Standards for the Wellbeing of Children and Adolescents Receiving Healthcare,* states that healthcare of children and adolescents should be family-centred, and all healthcare providers should assist a parent to stay with their child and accompany and support them during procedures (Paediatric Society of New Zealand, 2002). It was proposed that children and adolescents should be considered in partnership with their family and their cultural contexts, and all policy development and service delivery should reflect this (Paediatric Society of New Zealand, 2002). It was expected that in order to adhere to these standards, healthcare providers would have a written philosophy of family-centred care, and policy statements that required its implementation. It was also expected that parents would be included in care planning and supported to stay with their child at all times, with free accommodation and meals. Moreover, parents were to be involved in the strategic planning, evaluation of systems and service delivery, and the development of new initiatives in child healthcare (Paediatric Society of New Zealand, 2002).

Since then, in 2004, an international Taskforce on Health Promotion for Children and Adolescents, in and by hospitals and health services identified that although New Zealand was doing some things very well, there was still scope for improvement (Network., 2004). One of the key issues was a lack of a Charter of Children's and Young People's Rights in Health Care Services (Network., 2004). Through collaboration between the Children's Hospitals Australasia (CHA), a not-for-profit body for children's hospitals and paediatric units in Australasia, and The paediatric society of New Zealand, a Charter (*The Rights of Tamariki Children & Rangatahi Young People in Healthcare Services in Aotearoa New Zeraland)* was developed. This Charter was based on the United Nations Convention on the Rights of the Child, the New Zealand Code of Health and Disability Services Consumers' Rights, the Australian Charter of Healthcare

Rights and the Charter of the European Association for Children in Hospital (Andrews et al., 2004). It was proposed that this Charter would present positive approaches in the practical execution of rights for children and young people in health care services, health promotion and health education activities (Andrews, et al., 2004). This Charter includes eleven rights which aim to make sure children and young people receive healthcare that is appropriate to them and to their families/whānau. These rights are based on three broad principles, one of which is "the recognition that the family/whānau is the fundamental group in children's and young people's lives" (Andrews, 2004, p.6). The fifth right states:

> *Every child and young person has a right to be nurtured by their parents and family/whānau, and to have family/whānau relationships supported by the services in which the child or young person is receiving healthcare (Andrews, 2004, p. 12).*

It is stated in the Charter (2004, p.12) that this right will be accomplished by "actively facilitating participation by families/ whānau in decision-making, planning and the day to day care" of their child while in a healthcare service, therefore ensuring healthcare for children and young people is family/whānau–centred.

In New Zealand there are four tertiary hospitals that provide specialist paediatric services, and one that is a designated specialist paediatric hospital. Within these facilities the notion of FCC and the previously mentioned standards and Charter are claimed to underpin paediatric care. One District Health Board (DHB) states that their paediatric service aspires to promote and protect the rights of children and young people, and refers the reader to the *Charter on the Rights of Tamariki Children & Rangatahi Young People in Healthcare Sercices in Aotearoa New Zealand* (Canterbury District Health Board, 2003). This DHB also notes how their Family Advisory Council, formed in July 2010, works with the hospital and leadership staff to promote and improve family-centred care.

Another DHB claims that all its Children's Health services practise the principle of FCC, and it has used the Child Health Strategy (1998) to guide planning and setting goals and objectives (Southland District Health Board, 2010). The only designated paediatric facility in New Zealand makes reference to nurses providing FCC in its nursing vision and mission statements (Starship Hospital, 2010). This information is readily available to anyone who has access to a computer, possibly promoting an expectation amongst the general public of the level of care provided, but the exact nature of the FCC delivered is not made explicit.

Parents of children with chronic conditions have the expectation that they will have a high degree of participation in and control of their child's care because they have become very knowledgeable and proficient in the care of their child over time (Balling & McCubbin, 2001). Evidence suggests that if health care professionals respect and value the knowledge that these parents have, and facilitate an environment that is conducive to negotiation with both the child and caregiver about levels of involvement and participation, parent participation can be enhanced (Balling & McCubbin, 2001). However, research has also identified that different perspectives and expectations of FCC can exist between parents and health professionals (Smith & Coleman, 2010). Coyne and Cowley (2007) suggest parents have felt compelled to be with their child whether they wanted to or not because that was the expectation from nurses. This research also suggests that nurses believe parents can never truly be partners in care because nurses are the ones who control the boundaries of care. A study undertaken in New Zealand's only dedicated children's hospital, over ten years ago, identified that only 50% of parents recalled a nurse discussing any aspect of negotiation related to their child's care (Mulvay, 2001). This suggests that, like Coyne and Cowley's (2007) study, FCC as a philosophy may lack full integration on a day to day basis by health professionals in our health system. Clearly further research with parents and health professionals is needed to clarify how they can work collaboratively to deliver FCC.

It appears that the ideology of FCC as best practice is well entrenched within New Zealand policy, but it is unclear how well it is actually transferred into practice within paediatric health care facilities. As mentioned previously, one of the primary concerns regarding the philosophy of FCC is its applicability to practice (Lam et al., 2006; Pyke-Grimm, Stewart, Kelly & Degner, 2006). Shields et al., (2009) proposes that it is immoral for health professionals, institutions and services to endorse a model that is untested and possibly ineffective, and suggests that in order for models of care to be properly developed it is important that FCC is measured. Currently within New Zealand there is no research that has measured how well the philosophy of FCC has been applied to New Zealand paediatric services. Nor has there been a benchmarking of New Zealand's paediatric services, to gauge how well we as a whole are doing with the transference of philosophy into practice compared to other international facilities.

Therefore this research undertakes a benchmarking study to ascertain what stage New Zealand's major paediatric facilities are at in terms of implementing FCC, and how these facilities compare internationally. Further, in light of the evidence that continual parental responsibility for a child's chronic disease creates stress and has a huge psychological impact which can lead to parental depression (Farkas & Valdes, 2010; George & Vickers, 2007; Goldberg, Morris, Simmons, Fowler, & Levison, 1990; Streisand, Swift, Wickmark, Chen, & Holmes, 2005), this research investigates the links between partnerships in care and ways of coping, self-efficacy, anxiety and depression. It is hoped that findings from this mixed method research will assist with improving the collaboration between parents and health professionals in New Zealand, thus improving long–term outcomes for children living with chronic respiratory diseases, while lessening the burden for parents and health services.

The structure of the thesis is detailed below

Chapter 2: Literature review

  The literature surrounding the development and international progression of FCC is presented, in this chapter. The concepts of parental needs, coping, anxiety, depression and self-efficacy related to parental participation in caring for children's chronic disease are explored, and the rationale for undertaking this study is outlined.

Chapter 3: Methodology and methods

  This chapter presents the evolution of pragmatism and mixed method design, and provides the rationale for the use, in this study, of an embedded mixed method approach. This mixed method design involves two stages: stage one is a national benchmarking survey, while stage two is a semi structured interview and a survey pack comprised of four surveys. The process of the embedded mixed method design in this research is presented and the reliability and validity of the study design is discussed.

Chapter 4: Stage one findings

  This chapter presents the results from the FCC benchmarking survey undertaken with nurses in four New Zealand hospitals. These national results have been collated and then compared to international facilities.

Chapter 5: Stage Two: Part A-Quantitative findings

  This chapter presents findings from 50 parents who completed a survey pack that addressed key aspects of FCC: hospital design and policy, parental needs, coping, anxiety and depression. Correlations in the findings between parental needs, coping, anxiety and depression are shown.

Chapter 6: Stage Two: Part B-Qualitative findings

  This chapter presents the qualitative findings from 23 of the 50 parents surveyed, which have been analysed using an inductive approach and sorted into themes. The chapter concludes with a summary of the key findings.

Chapter 7: Discussion and Conclusion

This chapter synthesizes and integrates the findings from both stages, relating them to existing research and literature in the context of the Institute for Family and Patient Centred Care's four core concepts. Limitations and strengths of the study are discussed, and implications for practice and research are outlined.

The chapter concludes with the study's findings, highlighting those issues that were found to influence parental participation and thus FCC for parents of children with a chronic respiratory disease. Future research is outlined and recommendations proposed.

Chapter Two

Literature review

Introduction

This literature review is divided into three sections. Part one looks at the concept, development and international progression of family–centred care (FCC), and relevant literature is used to evaluate and discuss the effectiveness of this model of care. Part two presents and explores the perceptions of FCC from a family, nursing and organisational perspective. Part three introduces the concepts of parental needs, coping, anxiety, depression and self-efficacy and examines the relationship of these factors to parental participation and chronic illness amongst children. The chapter concludes with an overall summary of key findings from the existing research and a rationale for the present study.

History of FCC

FCC is based on the belief that for a child their family is a leading source of strength and support. As a concept it has been used to shape paediatric health care policies, programmes, facility design, and other day to day connections among patients, families, physicians and other health care professionals using a system wide approach (Johnson, 2000b). FCC has been postulated to lead to improved health outcomes and more equitable distribution of resources along with greater patient, family and professional satisfaction (Eichner & Johnson, 2003; Macnab, Thiessen, McLeod, & Hinton, 2000).

Practitioners of FCC recognize that parents and other close family members are experts in their children possessing essential information that can enhance their child's health care (Eichner & Johnson, 2003). By including families in hospital planning, evaluation and policy making children's care will be enhanced, while collaboration between families and professionals will shape best practice during hospitalisation (Macnab et al., 2000).

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The genesis of FCC has predominantly derived from research conducted by two British researchers, John Bowlby and James Robertson (Bowlby, 1960; Robertson & Robertson, 1989). Bowlby developed classic theories about maternal separation/deprivation while Robertson concentrated on mother and child separation due to hospitalisation (Jolley & Shields, 2009; Shields & Tanner, 2004). Between 1925 and 1950 accumulative evidence by a number of psychologists and psychiatrists working in the fields of child care added support to Bowlby's 1951 maternal deprivation theory (Bowlby, 1961). The majority of these studies were undertaken within orphanages or institutions and the findings were clear: when children are deprived of maternal care, their physical, emotional and social development is nearly always delayed, potentially forever (Bowlby, 1960). Bowlby proposed that the negative outcomes of maternal deprivation can differ in degree from partial deprivation to complete deprivation. Partial deprivation can result in acute anxiety, an excessive need for love and intense feelings of revenge, all of which can lead to guilt and depression, whereas complete deprivation can totally cripple a child's ability to form relationships due to the extra far-reaching effects on character development (Bowlby, 1960).

As a result of Bowlby's (1951) findings the British government in 1956 was prompted to commission a report. The conclusions of this report, known as the Platt Report (Platt 1959), stated that there should be unrestricted visiting for parents with children in hospital, there should be opportunities for parents to room in with their child and all medical and nursing training should recognise and promote the importance of the emotional needs of children (Ministry of Health, 1959; Shields & Tanner, 2004).

Since then and over the last four decades FCC has continued to evolve and develop as a result of accumulating evidence that emphasises the adverse effects of hospitalisation for both children and their parents (Coyne, 2007;

Eicher & Johnson, 2003; Johnson, 2000b). Initially FCC had its roots in the consumer and family support movements that began in the 1960s when changes in healthcare developed, and patients and families started looking for more control over their care (Johnson, 2000b). During this time women were seeking changes in maternity care as they questioned the high-tech methods involved in childbirth and insisted that fathers be allowed in the delivery room (Johnson, 2000b). Similarly, families of children with chronic diseases and/or disabilities were concerned about limited visiting and the lack of psychosocial support for children in hospitals (Johnson, 2000b). It was these women and family members advocating for more involvement in their child's care that provided the leadership for change within paediatrics (Johnson, 2000b; MacKean et al., 2005). During this time changes in visiting hours developed and mothers found themselves spending hours at their child's bedside with nothing to do. As a result mothers took an increasing role in caring for their hospitalised child, and the notion of hospital-based FCC emerged (Lee, 2004).

Since then the extent to which families have been involved in the care of their hospitalised child has varied depending on the culture and era (Lee, 2004). However, federal legislation in the United States of America in the late 1980s and 1990s provided additional support to the importance of family-centred principles (Eichner & Johnson, 2003). It was in a report by Shelton, Jeppson, and Johnson in 1987 entitled *Family Centred Care for Children with Special Health Care Needs* that the core concepts of FCC were initially articulated within the United States and a seminal definition of FCC was produced (Harrison, 2010; Johnson, 2000b). The overall purpose of this project was to develop a nationwide program to improve the implementation of a family centred approach to care for infants, children and adolescents with special health care needs (Shelton et al., 1987). Eight key elements designed to underpin a family-centred approach to care for children with chronic illnesses and special health care needs were identified:

1. Recognition that the family is the constant in the child's life while the service systems and personnel within these fluctuate

2. Facilitation of parent/professional collaboration at all levels of health care

3. Sharing of unbiased and complete information with parents about their child's care on an ongoing basis in an appropriate and supportive manner

4. Implementation of appropriate policies and programs that are comprehensive and provide emotional and financial support to meet the needs of families

5. Recognition of family strengths and individuality and respect for different methods of coping

6. Understanding and incorporating the developmental needs of infants, children and adolescents and their families into health care delivery systems

7. Encouragement and facilitation of parent to parent support

8. Assurance that the design of health care delivery systems is flexible, accessible and responsive to family needs

(Shelton et al., 1987)

It was these eight key elements that formed the U.S Surgeon General C. Everett Koop's national agenda (Johnson, 2000b) in Washington D.C in 1987 (General Koop, 1987).

At a similar time in England, Anne Casey, a paediatric nurse, originally from New Zealand, developed a partnership model of paediatric nursing. Up to this point no clear conceptual model to facilitate parent participation had existed (Coyne & Cowley, 2007). As one of the first attempts to develop a model of practice explicitly for child health nursing, its philosophy was founded on the notion that the best people to care for the child are the family, with support from assorted professionals (Casey, 1993). At the time Casey's partnership model was accepted by nurses and nurse educators as the best way to structure nursing interventions for parents and children, resulting in the view that families were to undertake the care for their hospitalised child (Coyne & Cowley, 2007).

Meanwhile in the United States, a group of health professionals and parents who had been influential in the 1980s FCC movement gathered in Washington in 1992 to assess the state of FCC, and put a plan in place to develop a self-sufficient infrastructure to support FCC theory that would be unaffected by alterations in political priorities and funding crises (Johnson, 2000b; Mitchell, 2005). This resulted in the development of the Institute for Family–Centered Care based in Maryland, a non-profit organisation that has contributed to numerous major health initiatives within the United States and now provides leadership, training, technical assistance, policy development and advice to healthcare programme planners and decision makers based on four core concepts respect and dignity, information sharing, participation and collaboration (Johnson, 2000b; Jolley & Shields, 2009). Similar organisations have developed in other countries, such as the European Association for Children in Hospital, Children in Hospital Ireland and the Australian Association for the Welfare of Children's Health (Jolley & Shields, 2009).

To date, a large amount of the research and literature regarding FCC has originated from the UK and the USA, although an awareness of the basic elements of FCC has been identified in non-developed countries (Irlam & Bruce, 2002; Shields & Nixon, 2004). However, a systematic review of the literature on FCC in 2009 claims that most of this extensive literature is anecdotal, including descriptions, stories and reports instead of research (Shields et al. 2009). Over the last 25 years, FCC theory with its many aspects has been called a multitude of terms such as: parental participation, parental involvement, partnership in care, parent-staff partnership, child and family-centred care, family participation, family centred practices, family centred services and family–centred help giving, care by parents and family nursing (Coleman, Smith & Bradshaw, 2003; Dunst et al., 2007; Kristensson-Hallstrom, 2000; Polly, 2004). However, regardless of this extensive research exploring the theory of FCC, and the families' and nurses' personal experience of FCC, no clear-cut definition or links to the different terminology in common use has been made (Coleman et al., 2003; Mikkelsen & Frederiksen, 2011).

Nevertheless, over the years parents have come to expect to be heavily involved in the physical, emotional and psychological care of their hospitalised child while also receiving psychosocial support for themselves (Jolley & Shields, 2009; Shields & Kristensson-Hallstrom, 2004), and it is also expected that nurses will use this philosophy of FCC to underpin their attitude toward clinical practice (Bradshaw, Coleman, & Smith, 2003). However, even though expectation of such a term "partnership" assumes that a nurse-parent relationship exists, research evidence over the last four decades suggests that nurses have difficulty supporting and facilitating parents' participation, while parents also experience trouble determining nurses' expectations (Coleman et al., 2003). Lee (1998) proposes that this problem is related to the fact that the concept of partnership has not been adequately defined or based on research evidence, and no formal assessment framework exists. This view is supported by Coyne (2007), who suggests that even though "partnership" is viewed as the accepted

norm, the philosophy has not been thought through in terms of relationships, benefits and challenges. Moreover, there is insufficient research into the views of children, parents and nurses about participation in hospital care (Coyne & Cowley, 2007).

It has been proposed that in order to practise in a family-centred way, health services need to change from a professionally–centred model to a collaborative model that acknowledges the family's participation as fundamental to the child's care (Ahmann & Johnson, 2000). However, Shields (2004) has questioned whether the pendulum has swung too far, and as a result of parents expecting to be involved in their child's care we do not give them any choice. This concern is supported by Macnab's (2000) study in Britain that looked at parental views on the adequacy and extent of family centred care practice; it was found that it is important that health professionals ensure that FCC is appropriate at meeting the individual needs of each family. These findings suggest that health professionals need to recognize that parents may vary in the degree to which they want to participate in the care of their child, and by asking for or assuming more involvement health professionals may in fact cause undue stress on parents. Therefore it is important that health professionals assess the individual needs of each family (Macnab et al., 2000).

Moreover, research to date with paediatric nurses has also identified that despite extensive knowledge and awareness of the importance of the elements of FCC, this is not enough to guarantee that it is actually practised (Mitchell, 2005). This was supported by Hallstrom's (2002) study which found evidence of inconsistencies between the declared aims and parents' actual experience of their level of participation in decisions during their child's hospitalisation. It has been proposed that in order to reduce the gap between the integration of FCC theory and practice, a clear definition needs to be developed along with tools to measure parents' and service providers' beliefs about the advantages, disadvantages and requirements of participating in this approach (Coleman et

al., 2003; King et al., 2003). This is of particular importance as more children are living longer, with increasingly complex and chronic diseases, and there is a widespread recognition that the existing medical model, which is designed primarily to manage acute and infectious diseases, is inadequate for child health-care professionals and families (NHC, 2007; World Health Organisation, 2008). In response to this knowledge, FCC has been regarded as best practice in child health-care settings (MacKean, et al., 2005). However, if the full potential of this philosophy is to actually benefit children, families and health professionals in the 21st century there appears to be a number of barriers and challenges to overcome (Bradshaw et al., 2003).

Advantages/disadvantages of FCC

It has been proposed that FCC benefits both families and health systems. When organisations adopt this model, relationships are valued, better outcomes are produced and consumer satisfaction is increased, leading to increased job satisfaction for health professionals (Ahmann & Johnson, 2000). Moreover, professionals who work in collaborative relationships benefit from parental experiential knowledge which they can use in conjunction with their professional expertise to identify the best interventions for the family (Steele, 2002). This knowledge can then be shared with other families in similar situations thus providing support (Steele, 2002).

However, despite identified advantages and the enthusiastic uptake of this model of care by academics, practitioners and educationalists, critics suggest there is inadequate evidence to endorse the use of family-centred practices (Carter, 2008; Dunst el al., 2007). This is supported in a meta-analysis undertaken by Shields et al. (2007) that assessed the effects of FCC models for children in hospitals. The authors concluded that a dearth of eligible studies meant it was difficult to determine the effectiveness of FCC compared to other care models (Shields et al., 2007). Moreover, despite being a mode of patient care that is debated in the literature and generally supported by institutions, FCC is viewed by some as one which is difficult to implement (Bruce et al., 2002;

Franck & Callery, 2004; Galvin et al., 2000; Petersen, Cohen, & Parsons, 2004). A review of studies conducted by Corlett (2006) into the negotiation of parental roles within FCC identified that the reality in practice does not necessarily equal the rhetoric. It was shown across these studies that the negotiation process may occur in an ad hoc way with nurses having set expectations of the level and type of parental involvement (Corlett & Twycross, 2006a). This is similar to the findings from Lee's (2007) study that explored stress in parents of children with chronic heart disease, where mothers found partnership to be practised in a variety of ways and approached in an ad hoc manner. Mitchell (2005) proposed that it was the nurses who elect to adopt or otherwise the attitudes and practices inherent in a nursing model.

Several studies have addressed and explored the barriers to and weaknesses of implementing FCC, the relational and attitudinal issues that compromise its effectiveness, and the number of ways in which FCC is not being achieved (Shields, 2011; Shields et al., 2006). King et al.'s (2003) study that measured parents' and service providers' beliefs about participation found service providers and parents within this study believed it was not practical or feasible to implement FCC. King et al identified a lack of familiarity, experience or training of service providers, and lack of parental understanding and awareness of expectations held of them, as the key issues. This finding is further supported by Bruce's (2002) study that explored health professionals' perceptions and practices of FCC. Health care providers cited inadequate education in relation to understanding and implementing the concepts of FCC into practice, and the lack of a shared understanding and commitment to FCC among health professionals and families as prompting the difficulties with implementation (Bruce et al., 2002). Further, Bradshaw (2003) suggested that while some professionals may be knowledgeable about FCC they do not perceive it as important, and therefore practise it minimally or erratically compared to others who are fully immersed in the breadth and depth of the philosophy (Bradshaw et al., 2003). This creates a patchy implementation of a

model of care that requires full support by all to ensure that it is delivered in a comprehensive manner.

Despite recognition that parental participation in their child's health care reduces stress and anxiety, Shield et al. (2009) suggest that in fact there may be potential disadvantages to this approach of care as some families may experience additional stress and anxiety because the expectation to care for their child in hospital may be beyond their expectations and capabilities (Shields et al. 2009). For some parents this expectation of hands on care leaves no room for families to take a break or have some respite, constraining their lifestyle and potentially increasing stress (Tong, Lowe, Sainsbury, & Craig, 2009). This view was supported by the mothers in Lam's (2006) study who had to rearrange their daily living schedule in order to stay with their child, while parents in Steele's (2002) study talked about how parents used the time away from hospital as an opportunity to talk, but health professionals underestimated the importance of having respite. It has also been identified that a lack of information about roles and levels of involvement adds to parents' feelings of anxiety and fear (Coyne & Cowley, 2007). Thus it has been recommended that health care providers are mindful that not all families are able emotionally or physically to embrace the demands of FCC (Corlett & Twycross, 2006a; Smith & Coleman, 2010). Additionally, empirical evidence suggests that other obstacles to executing this partnership between staff and parents exist, which include the lack of understanding of FCC concepts, lack of robust organizational support for FCC and its principles, and staff member perceptions that working collaboratively with families is either incompatible with or a risk to their professional identity (Galvin, et al., 2000; MacKay & Gregory, 2010; Newton, 2000). Therefore, because of the potential for increased frustration and dissatisfaction due to this mismatch between what parents desire and the level of participation offered by professionals, it is important that organisations understand consumers' needs and wishes (Carter, 2008; Steele, 2002).

In summary, although FCC has been recognised as best practice for children in hospital, research suggests that a dearth of evidence to determine its effectiveness and the difficulty of integrating it into practice remain problematic. Research indicates that a practice theory gap exists, where inconsistencies between what is proposed should happen, and what parents actually experience, is occurring. Moreover, it is acknowledged in the literature that it is difficult to implement FCC when parents are unaware of what is expected of them and health professionals lack familiarity, experience or training in this model of care. Research also suggests that this model of care may actually be disadvantageous to parents, as families may experience increased stress and anxiety when they are expected to be involved in the care of their child over and above their expectations or capabilities. Thus as FCC is complex, relational, dynamic and subject to internal and external factors, there is a need for better, more rigorous, valid research (Carter, 2008; Jolley & Shields, 2009).

Perceptions of Family–Centred Care

This section discusses the literature on family, nursing and organisational perceptions of FCC and the issues and challenges surrounding the implementation of this model of care. The literature included addresses and discusses parental knowledge and expertise, parental obligation, health professionals' workload, collaborations and role negotiation.

Parents' perceptions

Within the literature perceptions of parental identity, obligations to their children and expectations and responsibilities related to their parental role are all discussed as factors impacting on parental participation in FCC. A sense of parental duty or obligation was identified in the literature as a driver for parental participation. For some parents it was their duty or "moral imperative" as a parent to be involved in the care of their hospitalised child as this was crucial for their child's emotional and physical wellbeing (Coyne, 1995; Polly, 2004; Pyke-Grimm, Steward, Kelly, & Degner, 2006). For others it was important to be involved in order to maintain their parental role and preserve a routine for their

child (Blower & Morgan, 2000). This duty or obligation to participate in their hospitalised child's care has been shown to cause stress as parents try to balance being there for their child with family, occupational and personal roles (Coyne & Cowley, 2007).

Evidence suggests that levels of parent participation in FCC can be related to how parents perceive the professionals' expertise. Parents will engage in the care of their hospitalised child when they have concerns about the professionals' ability. Evidence suggests that parents participate in the care of their hospitalised child when they believe that professionals do not understand their child's specific needs, and they view themselves as being the expert with specialist knowledge of the child, particularly in situations of long term diseases (Coyne, 1995; Hallstrom, Runesson & Elander, 2002; Lam, Chang, & Morrissey, 2006; Pyke-Grimm et al., 2006). Conversely, there is evidence to suggest that parents may be reluctant to participate in the technical aspects of their child's care because of their perceived lack of knowledge. It has been recognised that in certain situations such as admissions, learning their child's diagnosis and alterations in their child's condition and treatment, parents lacked the resources to manage the situation or ask for help; in these circumstances it became the nurses' job to recognise the situation and take over the responsibility for the child's welfare (Coyne & Cowley, 2007; Hopia, Tomlinson, Paavilainen, & Astedt-Kurki, 2005). Exceptions were noted amongst parents of chronically ill children who considered themselves proficient in particular aspects of nursing care and therefore they were prepared to continue providing this care (Coyne & Cowley, 2007).

For some parents the relationship with healthcare professionals determined their engagement in FCC. Evidence suggests that parents wished to engage in collaborative relationships with health professionals, and when these occurred parents experienced increased parental satisfaction and participation (MacKean, et al., 2005; Pyke-Grimm et al., 2006). However, it has also been

identified that not all parents were able to participate in a collaborative arrangement; for some parents their perceived lack of expertise inhibited their involvement in care and led to them taking more of a passive role (Fawcett et al., 2005). However, it was postulated by the authors that cultural factors may have been influential in these parent's levels of participation.

For others, parental participation can stem from the concern about health professionals' workload. Parents have described having to maintain a vigilant bedside presence to ensure that their child's needs are met because nurses were too busy to be able to provide the continuous care that the parents could (Balling & McCubbin, 2001; Coyne & Cowley, 2007; Lam et al., 2006; Ygge & Arnetz, 2004). However, some parents have identified that remaining vigilant and engaged in parental participation is made difficult with inadequate organisational facilities such as sleeping arrangements, hygiene facilities and parental meals (Lam et al., 2006). In certain situations this can contribute to parents having to take time away from their child's bedside.

A number of studies have looked at parents' attitudes about their individual roles and identified that parents are interested in providing caring, emotional support for their child but want to leave the "nursing duties" to the nurses (Coyne & Cowley, 2007; Hopia et al., 2005). However, other evidence over a number of years suggests parents actually wish to participate at different stages and to varying degrees (Affleck, Tennen, Rowe, & Higgins, 1990; Kristensson-Hallstrom, 1999; MacKean et al., 2005). Role negotiation in FCC involves an open relationship between the nurse, child and parents whereby caring roles are established. It is essential that the nurse, child and parents negotiate their prospective roles and positions when discussing care arrangements as this provides the context for care. For example a family living with a child who has a serious chronic disease may want to use the hospitalization as respite care. Yet the parents of a child admitted for the first time may wish to be involved at every stage. Thus each family's situation

presents unique circumstances which shape their role and relationship with the nurse and determines whether real partnership develops (Newton, 2000).

However, despite negotiation of roles being an integral part of FCC, evidence has identified that role stress develops due to a lack of clear role negotiation (Coyne & Cowley, 2007; Ygge & Arnetz, 2004). In the literature parents described the concept of "vague boundaries" where they had trouble finding a balance between their role and that of a nurse because they were unsure what fell into the domain of nursing (Blower & Morgan, 2000; Ygge & Arnetz, 2004). Difficulties in forming partnerships also emerged where parents felt that nurses had different perceptions of what the roles entailed, and nurses' paternalistic attitude and lack of willingness to engage in negotiation meant parents were unable to increase their participation (Blower & Morgan, 2000; Corlett & Twycross, 2006b). Conversely, for some parents a lack of negotiation meant that they ended up being more involved in the care of their child than they wished (Blower & Morgan, 2000).

There have been a number of studies that address the concept of parental role alteration related to a child's hospitalisation and have identified that alterations in the parental role are one of the leading causes of stress for parents with a hospitalised child (Board, 2004; Board & Ryan-Wenger, 2002; Corlett & Twycross, 2006a; Ygge & Arnetz, 2004). It has also been noted that role deprivation can in fact have lasting implications for children, as parents experience feelings of failure and hopelessness which impact on their ability to care for their child in the long term (Coyne, 2007).

All of these research findings suggest that just having the desire to participate at a certain level of care is not necessarily enough to ensure that a parent is able to participate to the level they choose.

Nurses' perceptions

Professional (education, position) and personal (age, marital and parental status) characteristics of health personnel have been consistently identified over the years as having an effect on parental participation and FCC (Brown, Pearl, & Carrasco, 1991; Daneman, Macaluso, & Guzzetta, 2003; Gill, 1993; Seidl, 1969; Valentine, 1998) . It is proposed that those educators and administrators who are potentially older, more experienced and have less direct contact with families, have a more positive attitude about parental roles (Daneman et al., 2003; Dunn, 1979; Dunn, Reilly, Johnston, Hoopes & Abraham, 2006; King et al., 2003). Moreover, experts and those with many years of experience are able to call on a repertoire of successful relationships and positive experiences with parental participation which enables them to see parents as integral members of the child's family (Gill, 1993; King et al., 2003). In contrast, staff nurses who have more direct contact with the family/parent experience a less positive outlook as a result of having to deal with the demands of parents while struggling with limited resources, increased patient acuity and staff shortages (Dunn, 1979). Furthermore, staff nurses are often less experienced, younger than parents, and may perceive parental knowledge as a threat to their own knowledge and professionalism (Valentine, 1998). These findings have since been challenged by Young et al'.s (2006) study where nurses who had more experience were significantly less likely to agree that nurses were sensitive to parental needs.

Empirical evidence suggests that nurses hold set assumptions about the level and type of appropriate parental participation (Blower & Morgan, 2000; Coyne & Cowley, 2007; MacKean, Thurston, & Scott, 2005; O'Haire & Blackford, 2005; Polly, 2004; Shields, Pratt & Hunter, 2006). Findings suggest that even though nurses recognised that participation could put unrealistic expectations on parents because of other family obligations, care of dependent siblings and work responsibilities, nurses still assumed that parents would participate because it was the accepted norm (Coyne & Cowley, 2007; O'Haire & Blackford, 2005). The literature also suggests that some nurses view

themselves as facilitators rather than doers and actually expect the parent to be the leader in the care of their child (Coyne, 2007; Coyne & Cowley, 2007; MacKean et al., 2005). However, these findings have been challenged in other studies where nurses were concerned about handing over the power of care to the child's parents as it threatened their expert status (Polly, 2004; Steele, 2002). Other nurses have stated that they did not expect parents to participate because they believed what needed to be done was a nursing role; they felt that parents also viewed the child's care in a similar fashion and therefore would not expect to participate (Blower & Morgan, 2000). This indicates that despite parent participation being researched over many years and espoused as best practice, there appears to be a need for nurses to understand parents' wishes better and renegotiate roles regularly.

The literature also suggests that there are challenges to the philosophy of FCC when instead of collaboration, nursing coercion prompts parents to conform to a particular role that complies with nurses' expectations. It has been identified that nurses label parents "good" or "bad" depending on their levels of involvement, and will reward or punish, with time and support, depending on the label (Coyne & Cowley, 2007; Lee, 2007; O'Haire & Blackford, 2005). This finding prompted O'Haire (2005) to propose that parental participation cannot be negotiated where nurses are reluctant to communicate with difficult families. Furthermore, evidence indicates that having to "play the game" and be involved in the care of their child according to nurses' wishes places a huge stress on parents as they try and stay in favour, thus ensuring that their child receives the care they should (Coyne, 2007; Hallstrom et al., 2002; Shields et al., 2006; Steele, 2002; Tong et al., 2009). Again this highlights the need for research into nurses' perceptions, and the adoption of FCC and collaborative partnerships within paediatric organisations.

Organisational perceptions

Altering the paradigm of care to a patient-centred model is a substantial change that requires the leadership and participation of the senior management team. It is the management team that establishes the mood for the organisation, makes alterations a priority and authorises structures critical to the implementation of a new model (Ponte, et al., 2003). A patient-centred model of care is based on partnerships that are equally valuable to healthcare professionals, patients, and families, while the consequences for planning, delivery and evaluation of care under this model are enormous (Ponte, et al., 2003). FCC is considerably different from the biomedical model of care, which is structured around the needs and wishes of physicians and other healthcare professionals. For most hospital based organisations, restructuring healthcare around the needs of patients and their families is a massive challenge, requiring a significant change to a long existing culture (Ponte et al., 2003). Although most leaders in healthcare willingly support the philosophy of FCC, they often underestimate the commitment and significant adjustments needed to adopt a truly patient centred approach (Ponte, et al., 2003). Therefore research into the value of FCC practices, and the effect of FCC approaches on deployment of healthcare services and outcomes, needs to be undertaken so that healthcare leaders have data to support the decisions they make around allocation of resources (Ahmann & Johnson, 2000).

It has been suggested that the impetus for adopting the FCC approach amongst organisations today is driven more by social and economic factors as opposed to the historical concerns for welfare (Coyne & Cowley, 2007; MacKean et al., 2005). In healthcare such terms as efficiency, cost–effectiveness and business plans are commonly used, resulting in a growing focus on achieving more with fewer resources. Thus it is claimed by some that organisations may feel pressured into adopting FCC as a way of shifting the responsibility of care onto families to save money (MacKean et al., 2005). Nurses have acknowledged that they depended on parents to organise and

deliver care, suggesting that parent participation has been more about administrative efficiency than consumer empowerment, while parents have felt pressured to stay and deliver care for their child (Coyne & Cowley, 2007; Shields & Nixon, 2004). However, other evidence disputes this, suggesting that healthcare professionals do acknowledge the importance of allowing parents to choose the nature of their involvement, while also appreciating how important parents are in helping them interpret their child's condition (Mitchell, 2005; Polly, 2004).

It has been proposed that a collaborative relationship between parents, health professionals and organisations arises from the joint resolve of all participants (MacKean et al., 2005). However, evidence suggests that the role each partner performs and the resulting outcomes of partnerships are not always equally determined, as sometimes the actual reality of a collaborative relationship is in fact the transfer of responsibility of care from nurses to parents (MacKean et al., 2005). Alternatively Shields and Nixon (2004) suggest that parents cannot be considered by health professionals as equally integral to the FCC model when nurses prefer to work with children more than parents. Despite these barriers and challenges to this model of care, there is still a strong belief among organisations and consumers that the principles of FCC lead to benefits for both families and service providers (King et al., 2003). However, it does seem important that the viewpoint of parents should be considered in order to understand the reasons why they may or may not wish to seek participation in certain aspects of care (Coleman et al., 2003).

In summary it appears that parents expect that they will participate in their child's care as it is critical for a child's emotional and physical wellbeing. The research suggests that levels of parental participation are related to a variety of parental and nursing factors such as parental expertise and knowledge, parental obligation or duty, workload of health professionals, positive and negative collaborations and negotiation of expectations and roles between

parents and nurses. Moreover, the research indicates that support by nurses of FCC is influenced by their demographics and that nurses may reward or penalise parents with time and moral support according to how well parents comply with their personal expectations. Evidence also suggests that the drive for organisational adoption of this model of care may be financially and socially driven, rather than arise out of concern for the welfare of children and families.

Impact of Parental Needs, Coping, Depression, Anxiety and Self-efficacy on Participation

A parents ability and willingness to participate in a FCC model of care is dependent on their personal circumstances and psychological wellbeing (DeMore, Adams, Wilson, & Hogan, 2005; Farkas & Valdes, 2010; Jaser, Whittemore, Ambrosino, Lindemann, & Grey, 2009; Wong & Heriot, 2008). Parental depression and anxiety has been associated with reduced self-efficacy and poor management of their child's condition (Farkas & Valdes, 2010), while unmet parental needs may result in increased anxiety and reduced confidence. Therefore the focus of this section is on reviewing research in relation to parental needs, coping, depression, anxiety and self–efficacy, and the impact these concepts have on parental participation in the management of a child with a chronic condition.

Parental needs

Review of the literature revealed the importance of addressing parental needs. If the needs of parents are met they are more capable of participating in the partnership of care and support of their child and more likely to do so (Farrel, 1989; Sloper, 1996). It is thought that parents' needs are considerable, depending on their child's illness and how this illness is experienced (Coyne, 2007; Hallstrom & Elander, 2001; Hallstrom, Runesson, & Elander, 2002). Additionally it is assumed that care provided to parents will be based on their needs; however, the concept of need is difficult to define as parents and health professionals may have different perceptions of these needs (Hattstrom et al., 2002) These problems support the view that research with parents and

professionals on perceptions of parental needs is important in order to identify what care by professionals is appropriate for parents.

To date, the majority of the research into parental needs has evaluated different aspects of information and the implications for partnership of care when the needs are met or not by health professionals (Fisher, 2001; Hallstrom et al., 2002; Hopia et al., Hummelinck & Pollock, 2006; Lam et al., Lyte, Miles, Keating, & Finke, 2005; Matlby, Kristjanson, & Coleman, 2003; Rosenthal & Biesecker, 2001). Most parents view the need for information concerning their child's diagnosis and prognosis as the top priority (Fisher, 2001; Hummelinck & Pollock, 2006; Rosenthal & Biesecker, 2001). It is suggested that this type of information reduces parental anxiety and feelings of uncertainty while empowering parents to participate in their child's care (Hummelinck & Pollock, 2006; Lam et al., 2006). Information enables parents to regain control of the situation and engage in better partnerships with professionals (Fisher, 2001); however, concerns with the timing and type of information given to parents by health professionals are consistently mentioned in the literature as problematic for parents (Fisher, 2001; Hummelinck & Pollock, 2006; Lyte, Milnes, Keating, & Finke, 2005). Fisher (2001) identified that parents experience issues with obtaining information, being given insufficient information, receiving information too quickly and being given inaccurate information. The consequences of these issues have been noted to increase anxiety and insecurity, particularly for parents whose child has a chronic disease, while inconsistent and contradictory information undermined parental confidence in health professionals (Hummelinck & Pollock, 2006).

The need for partnership is also recognised as a priority for parents. Studies identified specifically the need for parents to participate in planning and decisions concerning their child's care and treatment (Balling & McCubbin, 2001; Hallstrom et al., 2002; Hodgekinson & Lester, 2002; Lindstrand, Brodin, & Lind, 2002). A study by Shields, Hunter and Hall (2004) that looked at the

differences between parents' and staffs' perception of parental needs identified that both ranked first in order of importance the need to trust. Thompson (2003) found that the development of trust was in fact met when parents believed in the technical competency of the staff. Conversely, security was the most prominent need during hospitalisation in an earlier study by Hallstrom (2002). In this study it was found that the need for security for these parents involved two themes: security for the parent and mediating security for the child. Like the need for trust, the need for parental security was derived from parents' need for competent health professionals. It is proposed that when parents and close relatives are actually given attention from professionals with the necessary expertise and competence in medicine, nursing, child development and emotional and family support, they feel more supported and the potential to fulfil their needs rises (Hodgekinson & Lester, 2002; Scharer, 2002; Sterling & Peterson, 2003). In summary, research suggests that parents prioritise the need for information, the need to trust and the need to participate in planning and deciding their child's care, and when these needs are met they feel more capable and are more likely to participate in the care and support of their child.

Coping

It is recognised in the literature examining chronic disease in children that parental coping has an impact on their participation in medical decision-making in health care, while also having an impact on self-management for those with a chronic disease (Schmidt, Petersen, & Bullinger, 2003; Sloper, 1996; Staab et al., 1998; Wong & Heriot, 2008). Consequently it is suggested that a parent's coping behaviour can determine levels of efficacy in managing their role as a parent along with participating and assisting in family adaption when their child has a chronic disease (Cayse, 1994; Melnyk, Feinstein, Moldenhouer, & Small, 2001; Wong & Heriot, 2008).

Coping can be defined as a self-regulatory process of continually altering cognitive and behavioural efforts to cope with particular external and internal demands that are judged challenging or beyond the resources of the person

(Lazarus, 2000). Coping is commonly defined from the position of the individual in stress and therefore is distinguished from actualised adaptive behaviour. According to Lazarus and Folkman (1984), coping can manifest as emotion focused (aimed at adapting the emotional reactions to problems) or problem focused (aimed at easing the problem). These two forms of coping can either impede or facilitate each other. Coping is an active force which affects the present and future and is influenced by people and the environment. Coping is also viewed as the behaviour that protects an individual from being psychologically harmed by a challenging social experience (Pearlin & Schooler, 1978).

The research on chronic paediatric conditions identifies that parents utilise both positive and negative coping strategies and these strategies impact on them, their levels of participation and thus their child (Cashin, Small, & Solberg, 2008; Hodgekinson & Lester, 2002; Knafl, 1985; Patistea, 2001; Wong & Heriot, 2008).

Positive coping

It is understood that an individual who is optimistic assumes that their actions will be successful in achieving a positive outcome; this prompts them to continue striving toward this outcome, whereas an individual who is not optimistic disengages from action and gives up striving (Lamontagne, Hepworth, Salisbury, & Riley, 2003). The literature confirms that parents who focussed their energies toward establishing and applying useful asthma management strategies instead of just focusing on the problem were able to see their circumstances in a positive light. They were optimistic that new and improved treatments would be developed or their child would grow out of their asthma (Cashin et al., 2008; Patistea, 2001). It has been shown that such parents are still able to be positive about their situation despite the gravity of their child's condition, which has led some researchers to propose that it is the positive view held by parents that enables them to identify management strategies for their child's illness, which in turn develops and sustains family

strengths (Katz, 2002b). A more recent study by Wong and Heriot (2008) suggests that in fact it is hope that aids disease management and improved outcomes. In Wong and Heriot's study hope was related to improved child physical functioning and child mental health, lower parent anxiety and depression, and decreased parent emotional impact. Hope was also linked to improved treatment adherence in children and adults with CF (Wong & Heriot, 2008).

Emotional support was recognized in the literature as being of particular importance for parental adaptation related to CF (Hodgekinson & Lester, 2002; Wong & Heriot, 2008). It has been identified that the more emotional support parents sought from family and friends, the less they experienced depression as a result of their child's chronic respiratory disease (Hodgekinson & Lester, 2002; Wong & Heriot, 2008). Similarly it has been reported that parents with inadequate practical support from their network and a low ability to ask their network for help scored more often for clinical burnout compared to those parents who had support available (Lindstrom, Aman, & Norberg, 2011). Conversely, emotional coping strategies were the least frequently used coping behaviour by mothers and fathers in Katz's (2002) study investigating the impact on parents of children's chronic disease. Katz does note that the findings in her study are contrary to previous research literature, particularly where social support played a more important role with the fathers in her study compared to the mothers.

Appraisal focused coping, which involves looking at a situation from another perspective and then mentally adjusting to the circumstances, was also discussed within the literature as a positive coping mechanism (Hodgekinson & Lester, 2002; Tong et al, 2009). The most frequently used appraisal–focused coping strategy by a group of parents within Hodgekinson and Lester's (2002) study was habituation in which the parents got used to their problems and then normalised them so that they developed into part of their daily life. Interestingly,

it was noted in this study that appraisal-focused coping was advocated by the specialist CF unit, in which parents were encouraged to compartmentalise their child's CF. However for a number of the mothers their stress levels and sense of failure only increased because they found it too hard trying to use this type of coping approach. Conversely, most of the parents in Tong's (2009) study who had children with chronic kidney disease did learn to cope with their circumstances by reframing the illness management as "normal" and minimising the seriousness of their own problems by comparing themselves to other families whom they perceived to be worse off. It could therefore be suggested that in fact it is the nature of the disease that impacts on how well parents are able to use appraisal coping as a strategy, as opposed to individual personalities.

Negative coping

Avoidant/escapist coping by parents of children with a chronic disease has been shown to have a negative effect on parents, children and their family (Cayse, 1994; Katz, 2002a; McGrath, 2001). Evidence showed that avoidant coping had an impact on maternal anxiety up to six months after their child's hospitalisation while their children had higher anxiety at baseline and poorer quality of life up to six months post hospital (Sales et al., 2008). Additionally, children reported more asthma-related symptoms and lower emotional functioning if their mothers used more avoidant coping, while mothers who engaged in more active, approach-orientated coping had children who reported fewer asthma–related limitations, and higher emotional functioning (Sales et al., 2008). The use of avoidant/escapist coping by individuals has also been shown to increase the burden of care for others within the family. Partners who noted this coping strategy in their spouses compensated for it by shouldering the practical responsibilities, thus increasing their own burden of care (Katz, 2002a; McGrath, 2001).

Self-blame and disengagement were also referred to within the literature as detrimental coping strategies. The use of self-blame by parents was associated

with maladjustment in parents and children. Parents who blamed themselves for their child's CF gave lower ratings for their child's mental health, had higher parental depression, and more parental emotional impact experienced as a consequence of the disease (Wong & Heriot, 2008). Similarly, poorer child mental health, higher parental anxiety and greater emotional impact was related to behavioural disengagement, in which parents avoided thinking about and responding to the child's CF and making long term plans. Thus parents who blamed themselves for their child's illness, or disengaged from pursuing goals for their child, were more at risk of experiencing high emotional distress as a result of the illness and had higher rates of anxiety and depression (Wong & Heriot, 2008).

This evidence seems to suggest that in fact parental coping plays a critical role in a child's quality of life, psychological well-being and outcomes (Lee, Yoo, & Yoo, 2007; Sales et al., 2008). In summary, various coping strategies can influence parental participation and efficacy in the management of their child's condition. Research suggests that for those parents who engage in strategies such as optimism/hope, emotional support and appraisal coping, health outcomes and management are improved, while avoidant and escapist coping creates negative outcomes.

Depression

Depression influences a parent's ability to manage their child's condition and engage in partnerships of care (Bartlett et al., 2004; Jaser et al., 2009; Shields & Tanner, 2004). Depression refers to an emotional state that is characterised by feelings of pessimism and failure that consume a person's day to day life, interfering with their ability to work, study, eat, sleep and have fun (Smith, Salsan, & Segal, 2011). For these individuals there is an intense and unrelenting feeling of helplessness, hopelessness and worthlessness in which there is little or no relief (Smith et al., 2008).

A child's chronic illness is associated with increased depression in parents (Bartlett et al., 2004; Jaser et al., 2009; Norberg & Boman, 2008; Streisand et al., 2008; Svavarsdottir, 2005). Research also indicates that parental depression is not related to a specific chronic disease and may in fact be time specific (Bartlett et al., 2004; Jaser et al., 2009; Norberg & Boman, 2008; Streisand et al., 2008). This is supported by Streisand's (2008) study that looked at parental anxiety and depression associated with caring for children with type 1 diabetes, and Norberg's (2008) study that assessed posttraumatic stress in parents of children with cancer. Findings in both studies showed that depressive symptoms in parents were higher upon diagnosis. However, these findings are disputed by a previous study (Svavarsdottir, 2005) investigating parents whose child had cancer, where no significant difference was found between depression and length of time from diagnosis. In a study by Jaser et al. (2009) depression was actually linked to fear and perceptions of coping; for the mothers in this study it was the fear and stress associated with trying to manage their child's diabetes that predicted levels of depression.

Shield and Tanner (2004) propose that the quality of a partnership between parents and health professionals is dependent on a parent's psychological robustness. Therefore parents who are depressed may find it harder to engage in collaborative relationships with health professionals due to low self-esteem and fatigue (Shields & Tanner, 2004). This finding is supported by Bartlett's (2004) study which assessed the impact of maternal depression on children's adherence to asthma therapy. Findings showed that those mothers with higher depressive symptoms reported significantly more problems with their child's asthma medication and equipment. Mothers also experienced reduced confidence and self-efficacy coping with acute asthma episodes. It was further found that depression and poor adherence to child's therapy were independently associated with increased asthma symptoms in the child. Bartlett (2004) suggests that maternal depression appeared to be related to a group of beliefs and attitudes regarding the child's asthma management, including less

confidence in asthma therapy, physician visits, and the doctor's ability to help the family to better control asthma symptoms.

In summary, depression appears to influence a parent's ability to manage their child's condition and engage in partnerships of care. Research also suggests that a chronic illness in a child can be associated with increased depression in parents, who then find it difficult to engage in collaborative relationships due to low self-esteem and fatigue.

Anxiety

Review of the literature revealed that parental anxiety can have a negative effect on parental management and child wellbeing (DeMore et al., 2005; Doerr & Jones, 1979; Hallstrom et al., 2002; Lamontagne, Hepworth, Salisbury, & Riley, 2001; Patterson, McCubbin & Warwick, 1990; Sallfors & Hallberg, 2003; Whelan & Kirkby, 2000). Anxiety is defined by Mosby's dictionary of medicine and health professions as a "an unpleasant feeling of apprehension caused by anticipation of danger, whether real or perceived." (Harris, Nagy, & Bard, 2006. p. 118). Over two decades ago, Raymond Cattell, a British and American psychologist was the first to become aware of the significance of differentiating between the emotional state of anxiety and the notion that anxiety exists in individuals differently as a consequence of their personality traits (Papay & Spielberger, 1986). Spielberger has since formulated this idea into the State-Trait Theory of Anxiety. Spielberger's theory proposes that a relationship between state and trait variables exists whereby individuals with high trait anxiety levels are more susceptible to anxiety because they perceive more situations as dangerous or threatening than those individuals who have low trait anxiety levels (Spielberger, 1966). Therefore the latter individuals, because of their vulnerability to stress, are inclined to respond more often and with more intense state anxiety reactions (Psychountaki, Zervas, Karteroliotis, & Spielberger, 2003).

In paediatric literature it is proposed parents can in fact contribute to their hospitalised child's anxiety and stress in one of two ways. Firstly, parents dealing with their own anxiety and fears are unable to provide their child with the accustomed emotional support, and if their anxiety is left untreated, their ability to advocate in the best interest and welfare of their child will be further inhibited (Hallstrom et al., 2002). Secondly, the phenomenon of anxiety contagion, of family to patient anxiety transference, may occur, whereby the parents' increased level of anxiety may be communicated to the child (Whelan & Kirkby, 2000). This theory proposes that when an individual comes into contact with a highly anxious person they may come to identify with this individual, thus experiencing an increase in anxiety (Doerr & Jones, 1979). A number of studies in paediatrics validate this theory of anxiety transference from parent to child. Those children who have highly anxious parents are more anxious, fearful or distressed (Carson, Council, & Gravley, 1991; Lamontagne, Hepworth, & Salisbury, 2001; Lamontagne, Hepworth, Salisbury, & Riley, 2003). It has therefore been suggested that by assessing and helping parents with the management of their own anxiety, the anxiety and distress of the child may be alleviated or lessened (Lamontagne et al., 2003).

Parental anxiety may also be influenced by demographics. A study by Mu (2002), which looked at father's family stress experience when caring for a child receiving cancer treatments, found that fathers with a university or higher level of education had the greatest amount of anxiety. However, lower income families in Streisand's (2008) study experienced more anxiety than higher income families. Gender was found to influence anxiety levels in both Streisand's (2008) and Bayat et al'.s (2008) studies, with higher anxiety in mothers than fathers. It was proposed by Bayat et al. (2008) that mothers may experience more anxiety than fathers because they spend more time with the ill child; however, it is noted that mothers' trait anxiety was higher than the fathers' in this study. Considering the State-Trait Theory of Anxiety mentioned above, it would seem rational that mothers' anxiety would be higher.

Evidence also suggests that levels of anxiety impact on a parent's ability to manage their child's chronic disease (DeMore et al., 2005; Patterson, McCubbin, & Warwick, 1990; Sallfors & Hallberg, 2003; Spurrier et al., 2003). A number of studies identified that increased anxiety meant parents were unable to manage their child's home treatment consistently, leading to deterioration in their child's chronic condition and increased use of primary health care (Patterson et al., 1990; Sallfors & Hallberg, 2003; Spurrier et al., 2003). A similar finding was noted by Trollvik and Severinsson (2004), who interviewed nine parents to explore the everyday experience of living with a child suffering from asthma. These authors found that anxiety, depression and helplessness occurred when a parent had a persistent stressful reaction, consequently these parents considered their circumstances more critical than they were, resulting in them being unable to master the situation in a constructive manner. A parent's anxiety state can also hamper the parent's ability to process information about participation in care (Coyne, 2007). However, an earlier study (DeMore, et al., 2005) had a different finding, where a higher level of parental distress and difficult child behavior was associated with higher levels of child medication adherence. This was an unexpected finding for these authors who thought the direction of association between parental distress and medication adherence would in fact be in the opposite direction. On this evidence they went on to propose that perhaps parents of children who exhibit challenging behaviors may be more likely to keep an eye on their child's asthma and medication use, which could in effect increase their distress while also increasing medication adherence (DeMore et al., 2005). On the above evidence it seems important that healthcare professionals are aware of these types of issues surrounding parental anxiety (Trollvik & Severinsson, 2004).

In summary, anxiety can negatively affect parental management and child wellbeing. Research suggests that when parents are anxious they find it hard to constantly manage their child's care, resulting in negative health

outcomes for their child. Moreover, high levels of anxiety in parents mean they are unable to emotionally support their child, or alternatively their child's anxiety increases as a result of anxiety transference.

Self–efficacy

Review of the literature revealed parents of children diagnosed with a chronic condition such as asthma or CF hold an expectation that they will self-manage the situation and manage their child's disease day and night. This results in parents acquiring new roles and responsibilities as they manage the physical and emotional demands of their child's illness, while still trying to carry on the normal family routines and other commitments in their lives (Morawska, Stelzer, & Burgess, 2008). It has been proposed that in order for parents to truly become partners with health professionals in their child's care they must feel confident that they have the ability to succeed in these new roles and responsibilities (Kieckhefer, Trahms, Churchill, & Simpson, 2009). This confidence is referred to as self-efficacy, a concept developed first by Albert Bandura (1977), and means the confidence, resources and ability an individual has to manage a particular situation. According to this theory, self-efficacy determines what activities an individual will engage in, how much effort they will use and how long they will carry on when the situation gets difficult. This definition suggests that self-efficacy has an important role to play in the prevention of health problems and therefore as a concept needs to be understood in terms of its relationship to a person's ability to execute a healthcare regimen for chronic diseases (Grus et al., 2001).

Perceived parental efficacy is described as the beliefs or judgements a parent has about their ability or confidence to organise and complete a set of tasks related to their parenting role (Farkas & Valdes, 2010). Many parents who face an illness in their child will question their ability to care for the child due to the constant and numerous interruptions to daily life (Matlby, Kristjanson, & Coleman, 2003). Maternal stress and perception of self-efficacy will affect a mother's performance and influence her ability to connect with her child, which

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in turn impacts on a child's personal development and medical management (Farkas & Valdes, 2010; Tong et al., 2009). Parents with increased perceptions of self-efficacy tend to take a more active role in their child's healthcare experience and participate more in medical decisions resulting in improved paediatric health outcomes (Grus et al., 2001; Strauss, Rodzilsky, Burack, & Colin, 2001; Tarini, Christakis, & Lozano, 2007; Wood, Price, Dake, Telljohann, & Khuder, 2010). This was evident in a study by Grus (2001) that investigated the relationship between parental self-efficacy and asthma related morbidity in 139 parents. Findings showed there was a relationship between parental perceptions of self-efficacy and asthma related morbidity in their child, whereby parents who reported a decreased ability in managing their child's asthma and life were more likely to experience asthma related morbidity {Grus, 2001 #744). This has been further corroborated by a later study that compared self-management behaviours of parents in two hospitals in Taiwan (Chiang et al., 2005). The results from both hospitals showed that self-efficacy of a parent's care of their child's asthma has a strong effect on self-management behaviours of parents. As this study was undertaken in Taiwan and the other studies in Europe or America, it would suggest that the influence of self-efficacy on competence is not culturally specific. Moreover, higher levels of self-efficacy were also shown to be associated with lower parental depression and stress, thus suggesting that self-efficacy promotes parental mental health (Jones & Prinz, 2005; Streisand et al., 2005).

Self-efficacy as a concept has only recently been investigated, and with limited appropriate investigation into its causal relationships (Montigny & Lacharite, 2005). Although there have been a number of studies that have explored the link between self-efficacy and self–management behaviours, research on self-efficacy and chronic respiratory diseases in paediatrics has concentrated on the aspect of perceived parental efficacy related to treatment adherence in children with chronic illness, and parental health literacy and preventative health habits (Chiang, Huang, & Lu, 2003; Clarke & Fletcher,

2003; Farkas & Valdes, 2010; Montigny & Lacharite, 2005; Wood et al., 2010). This research suggests a close circular link exists between self–efficacy and stress, as increased stress and anxiety decreases a parent's care giving ability, while mothers with low self-efficacy when faced with a stressful situation, are more likely to give up and make self-affirmations of failure, resulting in an increase in negative emotions (Farkas & Valdes, 2010).

Assessment of the literature looking at self-efficacy among parents of children with chronic disease suggests that self-efficacy can influence a parents feeling of competence (Jones & Prinz, 2005; Matlby et al., 2003; Morawska et al., 2008; Mu, Ma, Hwang, & Chao, 2002). Within Mu et al.s (2002) study that looked at the impact of anxiety on fathers whose child has cancer noted that a father's perception of doubt was negatively linked to their sense of mastery. As a consequence of these findings Mu et al. proposed that a father's care giving strategies in fact influence his belief in his ability to control the illness. This is corroborated by Matlby's (2003) study that looked at maternal perceptions of day to day life with asthma. Mothers in this study described the doubt and challenges they faced when trying to maintain a sense of parental competence managing their child's asthma. These mother's levels of competence fluctuated depending on the situation with their asthmatic child, where exacerbations of their child's asthma requiring hospitalisation would trigger a loss of competence (Matlby et al, 2003).

In summary, the literature suggests a parent's perception of self-efficacy affects their performance. Thus those parents with low self-efficacy are more likely to doubt their ability to manage their child's care, while those parents who have increased perceptions of self-efficacy will participate more in their child's care resulting in improved health outcomes.

Conclusion

This literature review has provided an overview of the development and progress of FCC, and assessed the international literature to understand FCC integration within organisations, while outlining the strengths and weaknesses of this philosophy of care.

Factors that may inhibit or support FCC, such as nurses' expectations/staff barriers, nurse coercion, parents' perspectives on parent participation and role conflict /negotiation were analysed. A discussion of other concepts relating to FCC such as parental needs, coping, anxiety, depression and self-efficacy, and the impact of these on parental participation amongst parents with children who have a chronic illness, were considered.

A link between organisational support, nurses' attitudes and knowledge around parental participation and the implementation of FCC has been established. An important aspect in relation to FCC is the role the nurse plays in negotiating partnerships. It would appear that role conflict and role negotiation between nurses and parents are key inhibitors to the successful implementation of the FCC model. Therefore it is important that organisations understand clearly how well parent participation and the concept of FCC is supported by nurses within facilities so that long term negative implications for parents and children can be avoided.

Moreover, it is evident that the priority parents place on needs varies depending on individual circumstances; this only adds strength to the argument that more research into parental needs should be undertaken to ensure that parents are actually receiving the care they feel they need, instead of the care that health professionals/organisations think they need. It has also been demonstrated that a parent's ability to participate in and manage the care of their chronically ill child is influenced by their ability to cope, their perceptions of self-efficacy, and their levels of depression and anxiety. Therefore the level of

understanding around these concepts needs to be raised so that health professionals can deliver evidenced-based and appropriate interventions to assist with the implementation of FCC, and the building of strong collaborations between parents and health professionals that will support active parental participation. One major gap in the research is the significance of how a parent's personal circumstances and psychological wellbeing impacts on their ability to manage their child's chronic respiratory disease and participate in collaborative relationships with health professionals. Accordingly this thesis examines the relationship between ways of coping, anxiety and depression, parental needs and self-efficacy amongst parents with a child who has a chronic respiratory disease, and parental participation and collaboration.

Chapter Three

Methodology and Methods

Introduction

Effective social research depends on the reliability and suitability of the theoretical perspective, methodology and epistemology employed in collecting and analysing data (Crotty, 1998). The theoretical perspective which underpins this study is pragmatism, while an embedded mixed methodology was the design chosen to carry out the research and analyse the results.

This chapter is divided into two main sections. The first section describes the research methodology of the study. A brief overview of the evolution of pragmatism and its key concepts is described with specific relevance to mixed methods research. The genesis of mixed methods research is outlined and Creswell's (2007) embedded design is presented as the most suitable mixed method design for this study. The second section explores the research methods employed and concludes with a discussion on issues surrounding reliability, validity and researcher bias.

Pragmatism

The philosophical paradigm is the worldview of the social science inquirer, taking into account an individual's assumptions regarding the nature of the set of beliefs, values and experiences that shape the manner in which one comprehends truth and reacts to that perception (Greene, 2008a). Pragmatism is the language of practice rather than theory, of action instead of contemplation, in which one can state something valuable regarding truth (James, 1907; Rorty, 1982). Pragmatism is an essentially American philosophy, originating from the work of the natural scientist and philosopher Charles Sander Peirce, who sought

a critical philosophy (Cherryholmes, 1992; Creswell & Plano Clark, 2007; Crotty, 1998; Greene, 2007).

Peirce outlined pragmatism as:

> *... a conception, that is, the rational purport of a word*
> *or other expression [that], lies exclusively in its conceivable*
> *bearing upon the conduct of life; so that, since obviously*
> *nothing that might not result from experiment can have*
> *any direct bearing upon conduct, if one can define*
> *accurately all the conceivable experimental phenomena*
> *which the affirmation or denial of a concept could imply,*
> *one will have therein a complete definition of the concept,*
> *and there is absolutely nothing more to it (Peirce, 1905, p.162).*

The most prominent aspect of Peirce's theory of pragmatism was the recognition of an undividable correlation between sound cognition and sound function (Peirce, 1905). However, this work of Peirce's went chiefly unacknowledged and unheard of until some years later when pragmatism became popularised through the work of psychologist and philosopher William James (Crotty, 1998; Greene, 2007). Meanwhile, John Dewey, a philosopher, psychologist and educationalist, had also became interested in pragmatism, and it was these versions by James and Dewey that became widely known (Crotty, 1998).

According to James, pragmatism:

> *...asks its usual question"Grant an idea or belief to be true," it*
> *says, "what concrete difference will its being true make in any*
> *one's actual life? How will the truth be realised.What*
> *experiences will be different from those which would obtain if the*
> *belief were false? What, in short, is the truth's cash value in*
> *experiential terms? (James, 1907, p.142).*

Therefore while the original version of pragmatism by Peirce sought to explain the value of intellectual ideas by tracing out their likely possible and realistic outcomes, James and Dewey moved the interest to the significance of

the consequences of actions based on individual ideas (Cherryholmes, 1992). Ultimately, though, all three remained concerned with exploring practical outcomes and empirical findings to help understand the importance of a philosophical position, and to assist with deciding which action to take next as they tried to understand real-world phenomena (Johnson & Onwuegbuzie, 2004).

Further important contributions to pragmatism were made in recent years by Murphy and Rorty (1990) and Cherryholmes (1992). With the influence of all these individuals, a variety of views on pragmatism have emerged, though the origins remain predominat derived from the diverse disciplinary roots and individual work of the initial pragmatists (Creswell & Plano Clark, 2007; Greene, 2007). This development has resulted in a pragmatism that embraces a what works approach, whereby numerous ideas and assorted methods are used, and both objective and subjective knowledge is respected (Creswell & Plano Clark, 2007; Denzin, 2010).

Pragmatism assumes all individuals are historically and socially positioned and that scientific research, directed by anticipated consequences, constantly arises within varied social, historical and political contexts, while ideals and visions of human action and contact initiate the hunt for descriptions, theories, clarification and narratives (Cherryholmes, 1992; Johnson & Onwuegbuzie, 2004). Thus pragmatism perceives knowledge as being mutually constructed and built on the reality of the world we understand and live in, whilst current truth, meaning, and knowledge is tentative and will change over time (Greene, 2008; Johnson & Onwuegbuzie, 2004).

As a theory pragmatism rejects dualism and acknowledges both realist and constructivist aspects of knowledge, therefore offering an epistemological rationale (through pragmatic principles) for combining different approaches and methods. Pragmatism acknowledges the concept of multiple and singular truths

open to practical examination while lending itself to solving practical problems in the existing world (Feilzer, 2010). It endorses the view that the outcomes are more important than the process, thus promoting eclecticism and a needs must approach to research methods (Doyle, Brady, & Byrne, 2009). Therefore as a logical, practical outcome–orientated method of inquiry, pragmatism is capable of assisting researchers in the selection of methodological mixes to help them better answer their research questions (Greene, 2008a; Johnson & Onwuegbuzie, 2004; Johnson, Onwuegbuzie, & Turner, 2004). Consequently, many writers argue that pragmatism is both the best paradigm and the catalyst for the new era or third research movement of mixed methods research, a movement that goes beyond the paradigm wars by presenting a logical and practical alternative to other paradigms (Alise & Teddlie, 2010; Creswell & Plano Clark, 2007; Doyle, Brady, & Byrne, 2009; Feilzer, 2010; Greene, 2008b; Johnson & Onwuegbuzie, 2004; Johnson et al., 2007).

The paradigm wars over the past four decades have all centred on questioning the assumptions of individual paradigms while trying to reconfigure the relationship between ethics, epistemology, methodology and paradigms (Alise & Teddie, 2010; Denzin, 2010; Greene, 2008). Historically, positivism dominated the first half of the twentieth century, but this gave way in the 1950s to post-positivism, which came to the fore in an effort to fix some of the issues with positivism (Alise & Teddlie, 2010; Denzin, 2010; Greene, 2008). This post-positivist paradigm, which proposes that the social world exists independent of our knowledge of it, came under attack when social scientists' use of experimental methodologies proved inadequate at evaluating the American 1960s social reforms (Greene, 2008a). However, during the 1970s and 1980s, researchers focused on the notion that different underlying paradigm beliefs were responsible for the foundations of quantitative and qualitative research, which fuelled the argument that quantitative and qualitative methods could not be mixed (Creswell & Plano Clark, 2007; Denzin, 2010). However, with the emergence of pragmatism and the compatibility thesis post 1990, there is debate

between those who believe it has become acceptable to combine quantitative and qualitative methods in their empirical inquiries, and others who still argue against this on the grounds of epistemological and ontological incompatibility, and who caution researchers to consider the naive acceptance of a research method in which the fundamental beliefs and differences between paradigms are disregarded (Denzin, 2010; Doyle et al., 2009; Mason, 2006).

This concept of mixing methods is not original and has been noted within the work of anthropologists dating back to the early twentieth century; however, it was not named "mixed methods" until many years later (Johnson et al., 2007). It is proposed by some that mixed method research is now the new movement/research paradigm that has developed in response to the polarization between qualitative and quantitative research, the limitations of using only one method (quantitative or qualitative), and changes in today's research world (Creswell & Plano Clark, 2007; Doyle et al., 2009; Gilbert, 2006; Greene, 2008b). According to a number of writers, research today is becoming progressively more interdisciplinary, multifaceted and vigorous and in order to answer specific research questions, in the best possible way, they suggest that researchers should consider taking a less purist attitude (Denzin, 2010; Gilbert, 2006; Greene, 2008a, 2008b; Wheeldon, 2010; Woolley, 2009). For those researchers who do embrace the less purist attitude of mixed methods, it is proposed that they will be able to generate stronger inferences, and solve research questions that existing methodologies cannot, while permitting a larger range of findings (Creswell & Plano Clark, 2007; Denzin, 2010; Doyle, Brady, & Byrne, 2008; Gilbert, 2006; Greene, 2007, 2008a, 2008b; Johnson & Onwuegbuzie, 2004; Johnson, Onwuegbuzie, & Turner, 2007).

In keeping with the pragmatic theoretical stance, this study embraced a practical "what works" perspective, in which a number of methods were chosen to best answer, within an assorted participant population the various research questions within an assorted participant population. With potential participants

being located in four separate hospitals, and made up of both parent and nursing populations, a mixed method approach on pragmatic grounds was appropriate to assist the researcher in addressing and understanding the complexity of a parent's experience of living with a child who has a chronic respiratory illness, and the concepts of family centred healthcare in the various locations in which this study was to take place (O'Cathain, Murphy, & Nicholl, 2007). This study used questionnaires and interviews to explore and understand parental reality around managing and living with their child's chronic respiratory condition, while questionnaires were used to identify parental and professional conceptions of FCC.

Mixed methods research

> *Mixed methods research is the type of research in which a researcher or team of researchers combines elements of qualitative and quantitative research approaches (e.g. use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the broad purposes of breath and depth of understanding and corroboration (Johnson, Onwuegbuzie & Turner, 2007, p.123).*

Over the last fifty years different terms have been used to describe mixed methods research, such as "multitrait/multimethod", "integrated" or "combined", "quantitative and qualitative methods", "hybrids", "methodological triangulation" and "mixed methods", making it difficult to pinpoint all the literature that may have referred to mixed methods research in the past (Greene, 2007; Sosulski & Lawrence, 2008). However, as a methodology today, mixed methods has progressed through the formative phase, the paradigm debate and the procedural period, to finally reach a stage in which interest is illustrated by public and state funding opportunities (Alise & Teddlie, 2010; Creswell & Plano Clark, 2007), and by the development of journals specific to mixed methodology such as the *Journal of Mixed Methods Research and the International Journal of Multiple Research Approaches*. With a prevalence rate of around 15%, mixed methods research is now applied within a variety of disciplines, including

education, psychology, social sciences and health sciences, suggesting there is a progression in the philosophical dispute about theoretical coherence in mixed research (Alise & Teddlie, 2010; Sosulski & Lawrence, 2008).

As an approach, mixed methods is proposed to be an expansive and innovative way of thinking, whereby the orientation toward social inquiry actively encourages the researcher to engage in a discourse around numerous ways of seeing, hearing and understanding the social world (Creswell & Plano Clark, 2007; Greene, 2007; Johnson & Onwuegbuzie, 2004). The assumption is that multiple legitimate approaches in social inquiry and the use of a mixture of methods provides an enhanced understanding of research problems, while use of any individual approach to social inquiry is certainly incomplete (Creswell & Plano Clark, 2007; Greene, 2008; Mason, 2006; O;Cathain, 2009). Moreover, it is postulated that research that mixes methodologies diminishes biases inherent in each tradition, creating a better understanding of the many-sided and complex characteristics of a social phenomenon, while initiating interdisciplinary collaboration as researchers from assorted worldviews wrestle complex problems, necessitating a combination of qualitative and quantitative methods (Creswell & Plano Clark, 2007; Doyle et al., 2009; Greene, 2008b; Johnson & Onwuegbuzie, 2004; Mason, 2006; O'Cathain, Murphy, & Nicholl, 2007; Sosulski & Lawrence, 2008).

Theorists on mixed method research stress the importance of justifying why selection of a mixed method approach is to be undertaken. While in general terms the purpose for mixing methods in social inquiry is proposed to increase our knowledge of the phenomena being studied, it is suggested by Greene, Caracelli, and Graham (1989), following their examination and review of empirical mixed method evaluations, that in fact there are five more distinct purposes for performing mixed methods research. Firstly there is triangulation, which is used within mixed methods to assess the same phenomenon, while pursuing convergence, corroboration, or correspondence of results by utilizing

methods with offsetting biases to balance any unrelated sources of inconsistency and/ or error. The second and most common purpose in practice is complementarity, where mixing methods is undertaken to elicit a broader, deeper more elaborate analysis of the study by using methods that draw on various aspects or dimensions of the same complex phenomenon. The third purpose is development, in which the results from one method are used to inform the development of the other method. Fourth is initiation, which is very similar to complementarity, where diverse methods are applied to measure different aspects of the same phenomenon, but the intended outcome is the detection of paradoxes and inconsistencies which may result in a re-framing of the research question. Lastly is expansion, where the purpose is to expand the scope and range of the study by applying different method choices for different inquiry components.

In this study one of the researcher's aims was to investigate different personal features and perceptions that could impact on a parent's experience of managing their child's chronic respiratory illness. Therefore the justification for using mixed methods in this study was expansion, in which the researcher selected the most appropriate method for each of the concepts (Greene, 2008). Within this study the concepts of anxiety, depression, coping and FCC were able to be explored with developed survey tools, while existing quantitative tools were inappropriate for investigating the concept of self-efficacy and its impact on the parent. However, through using interviews the researcher was able to gather rich data on self-efficacy, while also exploring the concept of community and family support.

Embedded mixed method research design

A research design is the method for gathering, analysing, interpreting and reporting data to answer the research questions (Creswell & Plano Clark, 2007; Crotty, 1998; Greene, Caracelli, & Graham, 1989; Greene, 2007; Polit & Beck, 2004). In order for any study to follow a logical pattern, the researcher must be meticulous in their choice of an appropriate research design, as the

research design guides the design of the methods which will be used to judge how interpretations will be made at the end of the study (Creswell & Plano Clark, 2007). Over the last twenty years a number of mixed methods research designs have been developed by numerous authors (Creswell & Plano Clark, 2007; Greene et al., 1989; Morse, 1991; Patton, 1990; Sandelowski, 2000; Steckler, McLeroy, Goodman, Bird, & McCormick, 1992; Tashakkori & Teddlie, 1998). However, for the purposes of this study the researcher drew on Creswell and Plano Clarke's (2007) four major mixed method designs, Triangulation, Embedded, Explanatory and Exploratory and their variants, which are based on the synthesis and classification of other mixed method designs (Creswell & Plano Clark, 2007).

Before deciding on a particular type of mixed method design Creswell and Plano Clarke (2007) suggest that the researcher should consider three points: will the qualitative and quantitative stages be conducted concurrently or sequentially? Will both methods be given equal priority? Where will the mixing of qualitative and quantitative methods occur? After considering these points using Creswell and Plano Clark's (2007) decision tree, the researcher identified an embedded mixed method design as the most appropriate design for this study.

The choice of an embedded mixed method design for this study was justified on the grounds that introduction of a qualitative component within a predominant quantitative study would provide the researcher with the opportunity to answer different questions related to self-efficacy which could not be answered with existing quantitative tools.

Moreover, the choice of Thomas' (2006) general inductive approach to analyse the qualitative data was appropriate as it would enable the qualitative research findings to surface from the recurrent, central, and important themes inherent in the raw data, without the restraints imposed by structured methodologies. This approach assumes that the researcher's objectives and

interpretations of data determine the data analysis, while allowing the researcher to investigate the participants' world rather than base it on the literature (Bishop & Ford-Bruins, 2003). Furthermore, this approach allows the researcher to realize the meaning in complex data by using a systematic set of procedures for exploring the qualitative data, yielding reliable and valid findings (Bishop & Ford-Bruins, 2003; Thomas, 2006). These procedures include preparing the raw text into a common format which can then be read thoroughly by the researcher; this enables the researcher to identify general categories and themes. Then summary categories can be formed that capture the main features within the raw text, which can then be considered by the researcher as the main themes, given the research objectives (Thomas, 2006).

Method

In order to assess the factors that can influence parental participation and the delivery of FCC, and with evidence suggesting that implementation of FCC within facilities is inconsistent, while parents' ability and willingness to participate in FCC is dependent on their personal circumstances and psychological wellbeing, it was important that research be undertaken with both parents and nurses. Therefore a two stage, embedded mixed method design was chosen. The first stage of this study involved a national survey of paediatric facilities to determine the degree to which nurses perceive Patient-Family Centred Care (PFCC) concepts are implemented within their organisation. The second stage, consisting of a quantitative component (Part A) and a qualitative component (Part B), explored how parents' personal circumstances and psychological wellbeing impacted on the management of their child's chronic respiratory disease. Quantitative data was gathered, via survey tools, to identify how parental needs, coping strategies, anxiety and depression may influence parental participation, while qualitative data, via interviews, was collected to explore parents' perceptions of self-efficacy.

Table 1: Overview of study

Stage 1: National benchmarking survey
Hospital A: online and paper PFCC survey
Hospital B: online and paper PFCC survey
Hospital C: paper PFCC survey
Hospital D: online PFCC survey
Stage 2: Part A: Survey of 50 parents at Hospital B 10 questions from PFCC, CHIP, NPQ, HADS
Part B: Qualitative interviews of 23 parents at Christchurch Hospital

PFCC= Patient family centred care, CHIP= Coping health inventory for parents, NPQ= Needs of parents questionnaire, HADS= Hospital anxiety and depression scale

Research Questions

For this study the following two research questions and sub-questions were developed

1) How do nurses within New Zealand perceive that paediatric services support the families of children with a chronic respiratory disease during hospitalisation?

   - What stage are New Zealand's major paediatric facilities at in terms of implementing FCC?

   - Do variations exist in the integration of FCC amongst the major paediatric facilities?

   - How does the New Zealand paediatric service compare to other countries in the implementation of PFCC?

- Do nurses' attitudes to FCC affect partnerships between nurses and parents?

2) What is the relationship between parental psychological wellbeing, parental circumstances, and parental management/participation in the care of a child's chronic respiratory disease and associated hospitalisations?

Ethical Approval

Ethical approval for this study was sought from the Multi-region Ethics Committee and granted on 26th June 2009. The process of securing locality assessment for four District Health Boards (DHB) was a drawn out process requiring a duplication of processes, and documentation. On application, the impact for parents of disclosing to the researcher sensitive material, anxiety and coercion was considered. Thus the information sheet [i](Appendix 14) outlined who to contact should parents identify problems related to anxiety and depression, while nursing personnel were to identify and initially approach those potential participants who met the inclusion/ exclusion criteria.

Initial feedback from the Multi-region Ethics Committee included concerns about the possible exclusion of other ethnicities related to the unavailability of a translator. The researcher contacted DHB administrators in the interpreter's office and was informed that the financial cost of providing an interpreter for this study would be the responsibility of the researcher. As the project had limited funding it was outside the researcher's scope for an interpreter to be made available. This response was conveyed to the Ethics Committee.

Maori Consultation Process

A meeting with Elizabeth Cunningham University of Otago, Christchurch, Research Manager–Maori was arranged to ensure that any issues for Maori regarding the conduct of the study could be identified and addressed. Given the high incidence of respiratory disease for Maori aged five to thirty five years old, who are more likely to be admitted to hospital for asthma than non-Maori (Ministry of Health, 2006), the Research Manager–Maori recommended that ethnic data should be collected using the Census 2006 ethnicity question. It was also discussed that as the findings from this study could contribute to the development of future research, it is appropriate that Maori researchers, Maori health providers and Maori health professionals are made aware of the findings of this study.

Setting

The study was conducted within four main tertiary hospitals in New Zealand. In order to capture the degree to which FCC concepts are implemented in New Zealand, a cross section of the major tertiary centres was considered appropriate. This resulted in the selection of two hospitals within the North Island and two in the South Island.

Hospital A

Hospital A is a 434 bedded tertiary hospital in an urban area that has 5.9% (448,956) of New Zealand's population (Statistics N.Z, 2006). It provides tertiary level care, including paediatric surgery to a population of around 900,000 (Ministry of Health, 2010a). This district is comparatively, advantaged in terms of socioeconomic deprivation, with nearly a quarter of the population living in the least deprived areas, while children on average are healthier than children from other parts of New Zealand (Ministry of Health, 2010b). Hospital A has two paediatric wards that provide secondary and tertiary care for acute, sub-acute and chronic conditions requiring medical and surgical intervention for children from birth to sixteen years (Henare, 2002). In accordance with other

DHB's, respiratory conditions account for a majority of paediatric admissions (Anderson & Douglas, 2009).

Hospital B

Hospital B is a 600-650 bed facility. It is the second largest DHB by population and the largest by geographical area (Ministry of Health, 2010). The catchment area includes rural communities with a population of 427,089 (Statistics New Zealand, 2002). While the health status of this population is the same if not better than other parts of New Zealand, around eighteen percent of all children zero to fifteen years, and twenty one percent of the community, live in high deciles of deprivation (Ministry of Health, 2010). Hospital B has three paediatric wards and a Children's Acute Assessment Unit that offer tertiary care for zero to fifteen year olds with acute, chronic diseases or arranged admissions requiring medical and or surgical intervention. As with other DHBs, there is a prevalence of paediatric respiratory disease, while hospitalisation rates for children under five with asthma are higher than the national average (James, Davies, & Cunliffe, 2008).

Hospital C

Hospital C, a 400 bed facility, is the most rural and second largest DHB geographically within New Zealand. Overall the demographics and socio-economic status of this population is disadvantaged, with a higher percentage of personal income being in the lowest categories (Thomas, 2005). Hospital C has one paediatric ward that provides secondary and tertiary inpatient services, including specialist assessment, investigation, diagnosis and treatment for children up to fifteen years of age. The Paediatric Assessment Unit also provides same day evaluation and treatment services for paediatric patients who self-present to the Emergency department or are referred by other community medical personnel (Ministry of Health, 2010b). Overall this facility has a similar percentage of chronic respiratory disease to other DHB's however hospital admission rates for asthma remain lower (Thomas, 2005).

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Hospital D

Hospital D is a dedicated paediatric hospital in a major urban centre that has a population of 1,303,068, which equates to 32.4% of the national population (Statistics N.Z, 2006). This hospital is located in the biggest District Health Board (DHB) by turnover within New Zealand (Ministry of Health, 2010b). Hospital D is a major teaching tertiary children's hospital and the first hospital dedicated to paediatrics within New Zealand (Ministry of Health, 2010b). As a specialist hospital with nine wards and 219 beds it is a leader in paediatric training and research within New Zealand. Hospital D provides healthcare services for children and young people all over New Zealand and the South Pacific with complex and chronic mental, surgical and medical conditions (Ministry of Health, 2010b). Within this DHB there are high degrees of deprivation related to poorer health status (Bradley & Davis, 2006) with a larger percentage of children living in both low and high degrees of deprivation, while less live in the mid deprivation areas. One of the leading causes of hospitalisations within Hospital D is respiratory illnesses and in 2001-03 they accounted for sixteen percent of all admissions (Jury & Hyman, 2006).

Staff recruitment

Recruitment was focused on all nurses working within the paediatric wards of Hospitals A,B,C and D between 10 June 2009 and 23 April 2010 (stage 1) and all parents of children with a chronic respiratory illness who met the inclusion/ exclusion criteria (Appendix 1) between November 2009 and October 2010 at Hospital B (stage 2).

In May 2008, prior to ethical approval, the researcher distributed a letter (Appendix 2) to the Research Offices of each DHB. This letter outlined the study and requested their assistance in identifying, from an organisational point

of view, what the correct procedure was to gain locality assessment and how best to identify a contact person within paediatrics.

Local investigators were identified via the DHB's Research Office, DHB websites, Ethics Committee or the DHB Paediatric Clinical Nurse Specialist. The local investigators were made up of a Director of nursing (Hospital D), Paediatric Nurse Leader (Hospital A), Paediatric Nurse Educator (Hospital C) and this Researcher (Hospital B).

An initial e-mail outlining the study and involvement required was sent to the local investigators in Hospital's A, C and D, (Appendix 3) to solicit buy in. This was followed up with a phone call to discuss any questions or concerns. An additional e-mail with the survey and cover letter attached was sent (Appendix 4). Further site visits to Hospitals A and C were made by this researcher to discuss the survey and information letter in person and address any anticipated issues with roll out of the survey. Hospital D's local investigator and this researcher felt it unnecessary to undertake a site visit due to online distribution of the survey, as all issues could be addressed either via e-mail or phone between the computer technicians.

Stage One: Patient family centred care benchmarking survey of four main centres within New Zealand

Aim

Stage One of the study comprised a cross-sectional benchmarking survey of paediatric nurses in four centres and looked at how nurses in New Zealand perceive that paediatric services support families of children with chronic respiratory disease during hospitalisation. This stage aimed firstly to identify what stages are New Zealand's major paediatric facilities at in terms of implementing FCC; secondly, whether variations exist amongst these facilities

with the integration of FCC; and lastly, whether nurses' attitudes to FCC affect partnerships between nurses and parents.

Design

A cross–sectional survey design was chosen because this type of research design is used for collecting data on relevant variables for all of a population or a representative group at one point in time (Polit & Beck, 2004). Cross sectional studies are often used to gather information on important health-related aspects, and people's knowledge, attitudes and practices (Last, 2010), such as patient–family-centred care. The design was appropriate for Stage One where the intent was to determine at what level PFCC concepts were being implemented within the four DHBs, rather than to detect cause and effect relationships.

Sample

All nurses working on a paediatric ward in the four hospitals were eligible to participate. Preliminary estimations of sample size were established by the local investigator of each DHB and the three Charge Nurses from Hospital B assessing either staff e-mail lists or staff rosters within each paediatric ward.

During the recruitment period there were 410 nurses working within the four paediatric facilities.

Data Collection

Data collection for Stage One commenced with Hospital A in June 2009, Hospital B in November 2009, Hospital C in July 2009 and Hospital D in August 2009. For all organisations, Stage One of this study was closed on 23 April 2010.

An e-mail was sent to the local investigator at Hospital D with a covering e-mail introducing the study, information sheet and survey link (Appendix, 4a, 4b). These were forwarded onto all of the 300 nurses working within the paediatric wards. For Hospital A, survey packs, made up of the PFCC survey, information sheet and demographic form, were sent to the local investigator who had agreed to distribute them to all nurses working on the two paediatric wards. Recruitment challenges resulted in the researcher contacting the local investigator to discuss alternative distribution methods. It was agreed that the survey would be distributed as an on-line version similar to Hospital D; this necessitated the technician altering two questions in the survey so that staff stipulated which organisation they belonged to. It was also stated in the introductory e-mail that staff were to fill out one survey only, either a paper survey or an on-line version. For Hospital C survey packs were delivered by the researcher to the local investigator to distribute to all the nurses working on the paediatric ward. For Hospital B an introductory e-mail outlining both stages of the study was sent to the three Charge Nurses who had agreed to forward it to all the staff. Over a two week period the researcher provided baking while attending the morning, afternoon and night nursing handovers. This provided an opportunity for the researcher to identify the best distribution method of the PFCC survey, while answering any questions. After discussions with the nursing staff it was decided to roll the survey out via e-mail while providing some hard copies for those staff who infrequently accessed their DHB e-mail. Similar to Hospital A, it was clearly stated in the introductory e-mail and at the handovers that each nurse must complete only one version of the PFCC.

All nurses were assured that individual responses would be anonymous, while all information obtained would stay confidential. In order to allow for staff illness or vacation, a further three e-mail reminders, spaced two weekly, were sent out via the local investigators in Hospitals D,A and C. In Hospital B, in order to stimulate recruitment and capture as many participants as possible, a flyer (Appendix 5) was placed in the staff room of each ward on 13 April 2010

which counted down the number of days till the survey was closed. The researcher visited the ward each day to alter the date.

Research Instruments

The Patient-Family-Centered Care (PFCC) survey

The Patient–Family-Centered Care (PFCC) survey (Appendix 6) developed by the Children's Medical Centre, Texas was used (Carmen, Teal, & Guzzetta, 2008). This survey has been piloted through a national benchmarking survey in the United States and psychometric validation published, a Cronbach alpha range of .76 to .94 for the subscales indicates a high internal consistency reliability (Carmen et al., 2008). The PFCC survey for leadership and staff contains 107 items within seventeen subscales.

Table 2: PFCC subscales and key concepts

Subscales	Key concept
Togetherness subscales	Extent families can stay with their child during procedures
Family Participation and Involvement subscales	Family's involvement in the treatment and evaluation of their child's health
Comprehensive Definition of PFCC subscales	Family and child involvement in hospital policy and design space
Design and Quality of Staff Areas subscales	Adequacy of respite areas available for staff
Attitudes of possible outcomes of implementing PFCC subscales	Outcomes of implementing PFCC
Organizational Benefits subscales	Enhancement of institutional operations related to implementation of PFCC concepts
Improved Retention subscales	Enhancement of job fulfilment, retention and satisfaction due to PFCC

Each item is rated on a four–point Likert scale ranging from one (strongly disagree that the PFCC concept is being practised in the organisation)

to four (strongly agree that the PFCC concept is being fully practised in the hospital). Frequency distributions and mean scores for each subscale are used to signify the level on which PFCC concepts are practised; a high score indicates that PFCC is being implemented at an advanced level of practice (Carmen et al., 2008).

Demographic questionnaire

As research suggests that health personnel's professional (education, position) and personal (age, marital and parental status) characteristics can have an effect on parental participation and FCC (Brown et al., 1991: Daneman et al., 2003; Gill, 1993; Seidl, 1969; Valentine, 1998), thirteen questions were developed to elicit key demographic data (Appendix 7).

Collection of on-line data

This researcher solicited the assistance of an independent software technician to create the online version. The online survey service, Limesurvey, was used for survey distribution. Limesurvey provides a web-based product for internet surveys with more than twenty different question formats, in addition to survey tokens that prevent repeat participants, and branching surveys that offer different questions depending on prior responses. Moreover, the survey administrator can control how the survey interface will appear to participants through a built–in editor. Once all the items on the PFFC and demographic form were entered into Limesurvey, a link to the web site hosting the survey was developed. This link was used in e-mail correspondence to invite prospective nurse respondents to participate in the survey and provide information about the study. Participants clicked on the link and were able to commence filling in the survey; at any stage they could exit out of the survey and come back to the same point later if they chose. In order to ensure there was a record of which facility the nurse was from, participants were unable to proceed onto another page until this question had been answered. Participants saw a total of six screens, and the on-line format of the survey mirrored the paper survey. Once the recruitment period had ended all data was condensed into a file and sent to the researcher's

e-mail address. It was then downloaded into a database and exported into SPSS where it was cleaned and the assorted variables were labelled.

Stage 2 -Part A: Survey of parents whose child has a chronic respiratory disease

Aim

Stage Two Part A of this study involved surveying fifty parents whose children were admitted to Hospital B, and looked at how their personal circumstances and psychological wellbeing influenced their participation in the care and management of their child's chronic respiratory disease and associated hospitalisation.

Design

A cross sectional survey design was chosen for this Stage Two Part A of this study, where the aim was to explore the possible association between the health related states of anxiety and depression, and parents' coping strategies and self-efficacy, and to identify similarities and discrepancies between staff perceptions of parental needs rather than establish any cause and effect-relationship (Last, 2010).

Inclusion/Exclusion criteria

All biological, step, foster and adoptive parents who could read and write English, with a child between zero and sixteen years of age diagnosed with a chronic respiratory disease, were eligible to participate in Parts A and B of stage two. Parents with children over sixteen years of age diagnosed with a non-respiratory chronic disease, who were incapable of independently filling out a questionnaire, were excluded.

Sample

A convenience sample of fifty parents was sought, based on consultation with a biostatistician.

Data Collection

Soliciting buy in from nursing personnel and recruitment of participants for Part A and Part B of stage two occurred concurrently. Participants were identified and approached by nursing personnel to gauge their interest in the study and given an information sheet. The researcher met with the potential participants twice, once to discuss the study and answer any questions, and the following day to give the survey pack and arrange an interview for those interested in participating. In most cases the survey pack had been completed for pick up at the scheduled interview. However, in situations where the participants needed more time to complete the surveys, an alternative time was arranged in which the researcher would revisit and pick the pack up personally or have them leave it in their letterbox.

The researcher visited the wards twice daily, once in the morning and then again in the evening. This approach enabled the researcher to potentially distribute the survey pack in the morning, following identification of participants by the nursing staff who had gauged interest and distributed the information sheet, and then collect it again in the evening or alternatively distribute it in the evening and collect it the following morning. Despite recruitment running during the winter months, the busiest time of year for chronic respiratory disease hospitalisations, recruitment was slow and took a further eight weeks to complete.

Initially it was the researcher's intention that the primary nurse involved in the child's care would complete the Needs for Parents Questionnaire (NPQ), so that similarities and discrepancies between the needs of the parent/s and staff

perceptions of these needs could be explored. Therefore, once parent participants had completed the survey pack, the primary nurse was identified by the Nurse Manager and approached by the researcher. The researcher gave the primary nurse a survey pack containing the NPQ and information sheet which outlined the study's aims, time commitment involved and assurance that all material would remain confidential, and that participation was voluntary with the option for withdrawal at any stage with no adverse effect. The researcher informed the primary nurse that the surveys could be returned to her or posted using the attached self-addressed envelope.

However, recruitment issues developed as a result of the specialised nature of some chronic respiratory illnesses. A number of the conditions required the experience of senior nurses, thus it became evident that only a handful of nurses would be recruited. After discussions with her supervisor, the researcher altered recruitment to include all nurses involved in the care of children with a chronic respiratory illness. The researcher, when visiting the ward daily, approached nursing personnel and distributed the surveys and followed this up with personal reminders. Despite altering the focus of recruitment, the nurses were reluctant to participate. It was decided by the researcher and her supervisor that as only two surveys had been returned in ten weeks recruitment would cease. It is proposed that as nurses had recently been recruited for the PFCC survey, they were not inclined to fill out any more surveys. Initially recruitment for both stages was to be staggered with a greater time lapse between. However, due to issues gaining locality assessment, both stages were rolled out concurrently, which could have resulted in ambivalence by nursing personnel and a sense of being over-surveyed.

Research instruments

Fifty parents completed The Patient-Family-Centered Care survey, Coping-Health Inventory for parents' survey, the Needs of Parents Questionnaire and the Hospital Anxiety and Depression scale.

Patient-Family-Centered Care (PFCC) survey

Ten questions from the PFCC survey (Carmen et al., 2008) (Appendix 8) were used to assess parents' perceptions of how hospital design supports PFCC. The questions invited participants to examine the extent to which the overall décor and design, hospital parking, hospital entrances, lounge areas, inpatient rooms, and procedure, treatment and consultation rooms in the hospital are influenced by FCC. Each item is rated on a four–point Likert scale ranging from strongly disagree to strongly agree.

Coping-Health Inventory for Parents (CHIP)

The CHIP (Appendix 9) a forty-five-item instrument developed by McCubbin, et al. (1983) was used in this study to measure parents' response to managing family life with a chronically ill child. This tool has been validated in numerous studies of parent populations whose children suffer from a diversity of chronic illnesses, including childhood and adolescent insulin-dependent diabetes mellitus, cancer and paediatric brain tumours, cerebral palsy, cystic fibrosis and developmental disabilities (Auslander, Bubb, Rogge, & Santiago, 1993; Austin & McDermott, 1988; Birenbaum, 1990; Block, Brandt, & Magyary, 1995; Blotcky, Racynski, Gurwitch, & Smith, 1985; Cappelli et al., 1988; Carlson-Green, Morris, & Krawiecki, 1995; Failla & Jones, 1991; Gibson, 1986; Grey, Cameron, & Thurber, 1991; McCubbin et al., 1983). The tool comprises three coping pattern subscales developed through factor analysis.

1) Coping Pattern I: maintaining family integration, cooperation and an optimistic definition of the situation. This subscale is made up of eighteen behaviours that centre on strengthening family life and relationships, and the parents' attitude to life and the chronically ill child.

2) Coping Pattern II: maintaining social support, self-esteem and psychological stability consists of seventeen behaviour items focusing on the parent's efforts to cultivate relationships with others,

engage in activities that boost feelings of individual well–being, and engage in behaviours to manage psychological tensions and strains.

3) Coping Pattern III: consists of eight behaviour items that embody parental efforts to comprehend chronic disease and acquire expertise in home care treatments and prescribed medical routines through discussions with healthcare professionals and other parents of chronically ill children. Participants respond on a four point scale ranging from zero (not helpful) to three (extremely helpful). CHIP scores are achieved by summing across all items, a higher score indicates that parents depend more on efforts to increase family growth, stability and efficacy (Aguilar-Vafaie, 2008). The maximum possible score for CHIP I is fifty four, CHIP II is fifty one and CHIP III twenty four. Reliability testing for the items on each coping pattern gave Crobach alpha of 0.79, 0.79 and 0.71 respectively (McCubbin, McCubbin, & Thompson, 1981).

The Needs of Parents Questionnaire (NPQ)

The NPQ (Appendix 10) by Kristjansottir (1995), which has been used in several countries (Sweden, England, Indonesia, Australia , Canada) and translated from Icelandic to French, Swedish and English (Shields & Kristensson-Hallstrom, 2004) was used to examine parental perceptions of needs during hospitalisation of their child with a chronic respiratory illness and staff perceptions of those needs. The original version by Kristjansottir (1995) contained forty-three statements of parental perceived needs. However, a further eight statements were subsequently added giving a total of fifty-one need statements. It was this updated version that was selected for the parent participants within this study. Shields and Kristensson-Hallstrom (2004), in their study investigating the influence of demographic characteristics on the perceived needs of parents, adapted the NPQ for use by staff. Minor changes to some statements within Kristjansottir's (1995) NPQ were checked by a panel of experts prior to being trialled, and reliability testing gave a Cronbach's alpha of

0.91 for the Staff NPQ which is comparable with those of Kristjansottir's (1995) (Shields & Kristensson-Hallstrom, 2004). This version was used within this study to assess staff perception of parental needs.

The NPQ need statements are related to parents who escort their child during a hospital admission and incorporate needs for participation in their child's care, support and informational needs, physical and emotional needs and the needs of parents in relation to other family members. Statements are explored from three distinct perspectives. Firstly the "importance score" assesses parents' perceived importance of each need statement in relation to their child's hospitalisation, and is examined with a five point Likert scale ranging from "does not concern me" to "very important". Secondly, the "fulfilment score" determines whether parents think each of the statements is fulfilled during their child's hospitalisation and is appraised with a five-point Likert scale ranging from "fully" to "not at all". The "independence score" identifies whether or not the parents feel they need support from staff to have their individual needs met and is measured by a dichotomous yes-no response. All three of the subscales have a reliability coefficient of 0.91 (Kristjansdottir, 1995). A further four questions invite parents to comment on their satisfaction with and expectations of hospital services, and the relevance and ease of the tool, while two questions invite comments on how to meet particular needs.

Hospital Anxiety and Depression Scale (HADS)

The HADS (Appendix 11) by Zigmond and Snaith (1983) is a recognised practical and suitable self-rating instrument for anxiety and depression (Mykletun, Stordal, & Dahl, 2001). It is available in over ten languages, a number of which have had psychometric validation published (Botega, Ponde, Medeiros, Lima, & Guerreiro, 1998; Herman & Buss, 1994; Leung, Ho, Kan, & Hung, 1993; Mykletun et al., 2001; Puaari, Delvaux, Farracques, & Robaye, 1989; Terol, Lopz-Roig, Rodriguez-Marin, Paster, & Reig, 2000). For the anxiety subscale Cronbach alpha has been found to be between 0.78-0.93 and

for the depression subscale 0.82-0.90 (Mykletun et al., 2001). The HADS was used in this study to assess the symptom severity and number of anxiety disorders and depression cases in parents with children hospitalised with a chronic respiratory disease. This tool contains fourteen questions divided equally into two subscales, the Anxiety subscale and Depression subscale. Measurement of the overall severity of anxiety and depression is rated on a four point (0-3) scale and answers correspond to a numerical value ranging from zero to three for each question. To overcome response bias the developers varied the order of responses, so eight items are scored from three to zero and six are scored from zero to three (Zigmond & Snaith, 1983). A total score of zero to seven suggests that the respondent does not have anxiety or depression; borderline cases score between eight and ten, and definite cases of anxiety and depression score eleven and above.

Demographic questionnaire

Twenty-two questions to collect key demographic data were developed (Appendix 12). General information relating to age, gender, marital status, ethnicity, employment status and levels of education was sought. Specific to their child's hospitalisation, participants were asked about the nature and severity of their child's admission, whether it was planned or unplanned, length of current hospitalisation and number of previous admissions. Participants were asked if they had other children, and if so, whether these children had experienced a hospital admission. Finally an open ended question asked participants to describe in their own words what "family centred care" meant to them.

Data Analysis

All data was entered into SPSS. Advice was sought from a biostatistician re sampling and analysis and this support continued during the analysis phase. Demographic characteristics and responses from the questionnaires underwent descriptive and inferential statistical analysis using SPSS for Windows software.

Descriptive statistics explored individual characteristics of the variables and included the mean, median, range, proportion, frequency and standard deviation. Inferential statistics were used to explore relationships between staff and parents, and the impact of depression on functioning and coping. Consultation with the biostatistician led to the recommendation that a sample size of 45 health professionals and 45 parents would allow for differences to be detected.

Stage 2: Part B: Qualitative interviews with parents

Aim

Stage Two Part B consisted of semi–structured interviews of twenty three, of the fifty parents whose child has a chronic respiratory disease surveyed in Part A, from the two paediatric wards at Hospital B. The interviews examined levels of self-efficacy, confidence and coping when managing recurrent hospital episodes and aimed to explore the relationship between partnerships in care and self-efficacy.

Design

Qualitative interviews were chosen for this stage of the study as they allow for the exploration of individual attitudes, feelings, ideas and thoughts (Beanland. C, Schneider. Z, LoBiondo-Wood.G, & Haber.J, 1999). Semi-structured interviews between fifteen and sixty minutes long were undertaken either in the hospital or at the participant's home. An interview schedule containing eight questions was used to guide the interviews (Appendix 13). The questions were designed to capture parental self-efficacy, community support and the impact on the family living with a child with a chronic respiratory disease.

The recruitment process: Stage 2: Part B

The researcher attended nursing handovers in order to outline the study and encourage participation in facilitating recruitment of parent participants. The

researcher visited the wards up to two times a day to discuss with nursing personnel the identification of potential parent participants.

Once potential participants were identified in either of the two wards by the Charge Nurse or other nursing personnel, the nurse assigned to care for the child approached the parent/s. This initial approach was to gauge parental interest in participating in the study and to deliver the information sheet for the parent to read. This sheet detailed what the study was investigating, inclusion/exclusion criteria, time commitment, interview process, survey tools, confidentiality of their identity, participant rights, timeframe of study, storage of information, what the information will contribute to and who to contact for support (Appendix 14). In order to keep track of which parents had been identified and approached by nursing personnel, a form (Appendix 15) was placed in the nursing stations. The staff/researcher recorded potential participant names and the nurse who had approached them. This prevented participants being approached a number of times and avoided the possibility of coercion.

After the nurse assigned to care for the chid had spoken with parents to ascertain their interest in the study, the researcher met with the interested participants to introduce herself and discuss the study further and answer any questions. The parents were then left overnight to consider whether they wished to participate. The following day the researcher re-approached the parents to gauge interest in the study and for those willing, arrange a time and venue that best suited. For the majority of participants home was their choice of venue for an interview, which was then scheduled to occur within four days of discharge from hospital. For the home interviews the researcher gathered the participant's contact details and informed the parent/s that she would phone them the evening before the scheduled meeting to ensure that the day and time was still convenient. There was a need on a number of occasions to reschedule the interview in order to capture both parents or accommodate other family/work commitments. Of those who agreed to participate only two withdrew. One

needed to reschedule twice for midwife visits and was only available outside the four day discharge criterion, and the other was moving house and felt overwhelmed. A total of twenty three agreed to participate.

The Interviews

Each interview was preceded by an introductory conversation in which the researcher established rapport by showing interest in the family and their unique history, while revisiting the purpose of the study and format of the interview. Consent was reviewed and signed prior to the commencement of the interview to ensure it was informed (Appendix 16). All parents were assured that they could stop the interview at any point and it would in no way affect any care and/or support they received for their child or themselves presently or in the future.

The researcher started the interview by asking the parents to identify their child's symptoms and what precipitated the hospital admission. Where possible the researcher let the parents direct the conversation, allowing for the emergence of topics pertinent to the individual parent. This frequently resulted in parents answering a number of the questions on the interview schedule. However, in interviews in which relevant topics where being omitted, the researcher used her individual reflective listening communication skills to direct the conversation back to relevant topics while encouraging elaboration of emerging topics.

The recorded interviews ranged from fifteen to sixty minutes; however, the interview process took anywhere from one hour to three and a half hours. This extensive interview process was a result of the interview location (participant's home) and the sensitive nature of the interview topic which necessitated a comprehensive exit strategy to ensure parents felt well supported. On completion of the interview the researcher thanked the parent for sharing their story and engaged in communication on topics of their choice. In numerous cases this resulted in further discussions around their child's experience and that

of their family which eventually moved to more general conversation, where upon the researcher felt that it was appropriate to terminate the visit.

Initially the researcher transcribed the taped interviews; however, progress was extremely slow, so a transcription secretary was hired to transcribe the remaining interviews. The transcription secretary had signed a departmental confidentiality agreement prior to being approached for this study. All interviews were downloaded onto the researcher's computer and digitally transferred to the transcription secretary who transcribed them and e-mailed them back to the researcher who checked them against the taped interviews.

The transcripts were put into a common format and read several times to consider possible meanings, and from these, emerging patterns were identified, classified and named. Tables were used to focus on what was emerging and to develop categories which were then conceptualised into broad themes by the researcher and her supervisor.

Saturation of themes was used to determine the number of participants recruited for this stage of the study. Data saturation occurs when the researcher is no longer hearing or seeing fresh information. Unlike quantitative researchers who delay data analysis until completion of the study, qualitative researchers analyse their data during their study (Kerr, Nixon, & Wild, 2010). In order for saturation to be recognised, the researcher, following transcription of interviews and re-checking against the tape, followed Thomas's (2006) general inductive approach and read each interview closely to become familiar with its content and gain an understanding of the themes and events covered within the interviews (Thomas, 2006). Once the researcher, in consultation with her supervisors, felt that no new information was being given, saturation was considered achieved. This occurred after a total of twenty-three interviews.

Reliability and validity of measures

All of the tools used in this study have previously been used to assess chronic disease, thus providing evidence that the chosen tools are valid at measuring parental needs, coping, anxiety and depression in this sample of participants (Polit & Beck, 2004). Additionally, all of these established tools have been psychometrically tested and have a Cronbach alpha over 0.7, suggesting that each of the instruments is homogeneous, and all of the items within these tools accurately measured their designated attributes (Polit & Beck, 2004).

However, these tools could have been at risk of response bias, where the participants may have wanted to present favourable images of themselves, and therefore misrepresented their responses to fit in with what they believed health professionals or organisations would deem to be appropriate. The researcher tried to alleviate this by ensuring complete anonymity was maintained and clearly stating within the information sheets that participants' employment or care of their child would in no way be affected by participation in this study (Polit & Beck, 2004). The literature also suggests that the validity of an established measure may be compromised when it is transferred from a paper format to an online version (Whitehead, 2007). However, the PFCC tool that was placed on-line in this study had previously been converted to an on-line survey, and psychometric testing by the developers has been done (Carmen et al., 2008).

Another potential risk to bias exists as the on-line PFCC survey was sent to nurses' work e-mail address. There is the potential that some nurses, who were away from work or were too busy while at work, were not able to access or complete the survey. This may have limited the recruitment to full time or permanent nurses or senior nurses who held senior positions, and therefore may have had more time at the computer as part of their role. However, in order to allow for this a number of reminders were sent out to allow for those nurses on

vacation, while nurses were also able to exit from the survey and return to fill it in at a later stage. Moreover, issues of repeat participation, in which participants could submit more than one survey (Whitehead, 2007), may have been a weakness in this study; however in the covering letter it was stated in bold type that all participants were to complete only one version of the study.

Trustworthiness: Personal reflection

Due to the influence that a researcher can have on the generation and analysis of data (Polit & Beck, 2004; Whitehead, 2007), it is important that I set out my personal circumstances (Clarke, 1998).

At the age of two my middle son was diagnosed with a chronic disease, though he had been symptomatic since birth. My experiences of living with a child's chronic disease were mirrored in the literature reviewed, the feelings of pressure trying to juggle everyone's needs, feelings of fear over his health and prognosis, and frustration about the lack of facilities available to parents. Although as a registered nurse I felt confident and capable of managing my son's disease while he was hospitalised, there were times when I felt I just wanted to be a parent and not a nurse, managing his treatments. However, at times I found this really hard. I was unsure if it was because health professionals had identified that I was a nurse and therefore assumed I would wish to take on the nursing duties of my son, or if in fact it was the expectation of health professionals that all parents would be responsible for the majority of their child's care. It was these questions that underpinned this inquiry into how well FCC is integrated in our facilities and how much parental psychological well-being and circumstances influences parents ability to manage and engage in partnership with health professionals in the care of their child.

Because of my position as a nurse and mother of a child with a chronic disease, it was important for the trustworthiness of this study that I reflected constantly on how my own values, beliefs and personal experience could have

affected this research process (Clarke, 1998). It was also important to solicit the assistance with analysis of a senior researcher who could ensure that my personal experience did not bias my interpretation of the data. The engagement of a senior investigator, who has a wealth of skill and expertise in the analysis and interpretation of qualitative data, is a strength of this study, offering a divergent perspective and triangulation (Polit & Beck, 2004).

Chapter Four

Results

Stage One Findings

Introduction

The main focus of this chapter is to present the results of the study.

Stage One examined how health professionals perceived the concepts of Patient–Family-Centered-Care (PFCC) to be practiced within the four main centres in New Zealand. In addition a national benchmark of the four hospitals was undertaken to establish the ranking of individual hospitals progress towards implementing PFCC. A further international benchmarking process was undertaken to identify how well the New Zealand paediatric service compares to other countries in the implementation of PFCC.

Following the benchmarking stage, Stage Two Part A examined parental needs, anxiety, depression and coping strategies, while Stage Two Part B explored parental self-efficacy.

Staff demographics

Eighty two questionnaires from nurses were returned from the four hospitals (table 1) the majority from Hospital D (n=52). Due to the distribution of the survey in three facilities by e-mail it was not possible to calculate the response rate related to surveys distributed. Fifty-four percent of the respondents were forty years and over reflecting the national and international trend of an aging nursing workforce (Dudley, 2009; Eaton et al., 2010; Graham & Duffield, 2010). Over fifty percent were married and seventy nine percent were of New Zealand European descent. Forty-eight percent reported having children and fifty-eight percent of those with children reported that one of their own children

had experienced a hospital admission. The respondents predominately worked between thirty two and forty hours a week. The majority were employed in the role of registered nurse, while only twenty eight percent held more senior roles. This corresponded with the percentage of nurses who had undertaken Postgraduate education (35%).

Table 3: Demographic description of sample of 82 participants

Variable	Number	Percentage
Hospital		
Hospital A	3	3.6
Hospital B	18	21.9
Hospital C	9	10.9
Hospital D	52	30.0
Age		
20-30 years	22	27.0
30-40 years	15	18.3
40-50 years	24	29.3
>60 years	20	24.4
Gender		
Male	1	1.2
Female	76	93.0
Marital state		
Single	16	19.5
Married	43	53.0
Defacto	16	19.5
Separated	2	2.4
Divorced	4	4.9
Ethnicity		
New Zealand European	65	79.3
Niuean	1	1.22
Chinese	4	4.9
Other	3	3.7
Number of children		
1	8	9.8
2	20	23.4
3	10	12.2
4	1	1.2
5 or more	1	1.2
Child admitted to hospital		
Yes	23	28.0
No	18	22.0
Role		
Registered nurse	52	63.0
Enrolled nurse	2	2.4
Nurse educator	13	16.0
Charge nurse	6	7.3
Nurse coordinator	2	2.4
Nurse practitioner	2	2.4
Hours of employment		
8 or less	1	1.2

8-16	4	4.9
16-24	10	12.2
24-32	11	13.4
32-40	35	43.0
40 or more	17	21.0
Highest nursing qualification		
Diploma	17	21.0
Degree	28	34.0
Postgraduate certificate	10	12.2
Postgraduate diploma	6	7.3
Masters	12	15.0

Evaluation of the individual hospital subscales

The PFCC score of each institution was calculated by totalling all participant scores on all items (Carmen et al., 2008). Cronbach's alpha was used to determine the internal consistency of the scales. All subscales showed a high internal consistency with Cronbach's alpha ranging from .70 to .99. The four hospitals were then categorized into one of three levels of PFCC practice developed by Carmen, Teal and Guzzetta (2008). These levels determined whether a hospital is at the beginning (mean<2.71), intermediate (mean=2.71-3.1) or advanced (mean>3.1) stage of PFCC practice (Carmen et al., 2008).

Table 4: Categories for PFCC practice

Level	*Mean*
1 (Beginning)	< 2.71
2 (Intermediate)	2.71-3.1
3 (Advanced)	> 3.1

Hospital A

An overall mean score of 1.66 suggests the nurses sampled see Hospital A at level one of PFCC practice. Examination of the subscales shows nurses perceive Hospital A as performing at level one in twelve of the subscales, at level two in five areas, and at level three in two areas: overall design of hospital (mean=3.25) and quality of nearby facilities (mean=3.50).

Hospital B

An overall mean score of 1.94 suggests the nurses sampled see Hospital B practising at level one of PFCC practice. Evaluation by subscales found nurses perceived Hospital B to be functioning at level one in eighteen of the subscales. Two subscales fell within level two of practice: allowing families to develop and provide a plan of care while participating in the evaluation of their child's condition (mean=2.76) and overall design of the hospital (mean=2.81).

Hospital C

An overall mean score of 3.39 suggests the nurses sampled saw Hospital C at level three of PFCC practice. Appraisal of the mean scores showed nurses perceived Hospital C was performing at level three in eleven of the subscales, at level two in one subscale and at level one in six areas. As depicted by means this hospital was assessed at level three in allowing families to participate and be involved in the planning, discharge and evaluation of their child's care (mean=4.61); overall design of hospital (mean=5.80); allowing parents to stay with their child in normal noncritical times (mean=3.89); and during critical times such as invasive procedures, CPR pre and post-surgical procedures (mean=3.25). Hospital C was also at level three of PFCC practice in overall décor of the hospital (mean=4.28) the quality of nearby facilities for families (mean 4.06); design and quality of inpatient rooms (mean=4-19) and lounge areas (mean=4.17). Additionally this hospital was at level three for involving children (mean=4.81) and families (mean=4.06) in hospital design and policy.

Hospital D

An overall mean score of 2.34 suggests the nurses sampled see Hospital D at level one of PFCC practice (table 3). Examination of the subscales found that nurses perceive Hospital D as performing at level one in twelve of the subscales, at level two in four areas and at level three in three areas. The four areas that nurses' perceived Hospital D to be practising at an advanced level were: allowing families to participate in assessing and evaluating their child's

condition and developing a care plan and discharge plan (mean=3.19); in the overall design of the hospital (mean =3.39) and with involving children in hospital design and policy (mean= 3.22).

Table 5: Mean Scores for Hospital A, B, C and D by subscale

Subscale	Hospital D Mean/ category		Hospital A Mean/ category		Hospital B Mean/ category		Hospital C Mean category	
Family Participation and Involvement	3.19	(3)	2.25	(1)	2.76	(2)	4.61	(3)
Overall Design of Hospital	3.39	(3)	3.25	(3)	2.81	(2)	5.80	(3)
Togetherness During Normal Times	2.63	(2)	2.00	(1)	2.50	(1)	3.89	(3)
Use of Signs Within Hospital	2.00	(1)	1.75	(1)	1.54	(1)	2.50	(1)
Consultation Rooms	1.29	(1)	1.17	(1)	0.78	(1)	1.50	(1)
Overall Décor of the Hospital	2.82	(2)	2.75	(2)	2.50	(1)	4.28	(3)
Organizational Benefits of PFCC	2.10	(1)	1.25	(1)	1.71	(1)	3.11	(2)
Quality of Nearby Facilities	2.61	(1)	3.50	(3)	2.06	(1)	4.06	(3)
Design and Quality of Lounge Areas	2.96	(2)	2.92	(2)	2.18	(1)	4.17	(3)
Improved Satisfaction due to PFCC Concepts	2.09	(1)	1.42	(1)	1.67	(1)	2.83	(2)
Procedures and Treatment Rooms	0.89	(1)	0.83	(1)	0.78	(1)	1.39	(1)
Design and Quality of Hospital Entrances	1.91	(1)	2.17	(1)	1.90	(1)	2.89	(2)
Clear Definition of PFCC	0.86	(1)	1.33	(1)	1.11	(1)	1.00	(1)
Togetherness During Critical Times	2.14	(1)	1.92	(1)	2.30	(1)	3.25	(3)
Improved Retention due to PFCC Concepts	1.84	(1)	0.00	(1)	1.39	(1)	2.52	(1)
Design and Quality of Staff Areas	1.39	(1)	1.50	(1)	1.33	(1)	2.22	(1)
Design and Quality of Inpatient Rooms	2.91	(2)	2.92	(2)	2.10	(1)	4.19	(3)
Design and Quality of Parking	2.10	(1)	2.75	(2)	1.80	(1)	2.47	(1)
Family Involvement in Hospital	2.99	(2)	2.08	(1)	2.25	(1)	4.06	(3)
Children Involvement in Hospital	3.22	(3)	2.67	(1)	2.60	(1)	4.81	(3)
Overall Score for Hospital	2.34	(1)	1.66	(1)	1.94	(1)	3.39	(3)

National benchmarking evaluation of the four hospitals

In line with Carmen et al's (2008) benchmarking survey, a minimum of ten respondents per hospital was required for an individual hospital to be included within the benchmarking process, therefore hospital A with only three respondents was excluded (Carmen et al., 2008). For the three hospitals benchmarked within New Zealand, overall mean PFCC scores indicates that Hospital C is the highest ranking hospital for the implementation of PFCC practice (table 4) with a mean score of 3.39. Hospital D ranks second with a mean score of 2.34 while Hospital B is third with a mean score of 1.94.

Hospital C with the highest mean indicates it is the only hospital measured within New Zealand performing at level three of PFCC practice while the other two are performing at level one of practice.

Hospital B

Hospital B was ranked third overall. One subscale ranked first but seventeen ranked third. Only two subscales were ranked second; Design and quality of Hospital entrances and togetherness during critical times.

Hospital C

Overall of the four hospitals benchmarked Hospital C was ranked first with all bar one subscale ranked top; having a clear definition of PFCC.

Hospital D

Hospital D ranked second for overall PFCC practice. Of the twenty subscales seventeen ranked second while two ranked third overall, one subscale design and quality of hospital entrances ranked second equal with Hospital B.

Table 6: Ranking of Hospitals by subscale (out of three)

Subscale	D	B	C
Family Participation and Involvement	2	3	1
Overall Design of Hospital	2	3	1
Togetherness During Normal Times	2	3	1
Use of Signs Within Hospital	2	3	1
Consultation Rooms	2	3	1
Overall Décor of the Hospital	2	3	1
Organizational Benefits of PFCC	2	3	1
Quality of Nearby Facilities	2	3	1
Design and Quality of Lounge Areas	2	3	1
Improved Satisfaction due to PFCC Concepts	2	3	1
Procedures and Treatment Rooms	2	3	1
Design and Quality of Hospital Entrances	2 equal	2 equal	1
Clear Definition of PFCC	3	1	2
Togetherness During Critical Times	3	2	1
Improved Retention due to PFCC Concepts	2	3	1
Design and Quality of Staff Areas	2	3	1
Design and Quality of Inpatient Rooms	2	3	1
Design and Quality of Parking	2	3	1
Family Involvement in Hospital	2	3	1
Children Involvement in Hospital	2	3	1
Overall ranking for Hospital	2	3	1

Comparison of hospitals by subscales - a New Zealand national benchmarking process

Family Participation and Involvement: addresses the families' involvement in assessing symptoms, evaluating responses, developing and providing care and discharge plans. Evaluation of means within this subscale indicate that two of the hospitals (Hospital C and Hospital D) are practicing at level three of PFCC practice while Hospital B (mean=3.39) is working at level two.

Overall Design of Hospital: explores whether the hospital is a place of healing, does it encourage partnerships between health personal and families; can families obtain information and support; does the hospital provide opportunities for families to learn about community resources, their child's illness and how to care for their child. Evaluation of means indicate two of the hospitals are practicing at level three of PFCC within this subscale while Hospital B (mean=2.80) is only practicing at level two.

Togetherness during Normal Times: assesses whether families are able to stay with their child twenty four hours a day, during shift changes and physician rounds. Assessment of means within this subscale indicates that Hospital C (mean=3.89) is the only hospital practicing at level three while the remaining two are at level one of practice.

Use of Signs within the Hospital: measures whether signs are understandable to patients who do not read English and if translation services are available; if signs are written at an appropriate reading age and worded positively and respectively. Evaluation of the means within this subscale indicates that signage within these New Zealand paediatric facilities is only at level one of PFCC practice with all three facilities scoring a mean of less than 2.71**.**

Consultation Rooms: measures how accessible consultation rooms are; if the facility has a family resource centre and a place for spiritual support, mediation and or prayer. Evaluation of the means within this subscale indicates that within those hospitals assessed in New Zealand accessibility of consultation rooms and family resource centres is only at level one of PFCC practice with all three facilities scoring a mean of less than 2.71.

Overall Décor of the Hospital: looks at whether the facility design creates a healing environment for patients and families through artwork, colours, views and security systems. Evaluation of the means within this subscale suggests that Hospital C paediatric service is the only hospital practicing at level three, while Hospital A is at level two and Hospital B is only at level one.

Organisational Benefits of PFCC: assesses whether PFCC has been adopted and is consistently practised; if operations have improved and benefits exist due to the organisation's commitment to PFCC. Assessment of the means for this subscale implies that while Hospital C is practicing at level three, the remaining are only at level one.

Quality of Nearby Facilities: looks at what facilities are available to families such as laundry facilities, showers, areas for food storage and preparation, coffee/tea making facilities. Evaluation of means suggests that Hospital C is practicing at level three, while Hospital B and Hospital D are only at level one.

Design and Quality of Lounge Areas: measures whether the reception area is accessible, welcoming and comfortable; if restrooms are accessible and convenient; clocks are visible and the television does not dominate the space visually or acoustically. Assessment of the means within this subscale indicates that Hospital C is practicing at level three, while Hospital D is at level two and Hospital B is only at level one.

Improved Satisfaction due to PFCC concepts: addresses inpatient, outpatient, nurse and doctor satisfaction. Evaluation of means for this subscale suggests that within these three hospitals increased satisfaction related to the introduction of PFCC concepts is not that evident. Two of the hospitals are only at level one for this subscale (Hospital B and Hospital D) while Hospital A is at level two.

Procedures and Treatment Rooms: looks at how adequate the rooms are at providing space for family members during procedures and if supplies and equipment are stored away to minimise interference for the family. Assessment of means for this subscale indicates that the physical environment provided for procedures, storing of equipment and supplies is only at level one within all three hospitals.

Design and Quality of Hospital Entrances: evaluates the facilities entrances based on visibility, identification, welcoming, protection and accessibility. Evaluation of means for this subscale suggests that Hospital C is practicing at a higher level (two) than both of the other hospitals which are only practicing at level one.

Clear Definition of PFCC: asks whether the facility includes PFCC concepts in performance reviews and job descriptions and if patients and families always define family and participate in staff education. Assessment of means indicates that these three paediatric facilities within New Zealand do not possess a clear definition of PFCC with all three hospitals only at level one of practice for this subscale.

Togetherness During Critical Times: assesses whether families are allowed to remain with their child during invasive procedures, CPR, pre induction and postoperatively. Evaluation of means suggests that two out of three of the hospitals assessed are only at level one of PFCC practice within this subscale with only Hospital C practicing at level three.

Improved Retention due to PFCC Concepts: assesses health professional and family support retention related to the facilities adoption of PFCC concepts. Evaluation of means suggest that all hospitals are only practicing at level one with Hospital C ranked first, Hospital D second and Hospital B third.

Design and Quality of Staff Areas: looks at the provision, design and convenience of staff respite areas. Appraisal of means within this subscale implies that paediatric services within the three major centres in New Zealand are only practicing at level one of PFCC practice.

Design and Quality of Inpatient Rooms: measures whether families can personalise their room along with its size and configuration. Also looks at availability within the room of a workspace, computer access, secure storage space, lighting and amenities such as plugs and tubs. Evaluation of means suggests variations on level of PFCC practice for this subscale exists between hospitals, with Hospital C practicing at level three, Hospital D practicing at level two and Hospital B at level one.

Design and Quality of Parking: evaluates the facilities parking on such factors as amount, accessibility, convenience, safety, cost, navigation and assistance. Assessment of means for

this subscale suggests that for all of these hospitals parking for relatives remains an issue with all facilities practicing at level one.

Family Involvement in Hospital: assesses the facilities involvement of families in the representation of hospitals in an outreach role, in the development of clinical education materials, policy and facility design, bio-ethics and other hospital committees. Appraisal of means for this subscale indicates that again variation between hospitals exists with Hospital C at level three of PFCC practice, Hospital D at level two while Hospital B is only at level one.

Children Involvement in Hospital: measures how much facilities include children in the design of space, patient to patient support groups, policy making, patient care and process change, development of amenities, programs that support patients and families and that represent the hospital in an outreach role. Evaluation of means for this subscale suggests that while both Hospital C and Hospital D are practicing at level three with involving children in the hospital, Hospital B scored only at level one for involving children.

International benchmarking

The overall mean PFCC score (table 5) for hospitals within New Zealand is 2.36 (SD 1.59; min=0, max=4.31) indicating an overall PFCC practice of level one. Evaluation of subscales shows nurses sampled perceive that New Zealand hospitals are performing at level one in ten of the subscales, at level two in four areas and at level three in three areas: allowing families to participate and be involved in the evaluation of their child's condition and care plan development (mean=3.22); overall design of the facilities (mean= 3.51) and involving children in hospital design and policy (mean= 3.23).

Table 7: benchmarking evaluation between 83 NACHRI hospitals (Carmen et al., 2008) and 3 New Zealand hospitals

Subscale	NACHRI Mean	New Zealand Mean
Family Participation and Involvement	3.20	3.22
Overall Design of Hospital	3.24	3.51
Togetherness During Normal Times	3.39	2.71
Use of Signs Within Hospital	3.19	1.94
Consultation Rooms	3.17	1.19
Overall Décor of the Hospital	3.11	2.90
Organizational Benefits of PFCC	3.20	2.09
Quality of Nearby Facilities	2.84	2.68
Design and Quality of Lounge Areas	2.96	2.92
Improved Satisfaction due to PFCC Concepts	3.16	2.05
Procedures and Treatment Rooms	2.82	0.92
Design and Quality of Hospital Entrances	2.96	2.02
Clear Definition of PFCC	2.92	2.34
Togetherness During Critical Times	2.84	2.29
Improved Retention due to PFCC Concepts	2.75	1.78
Design and Quality of Staff Areas	2.67	1.47
Design and Quality of Inpatient Rooms	2.64	2.87
Design and Quality of Parking	2.67	2.09
Family Involvement in Hospital	2.64	2.90
Children Involvement in Hospital	2.39	3.23
Overall Score for Hospital	2.92	2.36

Comparison of hospitals by subscales: An international benchmarking Process

After benchmarking New Zealand facilities against international facilities (Carmen et al., 2008) New Zealand is viewed as being better at implementing the following three concepts of PFCC compared to international facilities

- That children are included in hospital design and policy
- Availability of amenities for parents and ability for parents to personalise their space
- That parent's are involved in hospital policy and design.

New Zealand was viewed as being similar to international facilities at implementing the following six PFCC

- Involving family in assessing their child's symptoms and evaluating responses and developing and providing care
- Partnership between the family and health professional
- Creating a sense of healing
- Design and quality of lounge areas
- Provision, design and convenience of staff respite areas
- Accessibility, amount, convenience and cost of parking.

New Zealand was viewed as being worse at implementing the remaining eleven PFCC concepts compared to international facilities

- Allowing families to stay with their child during normal noncritical times
- Provision of adequate signage within facilities
- That consultation and resource facilities are accessible
- That PFCC has consistently been adopted and practised

- That nearby facilities for family members are available
- That there is improved satisfaction amongst personnel related to PFCC concepts
- The design of procedure and treatment rooms
- Design and quality of hospital entrances
- That PFCC concepts are included in performance reviews, job descriptions, staff education and that families always define family
- That families are able to stay with their child during invasive procedures such as CPR, pre induction and postoperatively
- That adoption of PFCC has resulted in retention of health professionals

Summary of the key findings

This benchmarking survey identifies that two of the paediatric facilities within New Zealand surveyed (Hospital D, and Hospital B) are only at level one in terms of the implementation of PFCC with only one facility, Hospital C, being at an advanced stage. This suggests that on the whole New Zealand is only at the beginning stages of integrating this philosophy of family–centred care into practice. Assessment of the findings identified that all participants believe that the basic concepts of PFCC are not well met and the implementation of PFCC has not resulted in improved job satisfaction and retention of staff within the facilities. Furthermore examination of means indicate that the physical environment in particular does not support the concept of PFCC evidenced by the following three subscales only scoring at a beginning stage within all facilities; accessibility of consultation rooms and providing a family resource centre or place for spiritual support; providing adequate space for family members during procedures and the provision and design of staff respite areas.

Additionally the majority of participants believe that the paediatric facilities (two out of the three) do not support families staying with their children during invasive and non-invasive procedures and do not believe that the concepts of

PFCC result in improved institutional operations. However the bulk of participants do consider that facilities within New Zealand encourage partnerships between health personnel and families whereby support and information about community resources, their child's illness and how to care for their child can easily be obtained by family members.

It is clear from the results variations between facilities exist with some hospitals performing well in certain areas of PFCC implementation compared to others. As expected because Hospital C is performing at an overall higher level than the other three facilities, they are performing better in the majority of subscales but in particular the degree to which families are able to stay with their child in invasive and non–invasive procedures; the degree to which families are allowed to be involved in the treatment and evaluation of their child's health; the positive impact PFCC concepts have had on institutional operations and the involvement families have in the development of hospital polices and design of space. Like Hospital C, Hospital D compared to other facilities is performing at a higher level of PFCC integration in areas of family participation in treatment and evaluation of their child's health along with involvement of children in policy development and overall design of space. Hospital B is performing best in areas of design and policy elements including overall design and décor of their facility.

When comparing the results of this national benchmarking survey to other facilities internationally, the results suggest that of the twenty concepts, New Zealand is similar to other facilities in the United States, Canada and Italy in the following six concepts; family participation and involvement; overall design of hospital; overall décor of hospital; design and quality of lounge areas; design and quality of staff areas and design and quality of parking. However New Zealand is well below in eleven of the concepts while being better in the following three; the extent to which facilities allow families to be involved in the treatment and evaluation of their child's health; design and quality of inpatient rooms and involvement of children in the development of hospital policy and

design of space. Overall it is evident that in order for the paediatric facilities within New Zealand to compete on an international level with the integration of PFCC then improvements need to be made over a majority of concepts.

Chapter Five

Quantitative results: Stage Two

Part A

Introduction

This section presents the findings from fifty one parent respondents with a child admitted to one hospital (Hospital B) with a chronic respiratory condition. Each participant was asked to complete four established tools: The Patient-Family–Centered Care survey (ten questions), Coping Health Inventory for Parents (CHIP), Needs of Parents of Hospitalised children (NPQ) and Hospital Anxiety and Depression Scale (HADS). Within this chapter participant demographics and the findings from each tool are presented. The chapter concludes with the key findings.

Parent demographics

A total of fifty-one parents participated within this stage of the study of which forty-four were mothers, four were fathers and three were grandparents. Eighty percent ($n=41$) of the participants were married/cohabitating and over half were in employment ($n=27$, 53%). Ten (20%) of the participants obtained bursary/NCEA3[1], while the majority ($n=13$, 25%) obtained School certificate/NCEA1[2].The majority of participants were of European/Pakeha ($n=41$, 80%) descent while fourteen percent ($n=7$) classified themselves as Maori, Samoan or Indian and six percent ($n=3$) classified themselves as other.

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[1] Bursary/NCEA3= highest School Qualification in New Zealand

[2] School certificate/NCEA 1= lowest School Qualification in New Zealand

The reasons for admission were an acute exacerbation of Asthma (*n*=22, 43%), Cystic fibrosis (*n*=18, 35%) or other chronic conditions such as laryngeal collapse, laryngeal papillomas was twenty-two percent (*n* =11). The majority of parents ranged between thirty-one to forty years of age (*n*=21, 41%) and over forty years of age (*n*=21, 41%), while the largest percentage of children were between three and six years old (n=21, 41%). Fifteen (29%) parents perceived their child's condition to be very severe, twenty- nine (57%) perceived it to be severe, whereas only six (12%) perceived it as not severe. For twenty (39%) children this was between their first and fifth hospital admission, for fifteen (29%) it was between their sixth and tenth hospital admission, while for the remaining thirteen children, five (10%) had experienced between eleven to fifteen hospitalisations, three (6%) had experienced between sixteen to twenty hospitalisations and five (10%) had experienced over twenty hospitalisations.

Eighty percent (*n*=41) of parents classified their child's admission as unplanned. The majority of hospital stays lasted between two and seven days (*n*=36, 70%) and only four percent (*n*=2) were more than fourteen days. Forty-one (80%) parents had other children in the household and seventy percent (*n*=36) of parents stated that within their family only their child with a chronic respiratory disease had experienced hospital. The majority of parents lived within travelling distance by car (1 day *n*=43) to hospital.

Table 8: Demographic description of the sample of fifty one parent participants

Variable	*Number*	*Percentage*
Relationship to child		
Mother	44	86
Father	4	8
Grandparent	3	6
Marital status		
Married/cohabitating	41	80
Divorced	3	6
Not married/not cohabitating	6	12
Employment		
Employed	27	53

Unemployed	9	18
Not in labour force	8	16
Not specified	6	12
Highest school qualification		
School certificate	13	25
Six form certificate	11	22
University entrance	9	18
Bursary	7	14
NCEA 1	1	2
NCEA 2	2	4
NCEA 3	3	6
Ethnicity		
Maori	4	8
New Zealand European	41	80
Samoan	2	4
Indian	1	2
Other	3	6
Type of admission		
Unplanned	41	80
Planned	10	20
Days in hospital		
2- 7 days	36	70
8-14 days	13	25
More than 14 days	2	4
Other hospital admissions		
With this child	36	70
With this child and my other children	10	20
With my other children	2	4
None	3	6
Number of children		
No other children	7	14
1 other child	18	35
2-3 other children	23	45
4 or more other children	3	6
Travelling distance to hospital by car		
Within daily travelling distance	43	84
Outside daily travelling distance	6	12
Support from family/friends		
Yes	45	88
No	6	12
Ward		
Ward 1	27	53
Ward 2	22	43

Child acute assessment unit (CAA)	2	4
Diagnosis		
Asthma	22	43
Cystic Fibrosis	18	35
Other	11	22
Age of parent		
16-20 years	2	4
21-30 years	7	14
31- 40 years	21	41
Over 40 years	21	41
Age of child		
0-2 years	7	14
3-6 years	21	41
7-11 years	10	20
12 -16 years	13	25
Severity		
Not severe	6	12
Severe	29	57
Very severe	15	29
Number of admissions		
1-5 times	20	39
6-10 times	15	29
11-15 times	5	10
16-20 times	3	6
Over 20 times	5	10

Patient-Family-Centred-Care survey

The PFCC survey is used to identify at what level PFCC concepts are practiced; a high score indicates that PFCC is being implemented at an advanced level. Ten subscales from the PFCC survey (Carmen et al., 2008) were used to assess parent's perceptions on how elements of hospital design support PFCC. Similar to the benchmarking survey undertaken in Stage One of this study and in accordance with the developers of the PFCC tool (Carmen et al., 2008), an overall mean PFCC score was determined to ascertain where parents perceived the integration and application of PFCC in relation to hospital design and policy sat (Level one/ Beginning mean =<2.71, Level two/ Intermediate mean=2.71-3.1 or Level three/ Advanced mean=>3.1).

Table 9: Comparison of Parent and Staff scores on the PFCC at Hospital C

	Parent Mean	SD	Level (L)	Staff Mean	SD	Level (L)
Overall design of Hospital	2.97	.52	(L= 2)	2.81	2.72	(L=2)
Use of Signs Within Hospital	3.02 *	.43	(L=2)	1.54 *	2.08	(L= 1)
Consultation Rooms	2.60	.49	(L=1)	.78	.80	(L=1)
Overall Décor of the Hospital	2.80 *	.53	(L=2)	2.50*	2.37	(L=1)
Quality of Nearby Facilities	2.77 *	.49	(L=2)	2.06*	1.96	(L= 1)
Design and Quality of Lounge Areas	2.74 *	.56	(L=2)	2.18*	2.08	(L=1)
Procedures and Treatment Rooms	3.00*	.55	(L=2)	.78*	.74	(L=1)
Design and Quality of Hospital Entrances	2.87*	.56	(L=2)	1.90*	1.77	(L=1)
Design and Quality of Inpatient Rooms	2.48	.61	(L=1)	2.10	2.05	(L=1)
Design and Quality of Parking	2.29	.74	(L=1)	1.80	1.68	(L=1)
Overall Score for Hospital	2.75	.34	(L=2)	1.85	1.72	(L=1)

*indicates variation in parent and staff perception by level.

Summary of PFCC findings

An overall mean score of 2.67 suggests that the parents sampled see this hospital at level two of PFCC practice in design. Parents rated seven of the design and policy subscales as being at level two and three were at level one; consultation rooms; design and quality of inpatient rooms and design and quality of parking. Parents generally believed that these concepts of PFCC were integrated and applied at a higher level than did staff, with six of the subscales rated higher at level two while only four of the subscales were rated at the same

level; overall design of hospital; consultation rooms; design and quality of inpatient rooms and design and quality of parking. Therefore the variance between the individual concepts and the actual overall mean score of these concepts by both groups was dissimilar, suggesting that parents viewed the integration and application of the PFCC concept, hospital design and policy to be at a higher level than staff within the facility.

Coping Health Inventory for Parents (CHIP)

The parents' response to handling family life with a chronically ill child was assessed using the CHIP. Cronbach's alpha was used to determine the internal consistency of the three scales. Reliability testing on CHIP 1 gave a Cronbach's alpha of .71, CHIP 2 subscale of .72 and CHIP 3 of .74. In order to facilitate comparison with the 'index of normative scores' by McCubbin (1987) and due to a limited response rate from fathers (n=4) and grandparents (n=3) analysis for the CHIP was limited to the forty four mothers only.

Table 10: Mean score ($\bar{x}$) and standard deviation (SD) on the CHIP subscales

Scale & Subscales	$\bar{x}$	SD
CHIP 1:Family integration	41.31	10
CHIP2:Support, esteem, stability	28.33	9
CHIP3: Medical communication	15.43	5

The predominant coping strategy used by mothers was family integration (41.31) followed by support, esteem and stability (28.33) and then Medical communication.

Mothers perceived that maintaining family relationships and a positive outlook on life (CHIP 1) along with focusing on efforts to maintain their own well-being, through social relationships and doing things to manage psychological tensions and strains (CHIP 2), more helpful than focusing on relationships with other parents in a similar situation and the medical staff (CHIP 3).

These findings reflect those of McCubbin et al (1987) (Table 11).

Table 11: "Index of normative scores of mothers" coping patterns in childhood chronic illness (McCubbin, 1987, p. 187)

Scale & Subscales	x	SD
Family integration	40	15
Support, esteem, stability	28	12
Medical communication	15	7

Analysis of each item revealed that the most common coping behaviours recorded by mothers (Table 12) as being extremely helpful were related to strategies associated with the believing in their child's medical care and focusing on the child. The coping behaviours that only a small number of mothers ranked as extremely helpful were related to strategies that focused on themselves and their reaction to stress.

Table 12: The coping behaviours most frequently ranked by mothers as extremely helpful

Exemplar items	n	%
1. Believing that my child is getting the best medical care possible	35	69
2. Trying to maintain family stability	35	69
3. Believing my child(ren) will get better	34	67
4. Doing things with my child(ren)	33	65
5. Being sure prescribed medical treatments for child(ren) are carried out at home on a daily basis	33	65

Table 13: The coping behaviours that mothers most frequently ranked as least helpful

Exemplar items	*n*	*%*
1. Allowing myself to get angry	12	24
2. Purchasing gifts for myself and / or other family members	10	20
3. Concentrating on hobbies (art, music, jogging, etc)	9	18
4. Believing in God	9	18

For each coping strategy mothers were able to identify those coping behaviours they chose not to use. The coping behaviours that mothers most frequently chose not to use (Table 14) were behaviours centred on developing relationships with others and engaging in activities which enhance feelings of individual identity and self -worth. For each coping strategy, if mothers did not find the coping strategy helpful, they could tick 'not possible to use'. The coping behaviours most frequently deemed 'not possible to use' (Table 15) centred on employment opportunities such as 'working outside the home' (*n*=9, 18%) and 'investing time and energy in my job' (*n*=9, 18%). Some mothers also considered it was 'not possible' to use the coping strategies 'being able to get away from the home' and 'talking with other parents in a similar situation' (*n*= 8, 16%, in both).

Table 14: CHIP Behaviours mothers' most commonly "Chose not to use"

Exemplar items	*n*	*%*
1. Believing in God	16	31
2. Talking to someone (not professional counsellor/doctor) about how I feel	9	18
3. Allowing myself to get angry	8	16
4. Purchasing gifts for myself and/or other family members	7	14
5. Working, outside employment	7	14

Table 15: CHIP behaviours that mothers' most frequently rated as 'not possible to use'

Exemplar items	n	%
1. Working, outside employment	9	18
2. Investing time and energy in my job	9	18
3. Being able to get away from the home care tasks and responsibilities for some relief.	8	16
4. Talking with other parents in the same type of situation and learning about their experiences.	8	16
5. Going out with my spouse on a regular basis	7	14

Table 16: Coping strategies and Parental demographics

Parental, Family and Child Demographic Characteristics	Parental Coping Pattern 1: Integration, Cooperation and Optimism			Parental Coping Pattern 2: Support, Esteem and Stability			Parental Coping Pattern 3: Medical Consultation and Communication		
Marital status	*Mean*	*Number*	*Sig.**	*Mean*	*Number*	*Sig.**	*Mean*	*Number*	*Sig.**
1) Married	45.00	25	.	29.00	25	.	14.36	25	.
2) Not married	46.00	2		41.50	2		15.00	2	
Employment status	*Mean*	*Number*		*Mean*	*Number*		*Mean*	*Number*	
1) Employed	45.11	27	.323	30.11	27	.666	14.40	27	.079
2) Not employed	45.00	27		30.11	27		14.40	27	
Type of admission	*Mean*	*Number*		*Mean*	*Number*		*Mean*	*Number*	
1) Unplanned admission	46.00	19	.541	28.37	19	.816	13.95	19	.396
2) Planned admission	43.00	8		34.25	8		15.50	8	
Number of days in hospital	*Mean*	*Number*		*Mean*	*Number*		*Mean*	*Number*	
1) Less than 7 days	45.37	16	.284	29.12	16	.627	16.06	16	.003*
2) Greater than 7 days	44.73	11		31.55	11		12.00	11	
Level of education	*Mean*	*Number*		*Mean*	*Number*		*Mean*	*Number*	

	Mean	Number		Mean	Number		Mean	Number	
1) NCEA 1,2; School Cert; 6th form cert	46.50	12	.218	28.66	12	.992	13.58	12	.484
2) NCEA3, U.E, Bursary	45.27	11		34.45	11		16.09	11	
Support from family and friends	*Mean*	*Number*		*Mean*	*Number*		*Mean*	*Number*	
1) Yes	47.20	24	.349	31.79	24	.653	14.71	24	.534
2) No	28.33	3		16.70	3		12.00	3	
Diagnosis	*Mean*	*Number*		*Mean*	*Number*		*Mean*	*Number*	
1) Asthma	47.66	9	.349	28.67	9	.653	15.44	9	.534
2) Cystic Fibrosis	42.23	13		30.07	13		13.61	13	

Independent t-test

Some evidence was noted of differences in the use of coping strategies by demographic variable (table 16); however, only one was statistically significant. When a child's admission was greater than 7 days, mothers were significantly less likely to use coping pattern 3, which include behaviours that develop more knowledge and understanding of their child's disease through communication and relationships with health professionals and other parents. While other findings were not significant a pattern was noted. The number of mothers not married was too small to make a meaningful comparison. The use of coping strategies by employment status was highly congruent. A difference was noted in the use of coping pattern 2 by admission type. Mothers whose child experienced an unplanned admission were less likely to use coping behaviour 2, such as behaviours that developed relationships with others or engaging in activities which enhanced feelings of individual identity and self-worth although this did not reach statistical significance. Educational level was again related to coping strategies employed with developing relationships with others and participating in activities that boosted feelings of individual identity and self-worth although this did not reach statistical significance. When mothers perceived the level of support from family and friends to be lacking they were less likely to use coping behaviours that focused on strengthening family life

and relationships or engage in activities that enhanced feelings of individual identity and self-worth (CHIP 1 & CHIP 2). Mothers whose child had CF were less likely to employ coping strategies that strengthened family life and relationships or maintain an optimistic definition of the situation (CHIP 1) although this did not reach statistical significance.

Summary of CHIP findings

Analysis of findings suggests that overall all parents within this study appeared to use coping strategies effectively when living with a child who has a chronic respiratory illness. It was also noted that the demographic variables marital status, type of admission, days of hospitalisation, perceived levels of support and respiratory condition appeared to have an influence on the use of the Coping Strategy: integration, cooperation and optimism.

Needs of Parents of Hospitalised Children (NPQ)

Parental perception of needs during hospitalisation of their child with a chronic respiratory disease was explored through the NPQ. For each need the NPQ assesses the importance of the need from the participant perspective, how far the need was met (fulfilment) and whether the participant required support to meet a need. Cronbach's alpha was used to determine the internal consistency of the scales. Reliability testing on the importance subscale gave a Cronbach's alpha of .93, the fulfilment subscale of .95 and the independence subscale of .77.

Table 17: Needs categories and the needs statements included in each category

Category	Description	Question
A	The need to trust	4,32
B	The need to be trusted	18,26,34,40
C	The need for information	6,8,15,19,24,31,38,43,49
D	The need for support and	2,3,7,9,11,13,16,17,36,42,44,50

	guidance	
E	Needs related to human and physical resources	1,5,10,12,14,21,33,35,37,39,41,45,46,47
F	Needs relating to the ill child and other family members	20,22,23,25,27,28,30,48

Table 17 sets out the needs categories and the statements which comprised each category as described by Krisjansdottir (1991, 1995).

Importance score

Of the forty four needs statements (table 18), forty were rated as important by over eighty percent of the parents who responded. While four were rated as important by all of the parent (n=51) sample these were

- That I get advice about the care of my child in preparation for my child's discharge,
- That I can stay with my child 24 hours a day if I wish
- To be able to trust that although I am not present my child will get the best available medical care
- That I get exact information about my child's condition.

The need rated least important by those parents who responded was to 'have a planned meeting with other parents to share and discuss the experience of my child's hospitalisation'.

Fulfilment scores

Fifteen of the needs statements were rated by over eighty percent of the parents who responded as 'not being fulfilled' (table 18). The need statement rated by most of the parents who responded (*n*=25, 100%) as 'not being met was' 'that I can stay with my child 24hours a day if I wish'. The two statements

rated by those parents who responded as being met the most (*n*=26, 74%) were 'To have a planned meeting with other parents to share and discuss the experience of my child's hospitalisation' and 'To be able to meet with parents with similar experiences of an ill child".

Independence scores

In thirty-six of the statements over eighty percent of the respondent parents felt that they needed help meeting the need (table 18). The two top equal need statements that parent respondents felt they needed help meeting were 'That I be prepared for the day of discharge and any change in that date' and ' That I be informed as soon as possible about results from tests done on my child' (*n*=50, 98% for both). While the top two statements that respondent parents rated as not needing assistance to meet were 'To have a planned meeting with other parents to share and discuss the experience of my child's hospitalisation' (*n*=27, 53%) and 'To be able to meet with parents with similar experiences of an ill child' (*n*= 24, 47%)

Summary of NPQ findings

All parents (*n*=51) viewed the most important needs as: receiving advice about the care of their child in preparation for discharge; if they cannot be there that their child will get the best available medical care; that they get the exact information about their child's condition and being able to stay with their child 24 hours a day. However even though all parents (*n*=51) felt that being able to stay with their child 24 hours a day was a priority forty eight out of a possible fifty one parents viewed it as the need that was most often not met. While the needs that over half of the parents viewed as most often met were having a planned meeting with other parents to share and discuss the experience of their child's hospitalisation (*n*=26) and to be able to meet with parents with similar experiences of an ill child (*n*=26). Consequently these two needs were the ones parent respondents rated the highest as not needing assistance to meet. Parents

wanted most support with being prepared for their child's discharge ($n=50$) and being informed of child's results and tests as soon as possible ($n=50$).

Table 18: Parents' response for each needs statement for each scoring system: importance, fulfilment and independence.

Needs statements	Importance score			Fulfilment score			Independence score		
	Important n (%)	Not Important n (%)	*Total Number responses*	Not met n (%)	Met n (%)	*Total Number responses*	Yes n (%)	No n (%)	*Total Number responses*
1 To have a special place in the unit where parents can be by themselves	47 (98)	1 (2)	48/51	20 (65)	11 (35)	31/51	38 (76)	12 (24)	50/51
2 To have a planned meeting with other parents to share and discuss experience of my child's hospitalisation	14 (39)	22 (61)	36/51	9 (26)	26 (74)	35/51	23 (46)	27 (54)	50/51
3 That staff encourage parents to ask questions and seek answers to them	49 (100)	0	49/51	32 (84)	6 (16)	38/51	48 (98)	1 (2)	49/51
4 To be sure that although am not present, my child will get the best available nursing care	50 (100)	0	50/51	40 (98)	1 (2)	42/51	48 (98)	1 (2)	48/51
5 That I get sufficient rest or adequate sleep	41 (93)	3 (7)	44/51	23 (70)	10 (30)	33/51	43 (86)	7 (14)	50/51

Table 18: Parents' response for each needs statement for each scoring system: importance, fulfilment and independence.

Needs statements	Importance score			Fulfilment score			Independence score		
	Important n (%)	Not Important n (%)	*Total Number responses*	Not met n (%)	Met n (%)	*Total Number responses*	Yes n (%)	No n (%)	*Total Number responses*
6 To be able to see a social worker to get information about financial assistance to help ease problems	39 (91)	4 (9)	43/51	23 (57)	17 (43)	40/51	44 (90)	5 (10)	49/51
7 To be able to meet with parents with similar experiences of an ill child	19 (59)	13 (41)	32/51	9 (26)	26 (74)	35/51	26 (52)	24 (48)	50/51
8 That I receive written information about my child's health status so I can review it later	43 (96)	2 (4)	45/51	32 (82)	7 (18)	39/51	49 (98)	1 (2)	50/51
9 To be able to ask nurses and doctors about how to explain the illness and / or tests to my child	46 (98)	1 (2)	46/51	34 (87)	5 (13)	39/51	47 (94)	3 (6)	50/51

Table 18: Parents' response for each needs statement for each scoring system: importance, fulfilment and independence.

Needs statements	Importance score			Fulfilment score			Independence score		
	Important n (%)	Not Important n (%)	*Total Number responses*	Not met n (%)	Met n (%)	*Total Number responses*	Yes n (%)	No n (%)	*Total Number responses*
10 That there is flexibility in the work of the unit according to parents' needs	39 (98)	1 (2)	40/51	26 (81)	6 (19)	32/51	46 (92)	4 (8)	50/51
11 To have a person in the unit (a nurse or a doctor) especially assigned to respond to parents' needs	28 (80)	7 (20)	35/51	23 (66)	12 (34)	35/51	37 (76)	12 (24)	49/51
12 That I get an opportunity to speak privately with a doctor or a nurse about my own feelings or worries	26 (70)	11 (30)	37/51	21 (68)	10 (32)	31/51	38 (78)	11 (22)	49/51
13 That I get advice about the care of my child in preparation for my child's discharge	51 (100)	0	51/51	45 (100)	0	45/51	47 (96)	2 (4)	49/51
14 That I be permitted to make the final decision about the treatment my child will	47 (96)	2 (4)	49/51	39 (91)	4 (9)	43/51	44 (92)	4 (8)	48/51

Table 18: Parents' response for each needs statement for each scoring system: importance, fulfilment and independence.

Needs statements	Importance score			Fulfilment score			Independence score		
	Important n (%)	Not Important n (%)	*Total Number responses*	Not met n (%)	Met n (%)	*Total Number responses*	Yes n (%)	No n (%)	*Total Number responses*
receive									
15 That I be informed about all known health outcomes for my child	50 (100)	0	50/51	42 (98)	1 (2)	43/51	48 (98)	1 (2)	49/51
16 To be encouraged by staff to come and stay with my child	50 (98)	1 (2)	51/51	39 (91)	4 (9)	43/51	46 (94)	3 (6)	49/51
17 That a nurse assists me to recognize my own needs, e.g. meals, sleep	32 (84)	6 (16)	38/51	20 (67)	10 (33)	30/51	40 (83)	8 (17)	48/51
18 To feel that I am trusted to be able to care for my child in hospital	50 (100)	0	50/51	45 (98)	1 (2)	46/51	44 (92)	4 (8)	48/51

Table 18: Parents' response for each needs statement for each scoring system: importance, fulfilment and independence.

Needs statements	Importance score			Fulfilment score			Independence score		
	Important n (%)	Not Important n (%)	*Total Number responses*	Not met n (%)	Met n (%)	*Total Number responses*	Yes n (%)	No n (%)	*Total Number responses*
19 That I be informed about all treatment that my child will receive	49 (100)	0	49/51	46 (98)	1 (2)	47/51	47 (98)	1 (2)	48/51
20 To have a person in the unit especially assigned to take care of the needs of my child	45 (98)	1 (2)	46/51	41 (95)	2 (5)	43/51	46 (94)	3 (6)	49/51
21 That I have a place to sleep in the hospital	47 (100)	0	47/51	37 (93)	3 (7)	40/51			
22 That a nurse follows up my child after discharge	49 (100)	0	49/51	42 (95)	2 (5)	44/51	43 (91)	4 (9)	47/51
23 To be able to participate in the nursing care of my child	45 (98)	1 (2)	46/51	39 (98)	1 (2)	40/51	45 (92)	4 (8)	49/51

Table 18: Parents' response for each needs statement for each scoring system: importance, fulfilment and independence.

Needs statements	Importance score			Fulfilment score			Independence score		
	Important n (%)	Not Important n (%)	*Total Number responses*	Not met n (%)	Met n (%)	*Total Number responses*	Yes n (%)	No n (%)	*Total Number responses*
24 To learn and be informed about how illness affects children's growth and development	47 (100)	0	47/51	25 (89)	3 (11)	28/51	45 (92)	4 (8)	49/51
25 That I can stay with my child 24 hours a day if I wish	51 (100)	0	51/51	48 (100)	0	48/51	46 (94)	3 (6)	49/51
26 To feel that I am not blamed for my child's illness	46 (94)	3 (6)	49/51	46 (96)	2 (4)	48/51	43 (88)	6 (12)	49/51
27 To be able to do physical care for my child, e.g. change nappy, bath, feed, etc	43 (100)	0	43/51	37 (95)	2 (5)	39/51	49 (98)	1 (2)	50/51
28 That I be able to explain things to my relations, friends, and my other child/children	47 (96)	2 (4)	49/51	43 (96)	2 (4)	45/51	36 (72)	14 (28)	50/51

Table 18: Parents' response for each needs statement for each scoring system: importance, fulfilment and independence.

Needs statements	Importance score			Fulfilment score			Independence score		
	Important n (%)	Not Important n (%)	*Total Number responses*	Not met n (%)	Met n (%)	*Total Number responses*	Yes n (%)	No n (%)	*Total Number responses*
29 That I be prepared for the day of discharge and any change in that date	48 (100)	0	48/51	38 (90)	4 (10)	42/51	50 (100)	0	50/51
30 That I have time to be with my other child/ children	47 (98)	1 (2)	48/51	26 (84)	5 (16)	31/51	42 (86)	7 (14)	49/51
31 That I be informed as soon as possible about results from tests done on my child	50 (100)	0	50/51	36 (95)	2 (5)	38/51	50 (100)	0	50/51
32 To be able to trust that although I am not present, my child will get the best available medical care	51 (100)	0	51/51	43 (100)	0	43/51	48 (98)	1 (2)	49/51
33 That nurses recognize and understand the feelings of parents	47 (96)	2 (4)	49/51	39 (95)	2 (5)	41/51	45 (96)	2 (4)	57/51

Table 18: Parents' response for each needs statement for each scoring system: importance, fulfilment and independence.

Needs statements	Importance score			Fulfilment score			Independence score		
	Important n (%)	Not Important n (%)	*Total Number responses*	Not met n (%)	Met n (%)	*Total Number responses*	Yes n (%)	No n (%)	*Total Number responses*
34 That nurses contact and consult me about the care that is needed for the nursing care of my child	50 (100)	0	50/51	45 (100)	0	45/51	48 (98)	1 (2)	49/51
35 To feel that I am important in contributing to my child's wellbeing	48 (100)	0	48/51	43 (96)	2 (4)	45/51	41 (87)	6 (13)	47/51
36 To know that I can contact the ward/ unit after my child has been discharged	48 (98)	1 (2)	49/51	39 (95)	2 (5)	41/51	46 (96)	2 (4)	48/51
37 That I get assistance and support to recognize and understand my own needs, e.g. anxiety, tiredness	34 (87)	5 (13)	39/51	16 (64)	9 (36)	25/51	37 (79)	10 (21)	47/51
38 That I get exact information about my child's condition	51 (100)	0	51/51	42 (100)	0	42/51	49 (96)	2 (4)	51/51

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Table 18: Parents' response for each needs statement for each scoring system: importance, fulfilment and independence.

Needs statements	Importance score			Fulfilment score			Independence score		
	Important n (%)	Not Important n (%)	*Total Number responses*	Not met n (%)	Met n (%)	*Total Number responses*	Yes n (%)	No n (%)	*Total Number responses*
39 That I feel less anxious	38 (88)	5 (12)	43/51	34 (94)	2 (6)	36/51	35 (73)	13 (27)	48/51
40 To feel that I am needed in the ward/ unit	36 (90)	4 (10)	40/51	37 (93)	3 (7)	40/51	38 (79)	10 (21)	48/51
41To be able to 'room in' with my child	49 (100)	0	49/51	46 (98)	1 (2)	47/51	47 (96)	2 (4)	49/51
42 That I get assistance to recognize the needs of my child	46 (98)	1 (2)	47/51	40 (95)	2 (5)	42/51	43 (91)	4 (9)	47/51
43 To be told about everything that is being done to or for my child and why	49 (100)	0	49/51	38 (100)	0	38/51	47 (98)	1 (2)	48/51

Table 18: Parents' response for each needs statement for each scoring system: importance, fulfilment and independence.

Needs statements	Importance score			Fulfilment score			Independence score		
	Important n (%)	Not Important n (%)	*Total Number responses*	Not met n (%)	Met n (%)	*Total Number responses*	Yes n (%)	No n (%)	*Total Number responses*
44 That I can continue to feel hopeful about my child's condition	48 (96)	2 (4)	50/51	38 (93)	3 (7)	41/51	39 (80)	10 (20)	49/51
45 That I can have meals with my child on the ward/unit	41 (91)	4 (9)	45/51	19 (50)	19 (50)	38/51	42 (89)	5 (11)	47/51
46 That there are bath and shower facilities for parents	44 (92)	4 (8)	48/51	42 (98)	1 (2)	43/51	46 (98)	1 (2)	47/51
47 To know that my child will get proper schooling so he/she will not fall behind in development	43 (96)	2 (4)	45/51	26 (67)	13 (33)	39/51	38 (83)	8 (17)	46/51

Table 18: Parents' response for each needs statement for each scoring system: importance, fulfilment and independence.

Needs statements	Importance score			Fulfilment score			Independence score		
	Important n (%)	Not Important n (%)	*Total Number responses*	Not met n (%)	Met n (%)	*Total Number responses*	Yes n (%)	No n (%)	*Total Number responses*
48 That the same nurses take care of my child most of the time	45 (98)	1 (2)	46/51	39 (98)	1 (2)	40/51	45 (94)	3 (6)	48/51
49 That one person (a nurse) coordinates the services and flow of information we get in hospital	43 (98)	1 (2)	44/51	38 (97)	1 (3)	39/51	46 (96)	2 (4)	48/51
50 That I do not feel hopeless	43 (90)	5 (10)	48/51	38 (90)	4 (10)	42/51	37 (80)	9 (20)	46/51
51 That qualified teachers are available to ensure that my child's development is maintained	29 (85)	5 (15)	34/51	22 (65)	12 (35)	34/51			

Hospital Anxiety and Depression Scale (HADS)

The HADS was used to assess symptoms of anxiety and depression in parents participating in the study. Cronbach's alpha was used to determine the internal consistency between scales. Reliability testing on the Anxiety subscale gave a Cronbach's alpha of .72 and for the Depression subscale .84.

A total of forty seven valid responses were obtained, with four missing responses for the seven anxiety questions. Anxiety scores ranged from one to twenty one (mean 8.85, SD=4.82) and were normally distributed. On the basis of the HADS 16 parents (34%) were classified as clinically anxious.

For the seven depression questions a total of forty six valid responses were obtained, with five missing responses. The range was three to seventeen (mean 7.43, SD=3.63) and on the basis of the HADS 8 parents (17%) were classified as depressed.

Of the thirty four participants that were anxious seventeen percent were also depressed.

Table 19: Relationship between parental anxiety and depression and parental and child characteristics

Parental, Family and Child Demographic Characteristics	*Anxiety*			*Depression*		
Marital status	*Mean*	*Number*	*Sig*	*Mean*	*Number*	*Sig*
1) Married	8.64	37		7.47	36	
			.045*			.309
2) Not married	9.77	9		7.11	9	
Employment status						
1) Employed	8.80	25		6.58	24	
			.901			.193
2) Not employed	9.07	15		9.33	15	

Type of admission						
1) Unplanned admission	9.27	37		7.63	36	
			.661			.741
2) Planned admission	7.30	10		6.70	10	
Number days in hospital						
1) Less than 7 days	9.35	34		7.79	33	
			.965			.983
2) Greater than 7 days	7.53	13		6.54	13	
Level of education						
1) NCEA 1,2; School Cert; 6th form cert	9.84	26		7.70	26	
			.151			.088
2) NCEA 3, U.E, Bursary	7.50	14		7.38	13	
Support from family and friends						
1) Yes	8.45	42		7.09	41	
			.770			.438
2) No	12.20	5		10.20	5	
Diagnosis						
1) Asthma	9.24	21		7.10	20	
			.692			.187
2) Cystic Fibrosis	7.87	16		8.00	16	

Some evidence was noted of differences in parental anxiety and depression by demographic variable (table 19). There was only one statistical significant finding between marital status and anxiety. Parents who were not married experienced higher levels of anxiety than those married. The small sample size meant there was limited statistical power; however, there were a number of patterns that did not reach statistical significance noted. Parents who were unemployed were more likely to have feelings of depression. Mothers whose child experienced an unplanned admission were more likely to feel anxious. When a child's admission was less than 7 days parents were more likely to experience anxiety. Educational level was related to anxiety, parents who held higher school qualifications were less likely to be depressed. Parents were more likely to be anxious and depressed if they perceived they had insufficient support from family and friends. A difference was noted in anxiety

by diagnosis; parents of children diagnosed with CF were less likely to feel anxious.

Summary of HADS findings

The majority of the parents who participated in this study were not experiencing symptoms of anxiety and depression. However it was noted that anxiety levels were related to type and duration of hospital admissions, levels of family and friend support and diagnosis, while depression was related to employment status and perceived levels of family and friend support.

Correlation co-efficient between HADS, CHIP and the NPQ

The relationship between coping style, parental needs and anxiety and depression were explored using Pearson Product Moment correlation co-efficient. Preliminary analyses were performed to ensure no violation of the assumptions of normality, linearity and homoscedasticity. Table 20 presents the correlation coefficient associations between the NPQ scale and the CHIP and HADS scales.

NPQ trust in doctors

There was a moderate negative correlation between CHIP subscale 1 and Trust on the NPQ, $r = -.398$, n =51, $p< 0.01$ and CHIP subscale 2 and Trust on the NPQ, $r = -.302$, n =51, $p< 0.01$. The use of Coping Strategies related with family integration and support, esteem and stability was associated with viewing trusting doctors and nurses as important. Conversely a moderate positive correlation was noted between depression and Trust on the NPQ, $r = .374$, n =51, $p<0.01$, indicating that higher scores on the depression scale were associated with viewing the need to trust doctors and nurses as met.

NPQ information

There was a moderate negative correlation between CHIP subscale 1 and information on the NPQ, $r =-.389$, n =51, $p< 0.01$. The use of coping strategies

related to maintaining family integration, co-operation and an optimistic definition of the situation was associated with viewing information as important.

NPQ family needs

There was a moderate negative correlation between CHIP 1 and family need on the NPQ, r = -.386, n =51, p< 0.01. The use of coping strategies related to maintaining family relationships and a positive outlook on life was associated with viewing participating in the nursing care of their child, staying with their child 24 hours a day and being able to explain things in connection to their child's hospitalisation with relatives, friends and other children as important. However a moderate positive correlations was seen between depression and needing help to fulfil the family need on the NPQ (r =.341, n =51, p<0.01) and the importance of the family need on the NPQ (r =.341, n =51, p<0.01), indicating that higher scores on the depression scale was associated with needing help to fulfil family needs.

NPQ trusted

There was a moderate negative correlation between how important being trusted on the NPQ and CHIP subscale 1 (r = -.386, n =51, p< 0.01), CHIP subscale 2 (r = -.309, n = 51, p< 0.01) and CHIP subscale 3 (r = -.326, n =51, p< 0.01). The use of coping strategies 1, 2 and 3 was associated with feeling trusted to care for their child in hospital, not feel blamed for a child's illness and feeling that nurses contacted and consulted about the care that was needed to nurse a child. There was also a moderate negative correlation between CHIP subscale 3 and whose job it is fulfil trust on the NPQ, r = -.325, n =51, p< 0.01. Indicating that focusing on the relationship between themselves and medical staff was associated with needing help to feel trusted.

NPQ resources

There was a moderate positive correlation between anxiety (r = 409, n =51, p< 0.01) and depression (r = .404, n =51, p< 0.01) and whether the need resources on the NPQ was met. Indicating that higher scores on the anxiety and

depression scales was associated with viewing the need to have a special place in the unit, getting sufficient rest, having flexibility in the work of the unit, having opportunities to speak privately with medical personal, being able to have the final decision about the treatment of their child etc, was met. There was a moderate negative correlation between the importance of the need resources on the NPQ and the CHIP subscale 2, r = -.326, n =51, p< 0.01. Indicating that focusing on efforts to enhance self-esteem and doing things to manage psychological tensions and strains was associated with viewing a special place in the unit to be by themselves or getting sufficient rest etc as important. Similarly a moderate negative correlation was noted between the importance of the need resources on the NPQ and the CHIP subscale 1, r = -.461, n =51, p< 0.01.

NPQ support

There was a large negative correlation between the importance of support on the NPQ and the CHIP subscale 3, (r = -.501, n =51, p< 0.01), while a moderate negative correlation was noted between CHIP subscale 2 and the importance of support on the NPQ (r = -.453, n =51, p< 0.01). Interestingly this correlation seems to contradict itself in that it indicates that Coping Strategies related to talking to other parents, medical staff and family about experiences was associated with viewing the needs connected to meeting other parents to discuss experiences, consult with nurses and doctors about the illness/tests etc., as important. However a moderate positive correlation was seen between the need support being met and depression (r =.405, n =51, p< 0.01) and anxiety (r =. 334, n =51, p< 0.01). This suggests a higher score on the depression and anxiety scale was associated with viewing engaging in planned meetings with others in similar situations to discuss their situation etc. were met. Conversely a moderate negative correlation was noted between the importance of support on the NPQ and anxiety, r = -.453, n =51, p< 0.01. Indicating that higher scores on the anxiety scale was associated with viewing needs related to such things as meeting with others in similar situations, encouraging parents to ask questions, getting advice about the care of their chid on discharge etc, as important. There

was a moderate negative correlation noted between the importance of support on the NPQ and CHIP subscale 1,   r = -.337, n =51, p< 0.01, suggesting that coping strategy one was associated with viewing this need as important.

Summary of correlation findings

Parents who have symptoms of anxiety were more likely to use the Coping Strategies that focused on relationships between other parents with an ill child and the medical staff. Parents who used Coping Strategies 2 (CHIP 2) and coping strategies 1 (CHIP1) were less likely to think that the needs related to trusting medical personnel was important however parents with symptoms of depression were more likely to view that this need was met. Parents who coped by maintaining family integration and a positive outlook on life and their child were less likely to view needs such as getting information about their child's condition, being informed about all of their child's treatments, being able to stay with their child 24hours a day, being able to participate in nursing care, being blamed for their child's condition and having planned meetings with other parents in similar situations as important. Parents who engaged in Coping Strategies that focused on their efforts to enhance their own self-esteem and manage their psychological tension were less likely to think they needed help fulfilling needs associated with being trusted and needs related to other family members, while they were less likely to view needs associated with support and guidance and being trusted as important. However these parents were more likely to view needs associated with human and physical resources as important. Parents who focused on relationships between other parents and medical staff as a way to cope were less likely to view needs related to being trusted, human and physical resources and support and guidance as important. Those parents who felt anxious were more likely to think needs associated with human and physical resources and support and guidance as met, while they did not view such needs as being able to consult with medical staff after their child is discharged or having a planned meeting with other parents as important. The parents whom felt depressed were more likely to think the needs connected to human and

physical resources and support and guidance were being met. They also felt that family needs were important but they needed help fulfilling this need.

Table 20: Pearson correlations between CHIP, HADS and NPQ

Scale	CHIP 1	CHIP 2	CHIP 3	Anxiety	Depression
1.CHIP 1	1				
2.CHIP 2	.598**	1			
3.CHIP 3	.360**	.288*	1		
4. Anxiety	.022	.240	.293*	1	
5.Depression	-.258	-.204	.176	.488**	1
6.NPQ Trust need Importance	-.398**	-.302*	-.148	-.021	.153
7.NPQ Trust need met	-.261	-.029	.028	.250	.374*
8.NPQ Trust support required to meet need	-.074	.095	.241	.127	-.102
9.NPQInformation importance	-.389**	-.145	-.252	-.067	.024
10.NPQInformation need met	-.061	-.040	-.126	.119	.167
11.NPQInformation support required to meet need	-.091	.126	.250	.169	-.012
12.NPQFamily importance	-.386**	-.266	-.184	.156	.341*
13.NPQFamily need met	-.157	-.064	-.043	.237	.282
14.NPQFamily support required to meet need	-.283*	-.276*	-.065	.275	.311*
15.NPQTrusted importance	-.341*	-.309*	-.326*	-.163	-.007
16.NPQTrusted need met	-.138	-.025	.125	.066	.143

Scale	CHIP 1	CHIP 2	CHIP 3	Anxiety	Depression
17.NPQTrusted support required to meet need	-.184	-.325*	-.052	.145	.287
18.NPQResources importance	-.233	-.368**	-.440**	-.232	-.065
19.NPQResources need met	-.055	-.060	-.046	.397**	-.065
20.NPQResources support required to meet need	-.087	-.032	.028	.147	.176
21.NPQSupport importance	-.337*	-.349*	-.501**	-.453**	-.160
22.NPQSupport need met	-.074	-.083	-.169	.334*	.405**
23.NPQSupport required to meet need	-.194	-.157	-.088	.075	-.007

*Correlation is significant at the 0.05 level (2-tailed)

**Correlation is significant at the 0.01 level (2-tailed)

Key Findings

Results from the CHIP indicate that parents appeared to cope well living with a child who has a chronic condition. Interestingly it was identified within the CHIP that one of the key coping strategies that mothers most frequently 'chose not to use' was talking about their feelings with nonprofessional's similarly nearly half of all parents within the NPQ rated the need 'to have a planned meeting with other parents to share and discuss the experience of my child's hospitalisation' as being of low importance. However it was identified within the CHIP that 'talking with other parent's in a similar situation' was a coping strategy mothers found not possible to meet while conversely responses in the NPQ identified that having a planned meeting with other parents to share and discuss the experience of their child's hospitalisation and being able to meet with parents with similar experiences of an ill child were the two needs most often met.

Overall mothers recorded the most helpful coping behaviour was believing that their child would get the best medical care possible this is in line with one of the key needs parents viewed as most important within the NPQ : if a parent cannot be there that their child will get the best available medical care. Parents also felt that it was very important that they were able to stay with their child 24hours a day however they reported this as a need that was most often not met.

Correlation studies suggest that anxiety may have had a positive influence on the coping strategies amongst parents. While coping strategies, anxiety and depression influenced parental perceptions of the importance of certain needs, whether these needs were met and who was responsible for fulfilling these needs.

Overall parent's assessed this one facility with regard to policy and hospital design to be at an intermediate stage of PFCC integration and application which is above the staff rating of the same organisation.

Chapter Six

Qualitative findings- Stage Two

Part B

Introduction

This chapter presents the participants' descriptions of their experiences living with a child who has a chronic respiratory illness. The focus of this chapter is on the findings from the qualitative data that addressed the following two questions

- How do parents cope living with their child's chronic respiratory disease?
- How confident are they managing their child's chronic respiratory disease?

Five themes emerged from the analysis

Demographics

Twenty-three parent participants were interviewed for this stage of the study and fell into three chronic respiratory categories: Cystic Fibrosis (n=10), Asthma (n=10) and Other (n=3). There were no discernible differences noted between the different respiratory categories except for gender in which all participating fathers (n=4) had a child with cystic fibrosis. The remaining nineteen were biological mothers while no grandparents, uncles or aunts, adoptive or foster parents were interviewed.

Eleven of the parents were employed as either: a manager, nurse, barrister, beauty therapist, supervisor, educator, pastor or self-employed. Six stated they were unemployed while five described themselves as not in the labour force and one did not specify. The lowest school qualification identified was school certificate (n=3) followed by NCEA 1 (n=2), sixth form certificate (n=8), University entrance (n=5) and Bursary (n=2). Thirteen of the parents had completed some form of tertiary education: diploma (n=6) and degree (n=4) while three parents were currently

undertaking some form of study. Seventy four percent (*n*=17) of the parents were Pakeha/European with the remaining twenty-six percent being divided into Maori (*n=3, 13%*), Other (*n=2, 9%*) and Samoan (*n=1, 4%*).

The majority of children's hospital admissions were unplanned (*n*=19) lasting between two and seven days (*n*=16) with only six lasting between eight and fourteen days with only one of more than fourteen days. Only three families lived more than a days' travel from the hospital (one in Blenheim, one in Greymouth and one in Kaikora). Hospital admissions were grouped into five categories ranging from less than five to over twenty hospitalisations: for thirty-nine percent, this was between their six to tenth hospitalisation, while twenty-six percent had experienced over twenty admissions. Most parents described their child's condition as severe or very severe (*n*=17).

Just over half of the parents were aged between thirty one and forty years old (*n*=12) with eight over forty and three younger than thirty years old. Twelve of the parents had between two and three other children while eight had one other child. Children ranged in age from under two to sixteen years of age, with the majority being between three and six years old (*n*=10) and the minority being under two (*n*=2). Table 22 shows demographics.

Table 22: Parent demographics

Scale	Number
Gender	
Mother	19
Father	4
Marital status	
Married	19
Not married	4
Employment	
Employed	11
Unemployed	6
Not in the labour force	5
Not specified	1
School Certificate	3
NCEA 1	2
6th form Certificate	8
University Entrance	5

Bursary	2
Pakeha/ European	17
Maori	3
Samoan	1
Other	2
Planned	4
Unplanned	19
2-7 days	16
8-14 days	6
Over 14 days	1
No other children	3
One child	8
2-3 other children	12
4 or more children	0
Within daily travelling distance from the hospital	21
Outside daily travelling distance from the hospital	2
16-20 years	1
21-30 years	2
31-40 years	12
Over 40 years old	8
0-2 years	2
3-6 years	10
7-11 years	4
12-16 years	7
Not severe	2
Severe	12
Very severe	5
1-5th times	5
6-10th times	9
11-15th times	1
16-20th times	2
Over 20 times	6

Overall twenty two categories were identified and from these five themes emerged, Confidence, Attitudes of others, Adaptation, The unpredictability of illness and Sense of responsibility. Table 23 illustrates the inductive process undertaken. CF = Cystic Fibrosis, A= Asthma and O= Other

Table 23: Example of inductive process

Theme	Sub theme	Illustration
Confidence	Informal and formal knowledge	*So until I got the confidence to say "no you are going to listen to me" and know what I was talking about it was really hard (A13)*
	Health professionals	*We don't really see the GP …..(he) doesn't have enough experience it would be pointless…(he) doesn't really have experience of the condition to make it worthwhile [so we don't have confidence] . (CF 2)*
	Interpreting the disease process	*I've come in (to hospital) a couple of hours too late and yeah, that knocks my confidence. (O 1)*
	Status of disease	*Probably the only time I feel confident is when he has come back from clinic and knowing he's put on weight because I see that as a measure of whether he's getting better and other indicators like um knowing that he's making progress with or maintaining things. (CF 3)*

Theme One: Confidence levels

The theme of confidence illustrates how parents felt their ability to manage their child's disease was either enhanced or inhibited

Participants described Confidence as being associated with

1. Informal and formal knowledge
2. Health professionals
3. Interpreting the disease process
4. Status of disease

Informal and formal knowledge

Within the context of informal and formal knowledge participants identified that only when they felt they had acquired personal knowledge did they feel confident about articulating their needs, as illustrated by this mother

> *So until I got the confidence to say "no you are going to listen to me" and know what I was talking about it was really hard (A13)*

Parents also described how their personal knowledge increased their confidence with the management of their child's care and hospitalisation. Parents discussed how it was their experience or intuition/instinct that gave them the confidence to identify any deterioration in their child's disease and manage the hospital experience, as depicted by these parents

> *I mean, I probably analyse a lot of stuff anyway because, I mean, I've worked in the medical field and I've worked in lots of those places and it definitely gives me an advantage over, I think if you don't have it definitely. (C 24)*

> *But almost all of it is instinct. I just know and I don't really know why I know. It must be just you know living it. (A 15)*

Some parents described how their personal experiential knowledge of managing their child's disease and successfully making the judgement on when to seek medical treatment and when not to over a number of years, gave them the confidence to identify the signs of deterioration in their child quicker than they did previously as illustrated by this mother

> *I never did (feel confident) at the start. We would be like, oh, we better take her to hospital, but now it's totally different. (CF 17)*

For some parents it was their personal research via the internet that provided the confidence to participate in the treatment of their child's disease. This was described by one father who felt research enabled him to contribute to discussions with the medical team about his child's therapy, he suggested that

> *Researching about drugs which have the potential to help will then (make me) feel a little better armed next time we go into the hospital to speak to someone like (DR) ... I then feel confident in speaking to him about the potential for this (treatment) to be beneficial for (daughter). (CF 5)*

Conversely some parents described the difficulty they initially experienced sourcing information about their child's disease, especially from knowledgeable health professionals, when there was so much to learn and understand, as illustrated by this mother

> *I would say it was a very difficult learning curve because you just weren't provided with enough information. (A 15)*

Confidence was also associated with parents' knowledge that they had done the best they could for their child. Some parents described how feeling like they were providing the best possible care and meeting all their child's needs built their confidence. For one mother the fact that her child was still alive brought a sense of knowing she had met all her child's health needs to date.

I think it's just we've done as much as we can and got him the stuff that he needs, and yeah as I said he's still alive and yeah, I guess it's what sort of gives you confidence. (A 40)

Other parents described how when others saw their child as "normal" they felt confident in the knowledge that they have provided the best care they could.

He's got older and he's just lived a really normal life and people don't, like most people wouldn't know that there's anything the matter with him. They just think that he's just a normal kid so I guess those sort of things help you to feel more confident (CF 22)

Therefore knowledge either informal or formal affected a parents confidence in managing their child's symptoms and care.

Health professionals' understanding

Parents described confidence as being associated with health professionals. Parents became disengaged from the General Practitioner service when they lost confidence in new or inexperienced health professionals who were unfamiliar with their child's disease and treatment.

Some parents described how their confidence in the General Practitioner's ability was undermined when they felt like the expert in their child's disease because the doctor did not seem to understand or have the experience with their child's disease; this resulted in them not seeking care from the primary health service as illustrated by these parents

We don't really see the GP .....(he) doesn't have enough experience it would be pointless...(he) doesn't really have experience of the condition to make it worthwhile. (CF 2)

So it's speaking to a GP, we would be teaching them things, I wouldn't see any advantage in that. (CF 5)

Equally criticism from health professionals around parent's interpretation of symptoms and judgements of needing additional support knocked parental confidence. Some parents described how they second guessed their ability to interpret

their child's symptoms and manage their child's disease when health professionals questioned their judgement of the situation as shown by this mother

> *I've been asked that question (do you need to be here?) I always second guess myself because……you know that's not fair to do that to people (A 20)*

Conversely specialist health professionals with expertise in their child's disease who provided continuity of care helped to increase parental confidence. This participant described how having the same health professionals from the beginning was something that boosted her confidence in managing her child's disease

> *(What increases confidence?) People at Christchurch hospital have kind of been fantastic like Dr……, (daughter) has had Dr………as a paediatrician right through and he's really good and .....(Respiratory outreach nurse) has seen (daughter) pretty much right through as well. (CF 22)*

Overall the level of understanding a health professional conveyed about a child's disease increased or decreased a parent's confidence and impacted on the level of service engagement.

Interpreting the disease process

The theme Confidence was also associated with interpreting the disease process. For some parents being unsure of how to interpret the disease and make the necessary decisions on when to go into hospital and when to wait provoked anxiety.

Participants described that when they managed to make a 'timely' decision, their confidence was enhanced. However when they felt they had waited too long their confidence was knocked as illustrated by this mother

> *I've come in (to hospital) a couple of hours too late and yeah, that knocks my confidence. (O 1)*

On the other hand, being able to interpret the symptoms correctly and recognise when their child was deteriorating or when the symptoms were going to pass, built a parent's confidence. A number of parents described how when they read

the situation correctly and made the appropriate decisions around what care needs to be undertaken, their confidence was built as demonstrated by this mother

> *But when it's like this you sort of think, no I am reading it right, it could have gone the other way, last time I did need to be in here…yes he really needs to be in here, you have done the right thing. (A 13)*

Yet being aware that they were responsible for correctly interpreting symptoms and that misinterpretation could have lasting and drastic consequences for their child affected confidence, as illustrated by this mother.

> *For me not to pick something up that was really serious, or something happened to him and I haven't picked anything up. (would knock my confidence) (O 23)*

However, having a set plan or path for interpreting symptoms and the appropriate way to manage them gave parents the confidence to manage the situation at home. Parents described how being able to follow an action plan built their confidence, this made it easier for them to identify what level of medical help they required and how to go about getting it shown by this parent

> *Really quite good this action plan thing it gives me quite a good idea, that you know, when to take her and when to go to the doctor, when can I, you know, give her the inhaler, so probably that, yeah (builds my confidence). (A 21)*

Therefore how well a parent was supported with or able to, interpret their child's symptoms and need for treatment impacted on their confidence.

Status of disease

Confidence was associated with the status of a child's disease and hospitalisation. When a child's health improved or was maintained, parents' confidence increased. Parents described how measurable markers such as weight and lung function tests became indicators that their child's disease was stable or

improving, which indicated that they were managing their child's disease successfully as illustrated by this father

> *Probably the only time I feel confident is when he has come back from clinic and knowing he's put on weight because I see that as a measure of whether he's getting better and other indicators like um knowing that he's making progress with or maintaining things. (CF 3)*

Equally deterioration in these markers and hospitalisation suggested a decline in their child's disease, with this father describing how his son's increased coughing and weight loss knocked his confidence

> *(When he was a) Lethargic blob… (with) .lots of coughing, weight loss and hospital admissions. Then Micro–bacteria was discovered which knocked the confidence a bit…..battling that, so that would have knocked the confidence for 2009. (CF 5)*

Hospitalisation also affected parental confidence as it became an indicator of the stabilisation or deterioration of a child's disease. Parents described that if they managed to keep their child out of hospital they were controlling the disease well and this built their confidence, illustrated by this mother

> *(What builds your confidence?) Staying out of hospital …yeah that's the main one. If he's staying out of hospital that's good really. (CF 17)*

In summary individual experience, interpretation and knowledge of their child's disease, relationships with health professionals and perceived status of their child's health all influenced parental self-efficacy and responsibility in the management of their child's respiratory disease.

Theme Two: Attitudes of others

The theme Attitudes of others illustrates how the approaches and judgments of friends, relatives or health professionals impacted on a parent's management and experience of living with a child who has a chronic respiratory disease.

Participants described Attitudes of others, as being associated with

1. Feeling judged
2. Feeling disregarded
3. Information sharing
4. Sense of failure as a parent.

Feeling judged

Within the context of Attitudes of others, parents described how they felt judged or blamed by doctors and nurses for incorrectly measuring the need for intervention; this made them unsure of their own ability to assess the situation as described by this mother.

> *One of the doctors did say, "he wasn't turning around," and she said, "well he was quite hypoxic when he came in," and didn't say a lot else, but the feel of the blame was there……..(so I worry about) not getting to hospital too early because they don't want you there, then not too late because they're not happy with that, you know, so really it's a fine line and I don't sometimes no…. . (A 15).*

While for some parents a health professionals' judgemental or casual attitude prompted them to disengage from the General Practitioner (G.P). A number of parents discussed how a casual attitude or being judged about their desired need for medical treatment, and being made to feel like a neurotic parent, provoked them to stay away from their G.P. as illustrated by this parent.

> *What are you doing here sort of thing….. so I didn't use them a lot last year because there was no point. Another doctor was so casual about it, it drives me crazy and probably that's why I wouldn't go in there to be honest (A 6).*

Therefore judgemental attitudes of health professionals resulted in parents questioning their abilities and potentially disengaging from the primary health service

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Feeling disregarded

Within the context of Attitudes of others parents described feeling disregarded. A number of parents discussed how health professionals fobbed them off and did not listen to their concerns or questions. Some parents thought that medical personnel only paid 'lip service' to them and ultimately did what they thought was right regardless of their concerns or queries as described by these mothers.

> *think that they listen to what I have to say but at the end of the day, I feel like they will still do what they believe, you know, is right, so …(A20)*

> *Some doctors are casual…some will listen to you and some won't. (A 15)*

` Moreover the concept of a partnership appeared tenuous because of the attitudes of some health professionals. A number of parents described how doctors dismissed their knowledge, experience and expertise of their child and his/her disease, suggesting that they are not truly valued as partners in their child's care which is illustrated by these parents.

> *But I feel that our current consultant is very condescending and ….sort of almost treats us like we're imbeciles, sometimes you know. (A 6)*

> *I think he (the doctor) felt that he was the medical professional which obviously he was, but then I have a lot of experience with (my son) and so you know like in some ways the registrar and I should pretty much make as good a team as he's (our son is) going to be able to get. (A 1)*

Therefore a disregarding attitude from health professionals made parents feel undervalued.

Information sharing

Attitudes of others was associated with information sharing. Parents described how information sharing between parents and professionals was influenced by the attitudes of health professionals. Some parents felt that health professionals acted as gate keepers of key information and knowledge either by withholding or offering mixed and sometimes inappropriate information, this made them feel vulnerable and made managing their child's disease difficult as shown by these parents.

> *They are the ones with the knowledge and the skill and so I'm dependent on them and that makes me really scared. (CF 2)*

> *Found it very difficult to manage because we were getting so (many) mixed messages from a lot of different people, every doctor that walked in the door gave us different advice. Everyone was different you know it was very difficult to start off with. (A 20)*

Parents also described how at times they themselves were gate keepers of information as illustrated by this mother.

> *So I had to be extremely careful about what I ask and tell them. (CF 11)*

Thus the attitudes of health professionals dictated how well information was shared between health professionals and parents, and at times made managing the child's disease challenging.

Sense of failure as a parent

Participants described attitudes of others as being associated with a sense of failure. Parents felt like a failure when others judged the way they managed their child's disease without necessarily knowing the whole situation as illustrated by this mother.

> *And even that perception comes from other people who have children with asthma (they make you feel like) you have failed, or not treated it properly to still be here (in hospital). (A 15)*

In summary parents had a sense of failure and uncertainty about their ability to manage their child's chronic respiratory disease when they perceived health professionals, friends and relatives to be judgmental and dismissive of their knowledge and expertise. Therefore the attitudes of others influenced how responsible, supported and successful the caregiver felt with self-managing their child's respiratory disease.

Theme Three: Adaptation

The theme of Adaptation illustrates how parents and families had to modify their lifestyle in order to accommodate their child's chronic respiratory disease.

Participants described Adaptation as being associated with

1. Managing the environment
2. Juggling
3. Restrictions
4. Emotional impact

Managing the environment

Participants described adaptation as being associated with managing the environment. Parents talked about having to control the environment and how this placed a restriction on the primary caregiver and family. A few parents described how they had to control the surrounding environment to ensure that their child remained safe, which became restrictive for them. These parents often opted to keep their child confined to certain places so that they could protect them from environments that could exacerbate the respiratory disease as illustrated by this mother.

> *So we stay in our house and he goes to his kindergarten   and we*
> *go to places that we know and you know friends can come here.*
> *(A1)*

However for some parents, they controlled the environment because they felt better being geographically close to medical help that they could access promptly.

> *Just sort of being close to a hospital and sort of close to the doctors. (A 40)*

Parents also described how having to adapt to their child's disease meant they had to be aware of who their child was exposed to. Certain respiratory diseases meant that some affected children and families were unable to get together because of the risk of exacerbating their disease through cross infection or alternatively because they did not know any other children with the same disease. This resulted in parents feeling isolated and unsupported as described by these parents

> *There is a sense of isolation that runs out of this so you have the pain and the isolation; (unlike us) cancer kids can all get together. (CF 1)*

> *We don't know other people with kids with CF...he's been the only child over there, so we're quite isolated. So we don't kind of tend to mix in with other CF families because we just don't know any. (CF 22)*

So in order for parents to adapt to living with their child's disease they had to constantly manage the physical environment.

Juggling

Adaptation was associated with having to juggle. Parents described how in order to accommodate for their child's chronic disease they needed to juggle their lives. All parents talked about the frustration and stress of having to juggle things. For many parents stress was created when they had to contend with the physical logistics of reorganising routines etcetera to accommodate hospitalisations as this mother illustrates.

> *But it's quite disruptive because you sort of have to rearrange the family.....upsets the routine really. (CF 22)*

For some it was an emotional juggle. For one mother, it was the emotional juggle between providing the necessary information, while maintaining some privacy for her son.

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> *So there's a real tension there between saying something and not saying too much. Giving him some privacy and discretion and giving people information that they need. (CF 3)*

While for others it was emotionally being pulled in many directions between their sick child, partner, other children and work commitments as described by this parent.

> *Emotionally I guess it's been a bit sort of hard….being pulled in a number of directions. (CF 5)*

However, for one mother it was hard juggling the seriousness of her son's disease and the need for medical support with the disruption this may cause her other children.

> *"Makes it hard because, you know, I've got other children and it is not just a matter of packing up and going (into hospital) and sometimes he comes right. (A1)*

Yet for some stress was created when health professionals did not appreciate that they had to juggle the needs of the sick child with the rest of the family's needs.

> *I need to juggle and you know, it's just really they don't sort of see it and again they're just focusing on (son)…but they forget that we're a family. (A6)*

Hence parents where continually having to juggle their circumstances in order to adapt to their child's hospitalisation which was often unnoticed by health professionals.

Restrictions

Adaptation was associated with restrictions. Parents described how restrictive family life was day to day due to the chronic disease. Family routines and plans revolved around the sick child and his or her disease and treatments as illustrated by this parent.

> *Day to day routine just revolves around her medication …so, you know, we are a bit tied as to where we can go and what we do; who she can go and play with…we can't go out to a*

friend's house for dinner. You have got to be here to do this (treatment). (CF1)

Parents also described how their plans were restricted because they were reluctant to leave their sick child in the care of others who had no knowledge or expertise in dealing with their child's specific disease. This meant they had to work out care arrangements amongst family or partners as shown by this mother.

It is things like babysitters and stuff, you know, we can't just leave him with whoever…it has to be someone who is used to dealing with it or isn't going to panic. (A 1)

Furthermore the chronic disease became life altering for parents as it continually interfered with their plans. There were some parents who were unable to arrange breaks away or social engagements because they needed to accommodate for their child's symptoms and hospitalisations as illustrated by these parents.

Because it's life altering. You've just got to move, you know, your plans around and change your day and all your week, depending on how long you're going to be in hospital. (O 1)

Yeah, we can't plan anything. We can't even go away because if we're too far away from hospital you know (and) if something happens, we'll be in trouble and like we plan…., we thought we'd have a trip to Hamner for two nights and we've rebooked it four times because of (son) so now we've given up. (A 99)

Furthermore a number of parents described how everything revolved around the chronic disease and everyday decisions were considered in relation to the disease, this is described by this mother.

Everything revolves around this centre of attention, which is great if you're the child but yeah, it's "what will we have for tea? Do you think she'll eat this?.." The focus is always there. (CF 5)

Therefore adaptation to living with their child's disease resulted in personal and professional restrictions.

Emotional impact

Adaptation was also associated with the emotional impact the disease had on the family and the families' ability to cope. Most parents described how their child's chronic disease had a negative emotional impact on the whole family. Some parents talked about the loss of dreams and feelings of hopelessness with their situation and the unnatural order of things, because their child has a potentially fatal chronic disease.

> *I have a pretty negative view of his illness overall and what that means for all of us. (CF 3)*

For these few parents, the loss of the dream of a healthy child and all that entails was harrowing. These parents discussed having to come to terms with the loss of their child's and family's life potential. For some parents, the chronic disease symbolised the loss of a future generation.

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> *That kind of fantasy dream that you have about family and how it might be and learning about (son's) CF that's gone. …….So the likelihood of me having lots of grandchildren is pretty remote and so that's a dream that has impacted on me ……So for me there is a lot of pain and grief and a lot of stuff going on in there that's never been resolved and I don't know if that ever will. So part of it for me...a lot of the journey is simply pain. (CF 3)*

While for some parents being told their child's life expectancy and having to deal with the concept of outliving their child was traumatic as shown by this parent.

> *You should always outlive your children I don't know, whatever they've got wrong with them, you should, that's the way it should be in life but it's not always that way…… I never really knew cystic fibrosis that much. Didn't really understand that 100% and one of the nurses, can't remember her name, turned around and said to me, like a reality check, that yeah true, it's shortened my son' s life and then it actually kind of hit then and there. (CF 17)*

Furthermore different facets of guilt were experienced by parents. A number of parents spoke about the guilt they experienced related to the chronic disease. For some it was guilt associated with being responsible for passing on the disease that is so life changing to their child.

> *"Feels guilty about it....carries guilt, thinking, you know, we have done this to her. (CF1)*

Parents also described how an individual's ability to emotionally manage their child's disease could impact on the family in both a constructive and unconstructive way. For some parents coming to terms with the hopelessness of the situation provided comfort. One mother described how she realised that when her son is acutely unwell there is nothing she can do but wait.

> *If his throat shuts at home, that's it, there is nothing I can do. CPR's not going to help, nothing. I literally just sat there and hugged him and I know that sounds really horrible but I knew there was nothing I could do until the ambulance got there. (O 23)*

While for another mother taking it one step at a time and not dwelling on it enabled her to cope.

> *There are a lot of things that can go wrong and that I could pick up but I just choose not to think about them cause it's kind of easier to deal with, to just go along with it and whatever happens, just take it. (O 23)*

Yet for some others believing that their child will grow out of the disease brought comfort as shown by this mother.

> *I'm hoping that she might grow out of it, that it might just be a cold type of asthma that she may grow out of. (A 21)*

For some believing that others are worse off provided comfort.

> *I think I have got a little more realistic now and realise he's not normal. I used to think a little bit "Oh poor me, why me,*

why not someone else", but then I'll grow up and think, "Gosh, it could be way worse, could be way worse", so, you know. (A 15)

In summary it appeared that family members were emotionally affected as a result of having to adapt to living with a sibling/child's chronic respiratory disease. For the parents it took over their day to day life, along with any future plans they may have, resulting in a huge sense of responsibility, isolation and a sense of hopelessness which was only slightly mitigated by their individual coping strategies.

Theme Four: The unpredictability of disease

The theme of unpredictability of disease illustrates how the irregularity of the chronic respiratory disease despite observation, experience and reason impacted on the management of their child's disease.

Participants described unpredictability of disease as being associated with

1. Speed of onset
2. Abnormal signs
3. Need to be on alert

Speed of onset

Participants described the unpredictability of the disease as being associated with the quick onset of symptoms. For some parents the speed at which symptoms developed made them feel anxious and on edge and also meant they had to constantly monitor their child's state in case it deteriorated and they needed to access medical care promptly.

...but even now it just throws us, generally within the space of a couple of hours, he gets really tired ...just you know like when he's not responding, you just know straight away and this can all happen over a period of a couple of hours, you know, like, just goes downhill very, very quickly ....deteriorates very quickly. (A 99)

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A number of parents described that having no warning or control of when their child's disease was going to deteriorate or how fast it progressed was hard and frustrating to treat as explained by this mother.

> *Really frustrating because as I was saying earlier you don't always get much of a warning...you don't get like two days warning. It's like two hours before, you know, the first symptoms to, you know, to the really bad, you know, the bad symptoms and then it's like prepare yourself...you don't know if he's going to go, you know, if he's going to get any worse ...or if it's just something that will just end, um, dying down. (O 1)*

Parents felt that the unpredictable speed at which their child's health could change made management difficult.

Abnormal signs

Within the context of unpredictability of disease parents described how it was the abnormal presentation that was in fact confusing and made treating the symptoms hard as described by this mother

> *Because he just wasn't normal, he wouldn't fit into the normal range of what they look for in an asthmatic kid having an attack. (A 13)*

One parent described how her child was continually treated inappropriately when his symptoms did not follow the typical asthmatic presentation.

> *Son's behaviour isn't normal, so initially you are treated like a normal asthmatic and then it's never working........so we were just on a spiral of always going down the same path. (A15)*

Thus parents found that when their child's symptoms did not follow the predictable pattern their child's treatment was mismanaged.

Need to be on alert

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Participants described unpredictability of disease as being associated with the need to be on alert. Parents talked of being controlled by their child's disease as their day to day life was put on hold waiting to see if and when he/she would get sick again as shown by this mother.

> *Normally wakes in the morning and he's quite snotty and that, and you don't know if it's going to be that kind of day, you know, all day we were on tender hook. (A 6)*

The constant need to be available at any time and for however long their child was unwell meant that some parents retrained as illustrated by this parent.

> *We made the decision quite some time ago that S.... would retrain in a business that she can run from home and she does that on a part time basis, which is, you know, part of the income for the family. The purpose of that is so she can go into hospital at the drop of a hat without having to have an understanding employer. (CF 5)*

For others job and career opportunities were constrained for some primary caregiver's because of the frequent and unpredictable need for medical intervention

> *So she hasn't been able to just do whatever job she wants....it's limited her choices (because she has to look after son). (CF 1)*

In summary the unpredictable nature of the disease made management difficult and increased parental responsibility as they always had to monitor the situation, never quite knowing when their life was going to be turned upside down which produced anxiety and a sense of being on edge.

Theme Five: Sense of responsibility

The theme sense of responsibility illustrates parents overwhelming sense of control and accountability for every aspect of their child's health and wellbeing.

Parents described sense of responsibility as being associated with

1. Accountability
2. Primary care giving role
3. Responsibility expected by Healthcare Practitioners

Accountability

Parents described sense of responsibility as being associated with accountability. For parents, being accountable was very stressful, plagued with constant anxiety and fear. A number of parents described how being the one accountable for managing their child's disease meant having to be vigilant and constantly reassessing their child's disease to ensure they did not miss anything as illustrated by this mother.

> *Guessing…so I don't know so I always think which is it?… Has he had enough? Has he had too much? …At the right time?…It's so complicated. It takes up a huge amount of time and energy …it's really, really stressful. (CF 2)*

Moreover as this mother shows some parents who felt accountable for the management of their child's disease worried and found it difficult letting others take responsibility for it .

> *It's just not like you can put that responsibility onto someone else. (A15)*

Thus for parents being accountable was stressful and meant they found it hard relinquishing the responsibility of managing their child's health to others.

Primary care giving role

Within the context responsibility parents described how the full control or accountability for their child's health and wellbeing was the responsibility of only one parent within the family. Within each family there emerged a primary caregiver who was responsible for the day to day and acute management and hospitalisation of the

sick child. For the primary caregiver, sole responsibility was onerous, all-consuming and sometimes reluctantly taken on, as illustrated by these parents.

Important that I not know everything. I don't want to be the sole "knower" of it all, but it's the way it's worked out. (A 15)

Huge responsibility when she is unwell because I'm the only one that can do it. (CF 1)

While the responsible primary career often struggled with the overall responsibility other family members did not know how or could not alleviate it as this couple describes

Dad: " Six and half out of ten ...it's not that I don't know what's happening, it's just that I'm not always sure about what I need to do to put it right."

Mum: "In 2008 it was really hard, really hard because he was only 1-2 and I tried, I have taught (husband) a lot, but like I said, he's at work and I think you take responsibility on board. (A 15)

For other parents the inability to assist with the responsibility of their child's disease stemmed from a lack of confidence in managing the disease as this mother suggests.

Managing that medical care at home? I'm fine with it. (Husband) refuses, he wouldn't do it. He's not confident; he's scared. (CF1)

Because the primary caregiver was responsible for the day to day and acute management of the chronic respiratory disease, others in the family missed out, having a negative impact on the family. A number of parents identified that in order for the primary care giver to maintain their child's health, siblings often had to miss out emotionally and/or physically as illustrated by these parents

So they have definitely missed out on some things, sometimes it has had some negative effects on their world. (CF 24)

Hence being solely responsible for their child's disease meant they became overwhelmed with the responsibility, while the other parent and family members suffered reduced confidence and were forced to miss out emotionally and/or physically.

Healthcare Practitioners

Participants described responsibility as being associated with Healthcare Practitioners. Parents talked about the pressure they felt from hospital staff to be fully responsible for the care of their child in hospital. One parent described how if she or her husband wished to take a break, they would need to find alternative child care.

> *On the ward I find that you are made to feel the pressures on, that you have to stay all the time and sometimes you just want to get out of there, you know both of you. You want to get out of there and unless we can call on our parents, we can't do that. …… (A 6)*

A sense of responsibility was also based on how much support primary caregivers felt they got from health professionals. Access to community medical personal affected how well parents felt supported with the responsibility of their child's disease. When access to medical personnel was readily available and a strong relationship existed, parents engaged well with the G.P service. It was identified by the following parent that a G.P who they had a relationship with, who provided good access and the necessary advice and education to manage their child's disease better, made them feel supported.

> *Doctors here are fantastic. we have a really good relationship with them. I just ring them and they see him straight away…. the GP talks to them as a person, you know, (son) wasn't taking his medication one period and so I just marched him in there and I says well (son) seems to think he doesn't need this and he goes, "Oh come on (son) you're 14, your mother doesn't need to tell you or hold your hand anymore." (A1)*

Conversely inconsistency and poor access to the G.P had a negative effect on parents' sense of support and engagement with the service. For some parents being unable to see the medical professional of their choice, at an appropriate time because

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the G.P worked part time or had a huge work load, frustrated them. As described by this parent, parents felt that they had built a rapport with a particular G.P and therefore had trust in that G.P who they felt knew them and their child's disease and it was that specific G.P they wanted to see.

> *There are doctors down there who are just are blasé and there*
> *will be one particular doctor I want and she's not always on or*
> *always available and she's brilliant. (A15)*

While for other parents fostering the relationship with the specialist respiratory nurse was what provided them with the necessary support to manage and be responsible for their child's chronic disease as described by this parent.

> *The interesting thing with CF is you actually have very little to*
> *do with your GP over it …it's handled by the specialist team*
> *and so the respiratory nurse specialist will come out. (CF 24)*

Thus for the primary caregiver the overall responsibility took over most aspects of their life and left them always having to be vigilant, sometimes at the expense of the needs of other siblings, as other members within the family were unable or unwilling to assist. Moreover this sense of responsibility appeared to either be increased or mitigated by the support they received from health professionals.
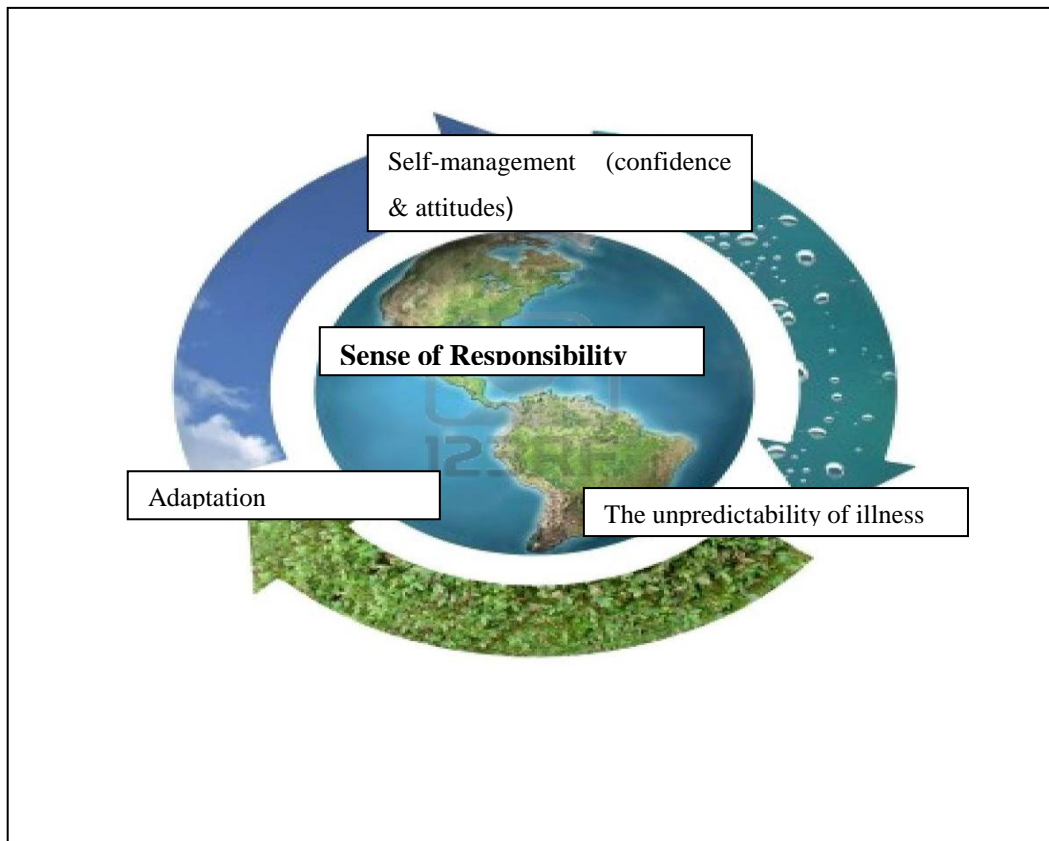
Diagram 0-1: Conceptual diagram of qualitative results called: World of responsibility

Overall findings

The findings suggest that for families to cope with the management of their child's respiratory disease one parent within the family needed to take on the primary caregiver role. This primary caregiver then became responsible for the overall management of their child's acute and daily care and with this continual responsibility parents developed the confidence to provide the appropriate care to their child.

However primary caregivers described the responsibility as onerous and overwhelming and shaped by the level of predictability of the disease process, how the family adapted to life with a chronic respiratory disease and the parent's own sense of self-management, which was influenced by the attitudes of others and their level of confidence (see Diagram 1). This sense of onerous responsibility was not static it appeared to ebb and flow in response to the unpredictability of the disease and a parent's sense of self-management. An unplanned exacerbation in a child's disease

seemed to increase a parent's sense of overwhelming responsibility while periods of good health and low hospital admissions diminished the impact on the family and potentially built a parent's confidence in the management of the disease, reducing the sense of all consuming responsibility.

For some parents there was a reluctance to become the primary caregiver solely responsible for the management of their child's disease within the family. This reluctance derived from the fact they always had to be responsible for their child and the management of his or her disease, which placed a huge restriction on them socially and emotionally. This position could be very onerous and all-consuming requiring a huge investment of time and energy in having to constantly remain vigilant, on call and ever present, while also having to juggle other daily life and family demands. With the emergence of this sole responsibility role, other parents within the family suffered reduced self-efficacy as their confidence and ability to manage the treatments independently were challenged by a lack of exposure and experience and the perception that the primary caregiver 'knows best'.

The unpredictability surrounding the management of a chronic disease also appeared to have a huge impact on the primary caregiver's sense of sole responsibility.   It was the unpredictable nature of the disease that prevented the sole caregiver engaging in employment or having the flexibility and freedom for social and personal activities, thus narrowing their opportunity to have a break or engage in employment.

The attitudes of health professionals within primary and secondary care also had an impact on how supported parents felt with the responsibility of their child. It was identified that health professionals made one parent feel they had to stay with their child, making it impossible for them to be relieved of their sole charge, unless they solicited the help of another family or support person. This was difficult for this mother who viewed hospital as a potential opportunity for respite from the responsibility of either the physical and/or emotional care of her child. It was also noted that when health professionals questioned some parents need for treatment, they would disengage from the G.P service thus potentially increasing their sense of sole

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responsibility. While having doctors fob them off and dismiss their knowledge, experience and expertise made them feel like they were not truly valued or supported as partners in their child's care.

Overall the data within this study suggested that in order for parents to cope with their child's chronic respiratory disease there had to be a primary caregiver within the family. However for the primary caregiver their whole life became restricted by their child's health needs, potentially placing huge stress and responsibility as they remained forever vigilant in their monitoring of the situation, while trying to juggle other commitments. The attitudes of health professionals appeared to also have fed into these parent's confidence, sense of support and responsibility as they felt at times judged or fobbed off when their concerns or experience and knowledge was not considered. Conversely, when they had good access and necessary advice they felt supported.

Chapter Seven

Discussion and conclusion

Introduction

In light of the fact that parents are expected to self-manage their situation and their child's chronic respiratory disease 24 hours a day, it is important there is knowledge of what personal circumstances may hinder and facilitate a parent's ability to manage the situation and how well the health service supports them to do so. Therefore it is imperative there is understanding of how well FCC, which is deemed best practice, is integrated within facilities, and what influence a parent's psychological wellbeing has on their ability to participate in the care of their child. This seems especially relevant as evidence suggests that a child's chronic disease is associated with elevated anxiety and depression amongst parents, which if coupled with ineffective coping strategies can negatively affect parental management and child well-being. At the same time, ineffective integration and support of FCC within organisations can result in poor outcomes for both the child and parent. Therefore this study aimed, through a benchmarking survey, to identify at what stage paediatric nurses perceived New Zealand paediatric facilities to be in terms of integrating FCC and how this compared internationally. Secondly, this study used both qualitative and quantitative methods to explore the relationship between a parent's psychological wellbeing and circumstances, and their management/participation in the care of their child's chronic respiratory disease and associated hospitalisations. This discussion begins with a summary of key findings. Results are then interpreted within the context of the Institute of Family Centered Care's four core concepts and existing international research. Further implications of these findings are presented, including a consideration of parental participation and clinical and service factors. The strengths and limitations of the research are outlined, followed by suggestions for future research and an overall conclusion.

Findings from this study identified that New Zealand is at an early stage of FCC as identified by staff at a national level. At a local level the survey of parents

found that overall they coped with the admission of their child to hospital with a chronic respiratory disease. Parents coped mainly by maintaining family integration and an optimistic outlook (CHIP 1); however, this coping strategy was influenced by the following parent and child demographics: marital status, type of admission, days in hospital, perceived level of support and type of respiratory disease. Additionally, to enable coping parents needed to focus on their child and believe in their child's medical care; however, they also identified that to be able to cope with their child's hospitalisation they needed help from medical personnel to prepare for the day of their child's discharge and get results and tests done. Parents thought that certain aspects of service delivery that centred on child access, discharge and care were very important in order to be able to cope, yet the aspect of service delivery that resulted in the most unmet need was also related to access: that they could not stay with their child 24 hours a day if they chose. For those parents who used coping styles associated with maintaining a sense of their own wellbeing through social relationships and doing activities to manage psychological tensions and strains (CHIP 2), it was important that their needs related to support and guidance and being trusted by professionals were met, yet they were less likely to trust medical personnel themselves.

Levels of depression and anxiety amongst the majority of parents were within the normal range. However, those who had symptoms of anxiety were more likely to use coping behaviours associated with understanding the medical situation through communication with other parents and consultation with medical staff (CHIP 3). It was also identified within this study that these parents had an overwhelming sense of being on their own with the responsibility of their child's chronic disease, shaped by the level of predictability of the disease process. The management of their child's chronic disease, which impacted on family life and the parents' own self-management, was influenced by others' attitudes and their own level of confidence. It is supposed that because PFCC was identified as being in the beginning stages of implementation this may have contributed to parents' overall sense of responsibility. It is proposed that nurses could assist parents with this sense of responsibility by ensuring support and advice with, and about, their child's disease; one area to consider in particular is 24 hour care.

The overall findings from this study showed that health professionals were not fully aware of what parents needed and the coping behaviours they used, thus suggesting that a FCC approach by health professionals to paediatric care within New Zealand was inconsistent. Moreover, because FCC was not well supported or implemented by health professionals within facilities, and there was no sense of partnership, parents experienced an overwhelming sense of responsibility for the day to day management of their child's chronic disease which impacted on their psychological wellbeing, personal/family circumstances and the levels at which they engaged in collaboration with health professionals and the health service.

As previously outlined, the findings will be interpreted within the context of the Institute for Family-and-Patient-Centred-Care's four core concepts; respect and dignity, information sharing, participation and collaboration (The Institute for Patient-and-Family-Centered-Care, 2011). Considering that the Institute for Patient-and-Family-Centered-Care has been established since 1992 and provides leadership, training, technical assistance, policy development and advice on FCC to healthcare program planners and decision makers internationally, it is appropriate to evaluate the findings of this study against these four concepts. A number of international facilities, such as the Cincinnati Children's Hospital and the Children's Hospital of Philadelphia, refer to these concepts within their philosophy of FCC; therefore it is proposed that these core concepts will provide the best platform to discuss and compare this study's findings, research outcomes and practice implications to other international facilities. Furthermore, as the core concepts are proposed to underpin FCC, they will provide a good structure to identify and discuss any links in this study's findings between a parent's psychological wellbeing, personal circumstances and FCC. For clarity a definition of each concept according to the Institute is presented, and where applicable relevant literature is used to support and discuss the findings.

Respect and dignity: This concept requires that health care practitioners listen to and honour patient and family perspectives and choices. Likewise patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care.

The personal accounts of parental experiences in this study described not being listened to or having their knowledge or choices respected by health professionals. Parents felt that health professionals either played lip service to their requests or just fobbed them off, this has been similarly noted in other studies (Bolitho & Huntington, 2006; George & Vickers, 2007; Trollvik & Severinsson, 2004). For parents in this study it was important that they were trusted by medical personnel to care for their child, however, they felt this seldom happened. Participants described how health professionals questioned their knowledge and interpretation of symptoms, which resulted in a loss of confidence and disengagement from health services. These participants described how health professionals did not value their expertise and implied parents were neurotic for continuing to seek medical assistance when their personal knowledge of their child suggested something was wrong. It could be postulated that health professionals in New Zealand do not value a parent's knowledge, expertise or management of their child's disease because instead of taking a patient-centred approach to care they are still taking a paternalistic approach to care, believing that they are the ones with expert medical knowledge and experience. Evidence suggests that health professionals who perceive themselves as experts are reluctant to share or hand over the care to parents as they feel that it threatens their professional status (Galvin, et al., 2000; MacKay & Gregory, 2010; Newton, 2000). A paternalistic approach to care, with its imbalance of power, does not cultivate partnership amongst parents and professionals, therefore, it is understandable that parents would feel excluded or not considered when the management of their child's care is being planned. Moreover, it could be assumed that when a paternalistic approach to care persists, and parents' knowledge and expertise are not considered, a parents' confidence/self-efficacy in their ability to manage their child's disease would decrease. This is noteworthy as reduced self-efficacy has been shown to negatively influence a parent's ability to manage and engage in their child's care (Farkas & Valdes, 2010; Tong et al., 2009) which can then result in negative outcomes for children (Grus, et al., 2001).

It was also identified that parents disengaged from the primary health service when they felt health professionals did not value their expertise. This is particularly concerning as the primary health sector in New Zealand is designed to be the first line

of medical support for parents (Ryall, 2007), especially with the introduction of the health care strategy in 2007 *Better, Sooner, More Convenient Health Care in the Community,* which proposes that the primary health sector will deliver more care and support to people with chronic diseases thereby enabling these people to stay healthier and have less unplanned hospitalisations (Ryall, 2007). However, for these parents the primary health service did not provide the necessary support, guidance and partnership, which resulted in some parents disengaging, and being left to manage in isolation as no alternative health support existed within the community. It is clear to see from this that better integration of FCC concepts in the primary health service need to be addressed to pre-empt unplanned hospitalisations and parents ending up unsupported and isolated with the responsibility of their child's disease.

Furthermore, results from this research showed that parents placed much importance on having the final say about the type of treatment their child should receive, but it seems this seldom occurred. Similar to previous studies, these parents identified that health professionals appeared to pay only "lip service" to their requests and concerns and then followed their own treatment plan (George & Vickers, 2007; NHC, 2007). Interestingly, research undertaken by New Zealand's National Health Committee (NHC) in 2007 also identified that families believed health professionals did not always value the knowledge and experience they had of their child's chronic disease, sometimes to the point that neither the child nor the family was consulted in clinical decisions. It could be suggested from the findings of this current study that New Zealand has not progressed as was expected towards a FCC approach to healthcare that includes families in the planning of their child's care, despite recommendations by the NHC, back in 2007, that the inclusion of the child and his/her Whanau or family's views should be actively promoted in the New Zealand health service. Again, the paternalistic attitude of health professionals, which is entrenched in the biomedical model that still underpins most medical teaching (Cunningham & Wilson, 2003) , may be contributing to this lack of progression. For if medical practitioners where taking a FCC approach, rather than a paternalistic approach, then they would engage in a therapeutic process that would assist them to negotiate a management plan with the parents (Cunningham & Wilson, 2003).

Interestingly, in this study a finding about health professionals' conflicted with the above subjective findings about parents. Nurses disagreed with parents' beliefs about how well parental views, knowledge and perceptions were integrated into the planning and delivery of care. The majority of nurse participants thought that parents were fully incorporated and supported to be involved in the assessment of their child's symptoms and evaluation of their child's therapy and treatment. Moreover, the nurses believed that parents were encouraged to be involved in decisions about care delivery processes. Although these findings support Carmen et al's (2008) study, caution needs to be exercised in comparing this research with Carmen's, as participants in Carmen et al's benchmarking survey included both different health professions and parents, while the current study assessed only nursing staff's perceptions. It is therefore suggested that New Zealand is in fact dissimilar to international facilities, whereby a dichotomy exists between what New Zealand nurses believe is occurring in practice and what parents see occurring in reality. This is of concern as evidence has identified that parents need to feel that they are participating in the planning and decisions concerning their child's treatment (Balling & McCubbin, 2001; Hallstrom et al., 2002; Hodgekinson & Lester, 2002; Lindstrand, Brodin, & Lind, 2002), and if such needs are not met then they find it difficult, and are less likely, to participate in partnerships of care (Farrel, 1989; Sloper, 1996).

In the current study qualitative findings also identified that parental confidence was influenced by professional expertise. Participants' accounts of their dealings with medical personnel described feeling well supported and confident when the specialist medical team, with vast experience, was consistently involved in their child's care. While similar to other studies, parents did not feel supported when health professionals lacked the necessary expertise and were unfamiliar with their child's disease (Hodgekinson & Lester, 2002; Steele, 2002), which resulted in disengagement from the service. Balling (2001) proposes that because inexperienced doctors feel threatened by the expertise of the parent, they become overwhelmed and uncomfortable with sharing the child's care. However, this results in parents believing that doctors do not value their knowledge. Furthermore, a tenuous situation occurs as parents end up seeing these professionals intermittently and therefore never have the opportunity to establish a trusting relationship. It is easy to understand from this how

parents become isolated if this cycle of disengagement evolves, where parents lose confidence in medical personnel and disengage, which then leaves no opportunity to establish a trusting relationship, which again results in disengagement.

It is clear from this study that regardless of what health professionals perceive, if parents do not feel their knowledge, values, beliefs, perspectives and choices are respected, they will disengage from services and be left to manage as isolated units. Moreover, it is easy to see that when the core FCC concept of respect and dignity is not practised across all service settings, then parents and children experience decreased support. This is of particular concern because when parents have decreased support their psychological wellbeing is compromised, which impacts on their ability to participate in and manage their child's chronic respiratory disease. These findings only serve to highlight the need for health professionals in New Zealand to start integrating FCC into every parental interaction, such as giving parents the opportunity to engage in open, honest communication and treating them as knowledgeable partners; this would then increase their sense of control and self-efficacy in the management of their child's chronic respiratory disease.

Information Sharing: Within this concept is the expectation that healthcare practitioners will communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Additionally, patients and families expect to receive timely, complete, and accurate information in order to participate effectively in care and decision-making.

The quantitative data from parents in this study identified a difficulty with acquiring knowledge related to their child's chronic respiratory disease, and a lack of adequate communication and information from those most knowledgeable. For parents in this study, it was very important that they received accurate information about their child's disease, treatments, test results and outcomes; however, they often felt this did not happen, which is comparable to other studies (Hummelinck & Pollock, 2006; Lam et al., 2006). Yet conversely, results from the benchmarking survey showed that, similar to international organisations, New Zealand nurses believed that these facilities were performing at an advanced level in enabling parents

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to obtain information, learn about their child's disease and manage their child after discharge. Again it appears that in New Zealand the reality for parents is divergent from what health professionals view as their practice. This is of concern, as evidence suggests this type of dichotomy, between what nurses and parents perceive as adequate information, results in increased parental anxiety and insecurity, affecting a parent's ability to participate in their child's care and partnerships with professionals (Fisher, 2001; Hummelinck & Pollock, 2006; Lam et al., 2006; Lyte, Milnes, Keating & Finke, 2005).

In this study qualitative accounts identified that gaining information influenced parental confidence and management of their child's disease. Parents described that it was their personal experience, their individual sourced information and having a set plan that increased their confidence to actively contribute to and independently manage the care of their child. Moreover, increased confidence reduced the need to ask for additional support and information from medical personnel. These findings support previous research that suggests parents who experience success in managing their child's chronic disease do not need to actively obtain further formal information (Hummelinck & Pollock, 2006). Moreover, in this current study, and similar to McCubbin's (1987) "normative scores of mothers" and other studies (Goldbeck, 2001; Mu, 2005; Patistea, 2005), parents preferred not to obtain information and communicate with medical professionals about their child's disease. Although this finding could have derived from the fact that these parents had a wealth of experience and success with managing their child's disease and therefore did not feel the need to acquire information from medical professionals, qualitative findings suggest differently. Parents in this study felt that health professionals were obstructive, which affected the type and amount of knowledge shared. Moreover, parents described receiving inappropriate and mixed information. It is reasonable to assume that this could lead to the undermining of trust and confidence in health professionals and the end to parents seeking informational support from them. This is of concern as evidence suggests that inconsistent and contradictory information leads to parents becoming confused, insecure and distrustful of health professionals, which can lead to decreased confidence in authority and expertise (Hummelinck & Pollock,

2006; Thompson, Hupcey, & Clark, 2003), which again can result in isolation due to disengagement from health services.

Contrary to other studies in this study nurse facilitated meetings for parents to discuss and share information were not helpful for participants. Findings in this study showed that nurses were very good at enabling parents to have planned meetings to share and discuss their situation, but, qualitative accounts of parents identified that such organised meetings caused stress and resulted in isolation. Parents in this study did not want to share information with other parents because their situations were unique and therefore not comparable. Parents described situations where they felt judged by others who were unaware of how their personal situations differed, which resulted in parents questioning   their abilities and keeping to themselves. This highlights issues around insufficient support networks for parents, as they are not receiving the desired support from either health professionals or other parents and therefore are left with the responsibility of managing in isolation, especially when findings from other studies identified that meetings amongst parents enabled sharing of information and made them feel supported (Chernoff et al., 2002; Halltrom et al., 2002; Lee et al., 2007).

In summary, the findings from this current study suggest that in New Zealand's tertiary paediatric facilities and primary care settings, the FCC concept information sharing is not as well implemented or supported as health professionals believe. Findings indicate that if parents do not receive the type of information and support from health professionals or others in an appropriate manner, their confidence in managing their child's care is impaired, and they experience a sense of isolation in the management and care of their child. This is important to note as a parental loss in confidence can lead to a decrease in participation and appropriate management of their child's chronic disease.

Participation: Within this concept it is assumed that patients and families are encouraged and supported in participating in care and decision-making at the level they choose.

Qualitative accounts from parents within this study suggest New Zealand parents, in fact, have limited choice in the level at which they wish to participate in the care of their child. Parents described situations where either they were not included or consulted about the management of their child, which is similar to other findings (Balling & McCubbin, 2001; Coyne & Cowley, 2007; Lindstrom et al., 2011; Shields et al., 2006), or they were left to manage in isolation. Parents in this research described how there was an expectation by health professionals that they would be constantly present and responsible for their hospitalised child. Findings suggest that respite care for parents within these facilities was not readily provided by health professionals but something parents had to independently negotiate with their relatives. This finding is of concern because it has been proposed that parents experience additional stress when nurses have set assumptions about levels of parental responsibility (Balling & McCubbin, 2001) and do not engage in negotiation with parents.

However, while the qualitative findings identified that parents felt pressured to participate because of nurse expectations, results from the NPQ intimate that pressure may have come out of concern for their child's welfare. Results showed that while over 98% of parents believed it was very important that their child receive the best nursing and medical care when they could not be present, over 75% of parents believed this did not happen. Therefore parents may have felt pressured to have at least one family member stay with their child, not because nurses dictated that, but more out of concern for their child's welfare and the worry that their child would not be properly looked after if left on their own. Research evidence has found that parents will maintain a vigilant bedside presence if they think nurses, due to heavy and intensive workloads, are unable to continually look after their child (Coyne & Cowley, 2007; Ygge & Arnetz, 2004).

Conversely, it was identified in this research that parents thought it was very important that they were able to stay with their child twenty four hours a day; however, most of the time this did not occur. It would be reasonable to postulate from the FCC survey findings that this may be influenced by a lack of organisational support, as results from the nurses' surveyed indicated that families were not well supported to stay with their child twenty four hours per day, including during invasive and non-invasive procedures. However, after evaluating all of the findings in this study, it is hard to decipher exactly why parents were not well supported within facilities to stay, whether it was due to hospital structure, nurses' attitudes or other external factors.

Results from nurses suggest that it could in fact be the hospital structure that prohibited parents' ability to stay with their child during invasive and non-invasive procedures, as they perceived that accessibility to consultation rooms and space for family members during procedures and treatments was inadequate. However, even though these findings show markedly lower than those found in Carmen's (2008) study, being able to remain in normal and critical times in both studies were similar. Therefore this suggests that the physical environment, related to consultation and treatment, does not in fact hugely impact on whether parents are well supported to stay with their child (Carmen et al., 2008). Empirical evidence suggests that a lack of other facilities such as provision of meals, a place to sleep and shower make it difficult for parents to stay with their child (Lee et al., 2007; Thompson et al., 2003). Yet results in the current study, from nurses nationally and parents at a local level, suggest that, similar to international organisations, New Zealand facilities are at an intermediate stage at providing quality inpatient rooms and nearby facilities such as showers, laundry facilities and areas for food preparation. Therefore, as New Zealand was below international facilities for supporting families to stay with their child, yet was perceived to provide the same quality and amount of facilities as overseas, it can be postulated that the physical environment and available facilities did not in fact influence whether parents could stay with their child 24 hours a day.

However, qualitative results from the parents suggest that not being able to be with their child twenty four hours a day could in fact have been influenced by other

external factors. Findings identified that, for parents, constantly having to juggle other responsibilities with looking after their hospitalised child was stressful, frustrating and not recognised by health professionals. Parents described being pulled in different directions as they had to juggle work commitments and the practical and emotional needs of other family members with being there for their hospitalised child. Therefore, the reason these parents felt they could not stay with their child 24 hours a day may have been because they found it hard balancing other competing roles with being present in hospital. These findings suggest that negotiation of parental participation is not actively undertaken by health professionals in New Zealand paediatric facilities, which is troubling when negotiation is a key concept of FCC providing choice to parents, and non-negotiation has been linked to deterioration of parental psychological well-being (Coyne, 2007). It is reasonable to assume that if negotiation of parental participation was in fact consistently discussed between parents and nurses within New Zealand facilities, then there would be arrangements made that support parents to be away from the hospital for family or professional reasons as needed.

Unlike other studies, the key finding in the qualitative analysis revealed an all-consuming onerous sense of responsibility which was not negotiated, and usually assumed by one parent. It was identified that being the one solely responsible for the child with the chronic disease was a role often reluctantly taken on, as it required a constant vigilance which placed a huge restriction on individuals socially and professionally. Unlike other studies, where responsibility was found to be connected more with the logistics of managing treatments and recognising symptoms (Katz, 2002a; MacKean et al., 2005; Matlby Kristjanson & Coleman, 2003; Tong et al., 2009), within this study responsibility encompassed every decision and aspect of parents' day to day life. It is therefore not surprising that primary caregiver's would become overwhelmed and isolated when managing their child's chronic respiratory disease. However, similar to previous research, these parents identified that whatever form responsibility takes, it usually becomes the mother's (Hodgekinson & Lester, 2002; Hovey, 2005; Katz, 2002b; Lam et al., 2006; Sullivan-Bolyai, Rosenberg & Bayard, 2006).

Qualitative findings in the current study identified that while mothers struggled with this overall responsibility, they felt the other parents in the family suffered reduced self-efficacy, as their confidence and ability to manage the treatments independently were challenged by a lack of exposure and experience. It was acknowledged by fathers that as the management of their child's respiratory disease increased, their understanding of their child's treatments and needs decreased, and they then would defer to the primary caregiver. This finding is different from previous studies which identified that fathers placed a huge importance on staying involved and "doing the care" so they could maintain their confidence to manage their child's chronic disease competently (Cashin et al., 2008; Sullivan-Bolyai et al., 2006). The findings in the current study do not provide a rationale for why these partners differ from those in other studies. It could be postulated that it is specific to New Zealand and related to how the tertiary and primary health system support or provide information and education to families, particularly when doctors' rounds and appointment times within facilities do not take into consideration the work hours of partners. Moreover, the majority of tertiary facilities in New Zealand allow only one parent to board in and care for their child which could encourage segregation of roles.

In the current study parents felt that being responsible for the chronic disease was life altering, as it limited their day to day life. Parents described having to alter plans frequently in order to accommodate the changing needs of the disease. Despite the majority of parents not showing clinical signs of anxiety as evidenced on the HADS , they did describe feeling frustrated, anxious and on edge when the quick onset of symptoms meant they had no warning or control over when the situation was going to deteriorate or improve, making management difficult. Similarly, both Cohen (1995) and Gibson (1995) reported that parents of children with various chronic diseases lived with unpredictability in their daily lives. Moreover, parents in the current study found their job and career opportunities constrained because of the frequent need for medical interventions and the constant need to be available, which has been identified as an issue in other studies (Fereday, MacDougall, Spizzo, Darbyshire & Schiller, 2009; Hodgekinson & Lester, 2002; Sallfors & Hallberg, 2003). The parents in this study talked about how the primary caregiver had to alter careers and even give up employment so that hospitalisations could be catered for. It

would be reasonable to propose that this type of family situation contributes to the complete segregation of roles and reduced self–efficacy of one partner, as the primary caregiver takes full control of their child's hospitalisation while the partner carries on at work, thus being less involved.

However, it was shown that the impact of disease unpredictability was mediated by availability of assistance from medical personnel. Findings from this study suggest that parents were supported with the responsibility of having to manage their child's unpredictable disease when access to necessary advice and education from health professionals was readily available; however, often it was not available. It is not surprising that these parents felt unsupported by medical professionals if they did not receive the necessary education and advice they required, because receiving accurate information was also found to be a need that all parents deemed important. It is therefore reasonable to assume that if parents felt the need they viewed as a priority was not being met, then they would feel unsupported with the management of their child's disease. These findings again highlight the issues in New Zealand around health professional and organisational support for parents, where parents are not receiving the type or level of support that they require. It seems reasonable to assume that this scenario only adds to the burden of responsibility parents experience in managing their child's disease.

International research identifies that the presence of depression and anxiety in parents negatively impacts on their ability to manage and participate in the care of their child (Bartlett et al., 2004; Coyne & Cowley, 2007; Jaser et al., 2009; Sallfors & Hallberg, 2003; Shields & Nixon, 2004; Spurrier et al., 2003). Although the qualitative findings in the current study indicated that the chronic disease could be onerous, placing personal restrictions on parents, results from the CHIP and HADS identified that the majority of parents' levels of anxiety and depression were within normal range, and they all coped with their child's chronic disease. These findings differ from other studies that have identified the presence of a chronic respiratory disease in a child, regardless of the characteristics of the disease itself, increased parental anxiety and depression (Bartlett et al., 2004; Yilmaz et al., 2008). It could be suggested that the reason the majority of parents in this study did not suffer symptoms

of depression and anxiety, despite the impact the disease had on family life, was due to their choice of coping behaviours associated with maintaining family integration. It could also be postulated that the reason parents utilised this type of coping pattern was because they did not feel well supported by organisations or medical personnel with the care of their child, thus they had to turn to the family to find the necessary support and help to cope. This highlights the importance of better understanding amongst health professionals about the type of coping strategies parents are utilising and why they may be using them, especially when research suggests that the quality of partnerships is dependent on the psychological robustness of parents (Shields & Nixon, 2004; Yimaz et al., 2008).

In summary, findings from this study support a study undertaken ten years ago in New Zealand by Mulvay (2001), showing negotiation between health professionals and parents' regarding levels of participation is not consistently undertaken. The findings in the current study suggest issues still exist, with the transference of FCC theory into practice within New Zealand, despite the recent introduction of organisational policy supporting FCC. Parents from the current study appeared to cope with living and managing their child's disease, however, they did feel isolated and at times overwhelmed by the responsibility. This suggests the need for health professionals to understand parental needs and the various coping strategies that parents' employ so that they receive the appropriate support to engage in negotiation of partnerships, especially as evidence suggests that if parental needs and psychology are not appropriately supported, then effective partnership and participation in care is inhibited (Coyne & Cowley, 2007; Lee, 2007; Yilmaz, et al., 2008) .

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Collaboration: This FCC concept expects patients and families to be included in healthcare on an institution-wide basis. Moreover it is expected that health care leaders will collaborate with patients and families in policy and programme development, implementation, and evaluation; in health care facility design; and in professional education, as well as in the delivery of care.

Findings from the current study suggest that New Zealand could do more to include families on an institution wide basis. These findings suggest that despite standards drafted by the Paediatric Society of New Zealand in 2002, which were proposed to underpin all health care services, collaboration between health professionals and families on an institution-wide basis has been patchy. This is concerning especially as it is proposed that collaboration with parents in policy and program development is vital to implementing a family centred system of care (Ahmann & Johnson, 2000; Johnson, 2000b). Under the Paediatric Society of New Zealand's policy it is expected that families should play a significant role in strategic planning, evaluation of systems and service delivery (Paediatric Society of New Zealand, 2002). However, in order for families to play a significant and widespread role, they must participate in all programme and policy planning, implementation and evaluation and not just be brought in to put a stamp of approval on ideas conceptualised by staff (Johnson, 2000). Yet in order for this to occur there must be a committed community of parents (Hanson, et al., 1994; Ponte, et al., 2003). It has been identified that those families affected by chronic diseases are in a particularly good position to offer a unique perspective on care and treatment and would be good candidates for such roles (Ponte, et al., 2003). From this it would be reasonable to infer that the high incidence of chronic respiratory disease in New Zealand means paediatric facilities should have good candidates available to collaborate with, which would lead to a better utilisation of such facilities for families of children with chronic respiratory disease. However, findings showed that New Zealand was only at an intermediate stage at including families in hospital policy and programme planning, which again highlights a gap in the implementation of FCC.

It was identified that nurses in the current study believed institutions lacked a clear definition of FCC, while more staff needed to consistently adopt and practise the concepts of FCC throughout their organisations. Therefore it could be suggested that

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parents were not included at an organisational level because such FCC values have not been properly included within policies. This is noteworthy as it is proposed that one of the key steps in the implementation of a FCC approach is to ensure FCC values are included in organisational mission statements and core philosophy (Ponte, et al., 2003). Moreover, a patient-centred care model cannot be properly integrated into practice unless every part of the organisation, and leaders representing care providers and supportive personnel from all areas, are involved (Ponte, et al., 2003). Therefore, if organisations are going to employ individuals with FCC skills and attitudes, they must integrate FCC concepts into the organisational policies and practices (Ahmann & Johnson, 2000). However, literature suggests that nurses predominately lack the skills to put FCC into practice because most have been trained in the medical model, which sees the service provider as expert. Consequently there is a lack of adequate education to understand and implement the concepts of FCC into practice (Bruce et al., 2002; Bruce & Ritchie, 1997; King et al., 2000; Lawlor & Mattingly, 1998). Historically, even though the training of nurses in New Zealand has included a holistic approach to care, it has not included the core concepts of FCC, thus suggesting that a large percentage of New Zealand nurses would not have adequate education and understanding of how to constructively and consistently transfer FCC theory into practice. With 54% of nurse respondents in this study being between forty and over sixty, it seems reasonable to assume that they would not have sufficient education in the philosophy of FCC. However, other evidence suggests that those with many years of experience, or who are in education and administration roles, are more able to draw on a range of previous positive experiences with parental participation, which means they understand the important part parents play in their child's care (Gill, 1993). Yet, only 28% of nurses in the current study held senior roles and it was not determined exactly how long each nurse had worked within the field of paediatrics.

Findings from this study suggest that New Zealand still has issues with integrating FCC into all levels of practice and policy. The evidence indicates this is made particularly challenging because historically New Zealand nurses have not been trained in the philosophy of FCC, and therefore may not have adequate knowledge and skills to draw on when negotiating with parents and developing policies.

Limitations of the current study

      This study has a number of limitations. Firstly there is the limitation associated with the research design of the thesis. Due to limited time and resources, an embedded design was a useful approach. However, it is difficult integrating the results when different methods are used to answer different research questions (Creswell & Plano Clark, 2007). Additionally, as the data collection of this thesis was cross-sectional, hence descriptive and only representative of a small subset at one specific time, one cannot be sure of the cause and effect relationship (Polit & Beck, 2004). Moreover limitations exist with the small sample size and the narrow demographics of parent participants, meaning Maori and Polynesian children are underrepresented, especially after adjusting for the higher representation of hospitalised male children of non-European descent under the age of five for asthma (Craig et al, 2007). Therefore generalisations arising from this study to other ethnicities and the wider community are limited.

      A further limitation relates to the selection of self-report questionnaires by a small sample of nurses. Caution needs to be exercised when interpreting the FCC findings as the sample members were self-selected nurses, which may have resulted in an over representation of individuals who have strong or set views on the integration of FCC in New Zealand, or conversely may have issues with hospital policy and/or management, producing a voluntary response bias (Polit & Beck, 2004). Moreover, the on-line survey may have resulted in non-response bias as some nurses may not have been able to participate, due to limited access to a computer. It was the expectation that nurses would complete the survey at work; however, potentially those more senior with other workload responsibilities may not have had the time. Furthermore, despite assurances from the researcher to parents that participating in this study would not impact on the care of their child, parents responses may have been biased toward what they believed was desirable to staff, to ensure their child's care was not compromised.

      Limitations also exist in that only parents could be recruited for the NPQ, so therefore a comparison between nurses and parents was not undertaken. It is the supposition of this researcher that this inability to engage nurses was due to the fact

they had recently been recruited to complete the FCC survey and had just come out of a hospital grid lock situation due to an outbreak of measles and swine flu. Similar recruitment issues have been noted in other studies, where low response rates amongst nurses has been attributed to nurses being short staffed and exposed to a number of investigations and questionnaires (Hallstrom & Elander, 2001). Furthermore, the recruitment of only three nurses from one facility meant that this hospital could not be included in some aspects of the benchmarking process.

There are also limitations associated with the qualitative part of the research. As qualitative research is interpretive, it is influenced by the interpretive process. However, the researcher took this into account, and coded the qualitative data and subsequent identified themes with the support of one of the research supervisors. While this facilitated a consistent approach to the method, having numerous perspectives would have allowed for a wider analysis of the data.

Finally, results from this study are specific to the demographics and situations of the participants recruited and therefore are not able to be generalised outside this group. However, it is possible that the data within this study can generate other questions which may be investigated in other samples.

Strengths of current study

The main strength of this study was the combination of approaches from different theoretical frameworks, and the use of these theories to explore the integration of FCC, and the psychological wellbeing of parents and how this influences parent participation. Furthermore, the recruitment of both nurses and parents enabled the researcher to understand the issues that impacted on the promotion of FCC from an organisational, parental and nursing staff point of view.

A further strength of the current study is the use of established tools which have all been psychometrically tested for reliability and validity, therefore suggesting that the constructs of FCC, anxiety and depression, coping and parental needs have been appropriately tested (Schneider, Elliott, LoBiondo-Wood & Haber., 2003).

Implications for future research

Results from the current study suggest further investigation is needed into nurses' understanding of the concepts of FCC. It is recommended that undergraduates and registered nurses across various paediatric facilities should be targeted to explore their knowledge of FCC theory and the level of FCC training within organisations and educational facilities.

Further investigation into supporting parental needs is indicated. The present study found that parents felt unsupported because they were given inaccurate and inappropriate information about their child. Ideally a randomised controlled intervention study would be appropriate, providing educational support for parents at home, with the use of self–report questionnaires to assess parents' quality of life and healthcare utilisation. The use of semi-structured interviews addressing support and coping strategies would strengthen the design.

Further research may examine the role of responsibility and its impact on parents. The use of self-report questionnaires and interviews to explore the role of the primary caregiver and the impact their role has on the support parent's self-efficacy is warranted.

The findings from the qualitative portion of this study cannot be generalised. As hospital admissions for asthma in New Zealand are higher for young children of non-European descent living in deprived areas (Craig, et al., 2007), further exploration around the issues of coping and parental needs for those from other cultural and ethnic groups is justified.

Implications for practice

The current study has implications for clinical practice and the provision of FCC services in New Zealand for parents of children with chronic respiratory disease. Findings from this study suggest that there is room for improvement with the implementation of FCC in New Zealand. The dichotomy between what nurses believed was occurring, and what parents experienced, indicates that nurses were unaware of what parents saw as important or challenging. A lack of negotiation and understanding between health professionals and parents highlighted the inconsistent approach to FCC, where parents at times felt their expertise was devalued and their confidence was consequently reduced. At the same time the struggle parents experienced juggling their sick child's needs with other competing family and professional needs suggests the logistics of remaining with their child were difficult, but not recognised by health professionals. These points highlight the need for health professionals and organisations to provide opportunities for discussions around what parents need and the levels of partnership they wish to engage in.

It is the researcher's suggestion that undergraduate and postgraduate nursing should have practical training and theoretical knowledge of FCC, as it has been shown to improve the preparation for family nursing activities and raise self-confidence for nurses working with families (Flowers, St John & Bell, 2008). Such things as the Practice Continuum tool by Smith, Coleman and Bradshaw (2002) or Wright and Bell's (2009) Family Nursing Interventions could be considered by organisations and training centres as they offer practical applications for FCC concepts within clinical environments, thus assisting with the theory-practice gap (Smith, Coleman & Bradshaw, 2002; Wright & Bell, 2009). The Family Nursing Interventions focus on creating collaborative relationships and therapeutic conversations on the families' most pressing concerns; this could teach practising nurses important skills to build therapeutic relationships, such as having established rituals of welcome and awareness of body language which set the tone for the relationship between parents and professionals (Wright & Bell, 2009). The Practice Continuum is a tool that incorporates a range of family input from nurse-led (where parents have no involvement) to parent–led care. Following this model nurses would be able to facilitate care within a range, and parents would have the flexibility to choose and

alter where they wished to be on the continuum, depending on their needs and circumstances.

Furthermore, the results suggest the need for organisations to develop better policies and more working groups to enhance the integration of FCC, and the cultivation of a work force that understands parental needs better and who are therefore able to include this philosophy of family participation in all aspects of care delivery. It is the researcher's opinion that a better integration by nurses of family involvement would be in keeping with New Zealand Nursing Council competencies (Nursing Council of New Zealand, 2007). Moreover, as a philosophy to underpin healthcare it would be complementary to the Whanau Ora strategy (Ministry of Maori Development, 2010).

There are also important clinical and service implications of the current study's findings. Even though in this study it was found that a parent's psychological stability was not affected by caring for a child with a chronic respiratory disease, they did feel isolated and at times overwhelmed by the responsibility of managing and caring for their child. This signifies how important it is for health professionals to understand a parent's emotional state and why they may choose certain mechanisms to cope especially as it is recognised that depression and anxiety in parents has a negative impact on parents' ability to manage and engage in partnerships of care with health professionals (Bartlett et al., 2004; Coyne & Cowley, 2007; Jaser et al., 2009; Sallfors & Hallberg, 2003; Shields & Nixon, 2004; Spurrier et al., 2003), while the choice of coping skills has been identified as influencing a parent's ability to handle their child's chronic disease (Lee, et al., 2007). It would be the researchers hope that service improvements would better support parents with their all-consuming responsibility, thus reducing disengagement from services and alleviating their sense of isolation.

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The overall focus of this thesis was to explore how well FCC was implemented within the New Zealand paediatric service, and how a parents' psychological wellbeing and circumstances influenced management of and participation in their child's care. The findings from this study suggest that New Zealand is inconsistent with the implementation and integration of FCC across the primary and tertiary health sector which contributes to primary caregivers and families of children with chronic respiratory diseases becoming isolated and burdened with an all-consuming sense of responsibility. In order to better support families managing the care of their child with a chronic respiratory disease there needs to be improvement and education in and about the concepts of FCC especially understanding parental needs, respecting parents' knowledge and expertise, and negotiating participation.

Findings identified that information sharing, knowledge and expertise, parental responsibility, negotiation of roles and a lack of organisational support are all key factors that negatively influence parental participation and thus FCC. It appears that there is a dichotomy in New Zealand between what health professionals perceive to be occurring in practice and what parents' experience. Findings suggest that despite the beliefs of health professionals, parents' knowledge and expertise are not respected, and their information needs are not appropriately met; which results in parents feeling isolated and less confident, which impacts on a parents sense of responsibility, and levels of participation and engagement with health services.

These findings are important as they suggest that the lack of consistent integration of FCC across the health service has contributed to parents of children with chronic respiratory diseases feeling isolated with the complete responsibility of their child, while health professionals remain unaware of service gaps and their influence on this. Therefore there is a need for parents to be included more in program and policy planning, FCC implementation and evaluation. This would provide a forum in which parents could express their needs, related to information and negotiation, and impart their knowledge and expertise which may then lead to parents engaging in better partnerships with health professionals as they feel valued, have their needs met and thus feel better supported.

Finally these findings provide new knowledge on how well paediatric facilities in New Zealand support the concepts of FCC and suggest the need for further education of health professionals on the principles and integration of FCC through such models of care as the practice continuum and family nursing. The original contribution to knowledge is the discovery of the overwhelming responsibility experienced by the primary caregiver, and reduced self-efficacy amongst fathers, which provides the potential for future research into other ways that health professionals can support parents with the responsibility of caring for a child with a chronic disease, especially in the community,

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Appendices

Appendix 1

Inclusion/Exclusion criteria

<u>Inclusion Criteria</u>

Children between 0-16 years of age

Children diagnosed with a chronic respiratory illness

Biological, Step, Foster and adoptive parents/caregivers

Parents who can read and write English

<u>Exclusion Criteria</u>

Children over 16 years of age

Children diagnosed with a non-respiratory chronic illness

Parents who are physically incapable of independently filling out a questionnaire

<u>Staff inclusion criteria:</u> Primary nurse of recruited child with chronic respiratory illness

Appendix 2

4th May 2008
Centre for Postgraduate Nursing
Otago Universtiy, Christchurch
72 Oxford Terrace
Christchurch.

Dear Sir/Madam,

I am a full time PhD student with the University of Otago undertaking a two stage mixed method study. I am writing to you with the hope of being able to undertake the first stage of my study within your organization.

Stage 1 is a national benchmarking survey on Family-centered care that all nurses within pediatrics are invited to complete.

Stage 2 involves a survey of 50 parents whose child has been re-hospitalized for a chronic respiratory illness. These surveys will explore the needs of parents and links between coping, self-efficacy, anxiety and depression.

I am aware that I will need to secure Locality assessment for your facility and a primary investigator. I was wondering if you would be able to assist me on identifying who would be the best person to talk to about the process of gaining Locality assessment within your facility.

I look forward to hearing from you
Kind Regards

Virginia Jones

Appendix 3

Hi ……

I am a full time PhD student with the University of Otago who is undertaking a two stage mixed method study.

Stage 1 is a national benchmarking survey on Family-centered care that all nurses within pediatrics are invited to complete.

Stage 2 involves a survey of 50 parents whose child has been re-hospitalized for a chronic respiratory illness. These surveys will explore the needs of parents and links between coping, self-efficacy, anxiety and depression.

I have been given your name as someone who might be willing to assist me rolling out Stage 1 within your facility. It would mean handing out a survey on Family – centered care to nurses working in pediatric services within your organization, and following up with a few reminders.

I would love to hear back from and discuss with you further any thoughts you may have.

You can e-mail me at virginiajns7@gmail.com or phone me on 03 364 3850.

Kind regard

Virginia Jones

Appendix 4

Letter to staff

Dear Colleague,
You are invited to participate in a national benchmarking survey on family-centred care. This is an online survey which has approval from the national ethics committee. The survey should take no more then 15 minutes to complete. To start the survey click on the link below. **You can save the survey and come back to it if you need to.**

http://www.pfcc.org.nz/index.php

I have attached the information sheet outlining the study as background.
Thank you very much for your time in taking part in this study.

If you have any questions accessing the information sheet or survey
please contact me by e-mail: jonvi105@student.otago.ac.nz or phone: 03
364 3856.

Kind regards,
Virginia Jones

Appendix 4

Information letter to staff

Study title: <u>Family-Centred Care in long term conditions.</u>

Primary Investigator: **Virginia Jones, PhD Student at Otago University, Centre for Postgraduate Nursing studies, 72 Oxford Terrace, Christchurch. Telephone: 03 364 3856 ext 3856.**

Supervisor: **Dr Lisa Whitehead, Senior Lecturer, Centre for Postgraduate Nursing Studies, 72 Oxford Terrace, Christchurch. Telephone: 03 364 3858.**

You are invited to take part in a research study that will explore factors that impact on the promotion of family-centred care from three view points; organizational, parental and nursing staff. You can take your time to decide whether you want to take part as we will be recruiting staff from May 2009 to the end of January 2010. Participation is voluntary you do not have to take part in this study and if you decide not to take part this will not affect your employment or standing within your DHB. If you do agree to participate you are free to withdraw from the study at any time without having to give a reason and your employment will in no way be affected.

The study will explore the degree with which leadership and staff members perceive Family-centred care concepts are practiced within the four main paediatric centers in New Zealand (Starship Auckland, Wellington public hospital, Christchurch public hospital and Dunedin Public hospital). The researcher in consultation with DHB administrators has identified you as some one who meets the studies inclusion/exclusion criteria and therefore suitable to take part. To be included within this study you must be employed within a paediatric service by the DHB in one of the following roles; enrolled nurse, registered nurse, nurse educator, charge nurse, nurse coordinator or nurse practioner.

The study will involve filling out The Patient-Family-Centred Care survey. You do not have to answer all the questions. Filling in the questionnaire should take no more than 30 minutes. You can choose to fill it out at a location that best suits you and post it using the attached self addressed stamped envelope. Please do not discuss this questionnaire with anyone else until you have filled it out. However if you do not understand some of the questions or wish to get more information about this study you may contact Virginia Jones at the address and phone number at the top of the

page. You may have a friend, family or Whanau support to help you understand the risks and/or benefits of this study and any other explanation you may require.

If you have any queries or concerns about your rights as a participant in this study you may wish to contact a Health and Disability Services Consumer Advocate,

- 0800 555 050 or
- Free fax 0800 2787 7678

Or email   **advocacy@hdc.org.nz**

The study will take 24 months to complete and you will be sent information about the results of the study if you would like to receive them. This is one of the questions asked on the demographic form. The results will be sent to you shortly after the study has finished in May 2011.

This study will provide a national overview of the family-centred nature of paediatric facilities in New Zealand with the aim of providing knowledge and information to promote family-centred-care for children living with long-term conditions in New Zealand.

Your confidentiality is assured and no material which could personally identify you will be used in any reports on this study. The questionnaire information will be coded and all files will be stored on a secure computer and paper copies will be stored in a locked filing cabinet in a secure office. After five years all of the data will be destroyed.

This study has received ethical approval from the Multiregional Ethics Committee.

Please feel free to contact the researchers Virginia Jones or Lisa Whitehead at the address and phone numbers given at the top of page one if you have any questions about this study.

Appendix 5

Flyer for Christchurch hospital

Family centered care survey

We are going to close the survey on the 23rd April

in

DAYS

If you haven't had a chance to fill it in we would **love** to have your input.
Just a reminder that if any of the questions don't apply or are difficult to answer you can leave them blank

So **YOU** have equal input with some of the other hospitals we need to have **35** nursing participants.
If we achieve the magic number we will shout morning & afternoon tea and supper on the 23rd.
Many thanks

Appendix 6

Patient-Family-Centred Care (PFCC) Survey

1. What is the name of the institution you are rating?

   _____

2. Which of the following best describes you? (Please circle)

   Leadership (Medical, Clinical, Administration)

   Patient Care Staff

3. If leadership, what is your job title?

   _____

4. If staff, what is your job title?

   _____

Overall Perceived level of Patient-Family-Centred Care Implementation

5. Has your institution implemented patient-family-centred care concepts according to the following definition "Patient-family-centred care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families". (please tick)

Yes	☐
No	☐

6. Does your institution have a clear definition of what patient-family-centred care is. (please tick).

Yes	☐
No	☐

7. How many years has your institution been committed to patient-family-centred care? (please tick).

<div style="margin-left: 2em">

0<1year   ☐

1<2years   ☐

2<5years   ☐

5<10years   ☐

10 or more years   ☐

</div>

Outcomes of Patient-Family-Centred Care

8. **Do you agree with the following statements?** (1=Strongly disagree, 2= Disagree, 3= Agree, 4= Strongly agree) (please circle)

Patient-family-centred care concepts are consistently practiced throughout our organisation	1 2 3 4
Our institution operations have improved since we implemented patient-family-centred care	1 2 3 4
Staff adoption of patient-family-centred care concepts has been successful	1 2 3 4
benefits exist from our organisation's commitment to patient-family-centred care	1 2 3 4

9. **Implementing patient-family-centred care has had a positive influence on the following** (1=Strongly disagree, 2= Disagree, 3= Agree, 4= Strongly agree) (please circle)

Nurse retention	1 2 3 4
Allied health staff retention (physical therapists, play therapist, etc)	1 2 3 4
Social worker position retention	1 2 3 4
Family support position retention	1 2 3 4

10. If you have specific examples or case studies showing positive influence on retention, please provide a brief description.

_____

_____

_____

_____

11. **Implementing patient-family-centred care concepts has positively influenced our:** (1=Strongly disagree, 2= Disagree, 3= Agree, 4= Strongly agree) (please circle)

Family satisfaction levels in the inpatient setting   1 2 3 4

Family satisfaction levels in the outpatient setting   1 2 3 4

Nurse satisfaction   1 2 3 4

Physician satisfaction   1 2 3 4

Patient-Family Involvement/Participation

12. **In our institution, families are always allowed to remain with their child:** (1=Strongly disagree, 2= Disagree, 3= Agree, 4= Strongly agree) (please circle)

24 hours per day (unrestricted visiting)   1 2 3 4

For change of shift reports (nursing)   1 2 3 4

For physician rounds   1 2 3 4

During procedures that are not too invasive, (e.g. needlesticks, dressing changes)   1 2 3 4

During procedures that are invasive (e.g chest tube insertion, endotracheal intubation)   1 2 3 4

During cardiopulmonary resuscitation   1 2 3 4

During pre-surgical anaesthetic induction   1 2 3 4

During immediate postoperative recovery   1 2 3 4

13. **In our institution, families are always involved in the following:**
(1=Strongly disagree, 2= Disagree, 3= Agree, 4= Strongly agree) (please circle)

Assessing their child's symptoms   1 2 3 4

Evaluating their child's response to therapy or treatment   1 2 3 4

Developing the plan of patient care   1 2 3 4

Providing patient care   1 2 3 4

Developing the discharge plan   1 2 3 4

14. **Do you agree with the following regarding your institution?**
(1=Strongly disagree, 2= Disagree, 3= Agree, 4= Strongly agree) (please circle)

Families always define who family is for each patient   1 2 3 4

Patients and families always participate in staff education or orientation   1 2 3 4

Job descriptions for staff always include essential patient-family centred care concepts   1 2 3 4

Performance reviews of staff always include patient-family-centred care concepts   1 2 3 4

15. **In our institution, families, are ALWAYS involved in the following:**
(1=Strongly disagree, 2= Disagree, 3= Agree, 4= Strongly agree)(please circle)

Design of facility and space   1 2 3 4

Decisions about care delivery processes   1 2 3 4

Standing hospital committees   1 2 3 4

Bio-ethics or quality of care committee participation   1 2 3 4

Developing amenities and programs to support patients and families	1 2 3 4
Representing the hospital in an outreach role (e.g philanthropy, education)	1 2 3 4
Developing clinical education materials	1 2 3 4

16. **In our institution, children (patients and siblings) are ALWAYS involved in the following** (1=Strongly disagree, 2= Disagree, 3= Agree, 4= Strongly agree) (please circle).

Design of space	1 2 3 4
Patient-to-patient support groups	1 2 3 4
Policy making	1 2 3 4
Patient care/process changes	1 2 3 4
Developing amenities and programs to support patients and families	1 2 3 4
Representing the institution in an outreach role (e.g philanthropy, education)	1 2 3 4
Employee related subjects (e.g job description wording, selection/hiring practices)	1 2 3 4
Training regarding patient-family-centred care	1 2 3 4

17. Do you have a Youth Advisory Board?

    Yes   ☐

    No   ☐

18. Do you have printed material for families explaining your philosophy and policies on patient-family-centred care?

    Yes   ☐

    No   ☐

19. Do you allow siblings to visit? (check all that apply)

      Yes   ☐

      No   ☐

      No age limit   ☐

      Age limited   ☐

      Length of visit limited   ☐

      Length of visit defined   ☐

      Time of day restricted   ☐

      In the patient room   ☐

      After screening for signs and symptoms   ☐
      of infection

Please specify other restrictions:

_____

_____

_____

20. Who prepared the siblings for the visit (Check all that apply)

      Parents only   ☐

      Child life   ☐

      Nursing   ☐

      Social worker   ☐

      Physicians   ☐

Other, please specify ☐

_____

21. Do you allow families/visitors to eat and /or drink while at the bedside of their Child? (Check all that apply)

    Drinks only ☐

    Food and drinks ☐

    No food or drinks ☐

Design elements for leadership/staff

22. Staff Work and Support Areas- How strongly do you agree with the following? (1=Strongly disagree, 2= Disagree, 3= Agree, 4= Strongly agree) (please circle).

Respite areas exist for staff   1 2 3 4

The design of staff work and support areas promotes   1 2 3 4
information sharing among staff within and across
disciplines

Support areas are conveniently located for staff which   1 2 3 4
promotes relaxation, informal networking and information
sharing

23. **Within inpatient rooms, does your facility provide** (Check all that apply)

Space for a recliner for a family member ☐
Space for 1 single bed for a family member ☐
Space for 1 single bed, plus 1 recliner for 2 family members ☐
Bed space for 2 family members (either a double bed or 2 singles) ☐
Additional sleep rooms on the unit for family members ☐
Additional sleep rooms in a central location for family members ☐
Both sleep rooms on the unit and in a central location ☐
None of the above ☐

Overall design of facility

24. **Do you agree that the overall design of the facility conveys that it is:**
    (please circle the number that bests reflects your level of agreement,
    1=Strongly disagree, 2= Disagree, 3= Agree, 4= Strongly agree)

    A place of healing, caring and compassion   1 2 3 4

    A place that encourages partnership with patients and families 1 2 3 4

    A place for patients and families to obtain information   1 2 3 4

    A place for patients and families to obtain emotional support 1 2 3 4

    A place for patients and families to learn about community   1 2 3 4
    resources

    A place where families can learn about their child's illness 1 2 3 4

    A place where families can learn how to care for their child   1 2 3 4
    after discharge

25. **Parking** – Please evaluate the facility's parking on the following factors
    (please circle the number that bests reflects your level of agreement,
    1=Strongly disagree, 2= Disagree, 3= Agree, 4= Strongly agree)

    Adequate amount –Spaces are easily found without   1 2 3 4
    repeatedly circulating the lot

    Accessibility – There is sufficient amounts of handicapped 1 2 3 4
    accessible and /or oversized van spaces

    Convenience – Parking is within a few hundred feet of the   1 2 3 4
    building entrance

    Safety- Good lighting, a well-defined perimeter, and security 1 2 3 4
    personnel provide a safe parking environment

    Cost- Parking is affordable or there are adjustable rates   1 2 3 4
    to meet families' financial circumstances

    Navigation- Finding entrances, understanding parking lot   1 2 3 4
    circulation and finding exits are easy for first time users

    Assistance- Valets or attendants are usually available to assist 1 2 3 4
    with loading/unloading equipment or to stay with family
    member while a car is parked

26. **Entrances –** Please evaluate the facility's entrance based on the following factors (please circle the number that bests reflects your level of agreement, 1=Strongly disagree, 2= Disagree, 3= Agree, 4= Strongly agree)

Visibility- Entrances are easy to find   1 2 3 4

Identification- Where multiple entrances exist, each is clearly marked for which services   1 2 3 4

Welcoming- Entrances create positive first impressions   1 2 3 4

Protection- Entrances offer cover from weather and separation from traffic with adequate unloading space   1 2 3 4

Accessibility- Entrances meet needs of persons in wheelchairs and/or persons with strollers   1 2 3 4

27. **The overall facility design creates a healing environment for patients, families and staff through the use of :** (please circle the number that bests reflects your level of agreement, 1=Strongly disagree, 2= Disagree, 3= Agree, 4= Strongly agree)

Artwork is relevant to individuals, families and the communities we serve   1 2 3 4

Colours and lighting have pleasing tones   1 2 3 4

There are views to the outdoors throughout the facility   1 2 3 4

Respite areas exist for families   1 2 3 4

Security systems are in place to assure the safety and comfort of patients, families, and staff without being intrusive   1 2 3 4

Nursing stations reinforce the concept that patients and families are partners in care   1 2 3 4

28. **Signage/Language – Please rate the facility on the following** (please circle the number that bests reflects your level of agreement, 1=Strongly disagree, 2= Disagree, 3= Agree, 4= Strongly agree)

Signs and papers provided to patients and families are worded positively and respectfully   1 2 3 4

Signs are understandable to patients and families who do not read English   1 2 3 4

Translation services are available 24 hours a day/7 days a week   1 2 3 4

Signs are written at a reading level understood by patients and families who use the facility   1 2 3 4

29. **Reception and lounge Areas** (please circle the number that bests reflects your level of agreement, 1=Strongly disagree, 2= Disagree, 3= Agree, 4= Strongly agree)

Reception is located directly inside each entrance   1 2 3 4

Furniture and equipment in reception and lounges are arranged To enhance the greeting and welcoming of patients/families   1 2 3 4

Seating in reception/lounges is comfortable and accessible for families, 24 hours a day/7 days a week   1 2 3 4

There are items of visual interest (Aquariums, mobiles, art work etc)   1 2 3 4

A clock is visible to patients and families consistently throughout the facility   1 2 3 4

Television does not dominate space visually or acoustically   1 2 3 4

Restrooms are universally accessible, conveniently located and fitted with a diaper changing station.   1 2 3 4

30. **Inpatient Rooms** (please circle the number that bests reflects your level of agreement, 1=Strongly disagree, 2= Disagree, 3= Agree, 4= Strongly agree)

Room is large enough to support acuity of care functions and Interactions with patient, family and staff   1 2 3 4

Patient rooms are configured to have separate space for family   1 2 3 4

A desk or workspace is provided for patient and family in each room   1 2 3 4

A computer or internet access is provided for patient and family in each room   1 2 3 4

There are secure storage spaces in room for patient and family members' personal items   1 2 3 4

There are opportunities for patients and families to personalize space   1 2 3 4

Lightening levels are adjustable   1 2 3 4
The physical space reduces noise level

There are amenities for patients and family in bathroom   1 2 3 4
(convenient shelf, accessible plug, hairdryer, tub etc.
fitted with diaper changing station)

31. **There is a comfortable space near the unit for families that provides**
(please circle the number that bests reflects your level of agreement,
1=Strongly disagree, 2= Disagree, 3= Agree, 4= Strongly agree)

Tub/showers   1 2 3 4

Laundry facilities   1 2 3 4

Areas for food preparation   1 2 3 4

Areas for family food storage   1 2 3 4

Families are provided access to coffee/tea   1 2 3 4

Families are provided access to ice   1 2 3 4

32. **Procedure/Treatment** (please circle the number that bests reflects your level
of agreement, 1=Strongly disagree, 2= Disagree, 3= Agree, 4= Strongly agree)

There is adequate space for family members within the room   1 2 3 4
during procedures.

Supplies and equipment are stored to minimize interference with   1 2 3 4
families and patients (i.e disturbing items are put away; no
glass or needles are visible, etc)

33. **Consultation/Education/Support** (please circle the number that bests reflects
your level of agreement, 1=Strongly disagree, 2= Disagree, 3= Agree, 4=
Strongly agree)

Facility has a patient and family resource centre   1 2 3 4

Consultation rooms are readily available   1 2 3 4

There is space for spiritual support, mediation and prayer   1 2 3 4

34. **How influential were the following people in driving your institution to implement patient-family-centred care concepts?** (1=Not influential at all, 2= Not very influential, 3= somewhat influential, 4= extremely influential, Please circle).

Families   1 2 3 4

Nursing staff   1 2 3 4

Physicians   1 2 3 4

Administrative leaders   1 2 3 4

Board members   1 2 3 4

Others (please identify below)   1 2 3 4

_____

_____

35. What other parties were influential in driving your institution to implement patient-family-centred care concepts?

_____

_____

_____

36. **How important were the following factors in driving your institution to implement patient-family-centred care concepts?** (1=Not influential at all, 2= Not very influential, 3= somewhat influential, 4= extremely influential, Please circle).

Patient safety   1 2 3 4

Operational efficiency   1 2 3 4

Patient and family satisfaction   1 2 3 4

Caregiver satisfaction   1 2 3 4

Regulatory requirements   1 2 3 4

Meeting standard of care advocated by professional   1 2 3 4
organizations

Other factors (Please describe below)   1 2 3 4

_____

_____

_____

37. What other factors were important in your institution's decision to implement patient –family-centred care concepts?

_____

_____

_____

38. How many of your beds are in the following?

Private rooms _____

Semi-private rooms _____

Open pods, clusters or wards _____

If in pods, how many beds are within each pod? _____

39. If your ward has all single rooms, have you documented any improved outcomes due to this environment ?

       Yes   ☐

       No   ☐

Future Implementation of patient-family-centred care concepts

40. **In the next two years, my facility has made it a priority to improve the following factors to better implement family-centred-care:**
(check all that apply)

Unrestricted family visiting hours ☐

Family presence during nursing change of shift reports and or physician rounds ☐

Family presence during invasive procedures and/or CPR ☐

Family presence during anaesthetic induction or postoperative recovery ☐

Family involvement with patient care ☐

Patient-family participation in policy making and/or care delivery processes ☐

Inclusion of patients-families on various hospital committees ☐

Development of a family and/or youth advisory board ☐

Patient-family participation in the overall design of facility and space ☐

Parking ☐

Building entrances ☐

Signage ☐

Reception and lounge areas ☐

Inpatient rooms ☐

Consultation/Education/Spiritual support rooms for patients-families ☐

Staff work and support areas ☐

My facility does not intend to change any of the above in the next 2 years ☐

41. **In planning for renovation, new construction, or interior design, my facility incorporates a patient-family-centred philosophy**(check all that apply)

Strongly agree ☐

Disagree ☐

Agree ☐

Strongly agree ☐

Thank you very much for participating in this study

Appendix 7

Staff demographic form for stage one

Factors impacting on family centred care for children with a chronic respiratory illness.

Staff Demographics

1. What is your age?

   <20 ☐

   20-30 ☐

   30-40 ☐

   40-50 ☐

   >60 ☐

2. Are you:

   Male ☐

   Female ☐

3. Are you:

   Single ☐

   Married ☐

   Defacto ☐

   Separated ☐

   Divorced ☐

4. Which ethnic group do you belong to?

NZ European   ☐

Maori   ☐

Samoan   ☐

Cook Island Maori   ☐

Niuean   ☐

Chinese   ☐

Indian   ☐

Other- please specify below

Other: _____

5. Do you have any children? If you answered No go to question 8

Yes   ☐

No   ☐

6. How many?

1.   ☐
2.   ☐
3.   ☐
4.   ☐
5 or more   ☐

7. Have any of your children been admitted to hospital

       Yes   ☐

No   ☐

8. Are you employed as a

       Registered staff nurse   ☐

       Enrolled nurse   ☐

       Nurse educator   ☐

       Charge nurse   ☐

       Nurse co-ordinator   ☐

       Nurse Practioner   ☐

9. How many hours are you employed to work in this role

       8 or less   ☐

       8-16   ☐

       16-24   ☐

  24-32   ☐

  32-40   ☐

       40 or more   ☐

10. What is your highest nursing qualification?

_____

11. What is your highest tertiary education?

_____

12. Once this research is finished do you wish to receive the results?

       Yes   ☐

No   ☐

1. If you answered yes to question 12 please provide your postal address.

_____

_____

_____

Appendix 8

Patient-Family-Centered Care (PFCC) Survey

Overall Design of Facility

1. **Do you agree that the overall design of the facility conveys that it is:**
   (Please circle the number that bests reflects your level of agreement, 1=
   Strongly disagree, 2 =Disagree, 3= Agree, 4= Strongly agree) (Please circle)

   A place of healing, caring and compassion   1   2   3   4

   A place that encourages partnerships with patients and families   1   2   3   4

   A place for patients and families to obtain information   1   2   3   4

   A place for patients and families to obtain emotional support   1   2   3   4

   A place for patients and families to learn about community
   resources.   1   2   3   4

   A place where families can learn about their child's illness   1   2   3   4

   A place where families can learn how to care for their child
   after discharge   1   2   3   4

2. **Parking** – Please evaluate the facility's parking on the following factors (1=
   Strongly disagree, 2= Disagree, 3= Agree, 4= Strongly agree) (Please circle)

   Adequate amount- Spaces are easily found without
   repeatedly circulating the lot   1   2   3   4

   Accessibility- There are sufficient amounts of handicapped
   accessible and/ or oversized van spaces   1   2   3   4

   Convenience- Parking is within a few hundred feet of the
   building entrance   1   2   3   4

   Safety- Good lighting, a well defined perimeter, and
   security personnel provide a safe parking environment   1   2   3   4

   Cost-Parking is affordable or there are adjustable rates
   to meet families' financial circumstances   1   2   3   4

   Navigation- Finding entrances, understanding parking
   lot circulation and finding exits are easy for first time users   1   2   3   4

   Assistance- Valets or attendants are usually available to

assist with loading/unloading equipment or to stay with
family member while a car is parked   1   2   3   4

3. **Entrances-** Please evaluate the facility's entrance based on the following
   factors (1= Strongly disagree, 2= Disagree, 3= Agree, 4= Strongly agree)
   (Please circle)

   Visibility- Entrances are easy to find   1   2   3   4

   Identification-Where multiple entrances exist, each is
   clearly marked for which services.   1   2   3   4

   Welcoming- Entrances create positive first impressions   1   2   3   4

   Protection- Entrances offer cover from weather and
   separation form traffic with adequate unloading space   1   2   3   4

   Accessibility- Entrances meet needs of persons in wheelchairs
   and/or persons with strollers   1   2   3   4

4. **The overall facility design creates a healing environment for patients,
   families and staff through use of** :(1= Strongly disagree, 2= Disagree, 3=
   Agree, 4= Strongly disagree) (Please circle)

   Artwork is relevant to individuals, families and the
   Communities we serve.   1   2   3   4

   Colours and lighting have pleasing tones   1   2   3   4

   There are views to the outdoors throughout the facility   1   2   3   4

   Respite areas exist for families.   1   2   3   4

   Security systems are in place to assure the safety and comfort of
   Patients, families, and staff without being intrusive.   1   2   3   4

   Nursing stations reinforce the concept that patients and families
   are partners in care.   1   2   3   4

5. **Signage/Language- Please rate the facility on the following** (1= Strongly
   disagree, 2= Disagree, 3= Agree, 4= Strongly agree, 5= Not applicable)
   (Please circle)

Signs and papers provided to patients and families are worded
positively and respectfully.   1   2   3   4

Signs are understandable to patients and families who do

not read English. 1 2 3 4

Translation services are available 24 hours a day/7days a week 1 2 3 4

Signs are written at a reading level understood by patients and
families who use the facility. 1 2 3 4

6. **Reception and lounge Areas** (1= Strongly disagree, 2= Disagree, 3= Agree,
4= Strongly agree) (Please circle)

Receptionist is located directly inside each entrance 1 2 3 4

Furniture and equipment in reception and lounges are arranged
to enhance the greeting and welcoming of patients/families 1 2 3 4

Seating in reception/lounges is comfortable and accessible
for families, 24 hours a day/7 days a week 1 2 3 4

There are items of visual interest (aquariums, mobiles, art work
etc.) 1 2 3 4

A clock is visible to patients and families consistently throughout
the facility 1 2 3 4

Television does not dominate space visually or acoustically 1 2 3 4

Restrooms are universally accessible, conveniently located and
fitted with a diaper changing station. 1 2 3 4

7. **Inpatient Rooms** (1= Strongly disagree, 2= Disagree, 3= Agree, 4= Strongly
agree) (Please circle)

Room is large enough to support acuity of care functions and
interactions with patient, family and staff 1 2 3 4

Patient rooms are configured to have separate space
for families 1 2 3 4

A desk or workspace is provided for patient and family
in each room 1 2 3 4

A computer or internet access is provided for patient
and family in each room 1 2 3 4

There are secure storage spaces in room for patient
and family members' personal items 1 2 3 4

There are opportunities for patients and families to
personalize space 1 2 3 4

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Lighting levels are adjustable
The physical space reduces noise level   1   2   3   4

There are amenities for patients and family in bathroom
(convenient shelf, accessible plug, hairdryer, tub, etc.)
 fitted with diaper changing station.   1   2   3   4

8. **There is a comfortable space near the unit for families that provides**(1=Strongly disagree, 2= Disagree, 3= Agree, 4= Strongly agree) (Please circle)

Tub/showers   1   2   3   4

Laundry facilities   1   2   3   4

Areas for food preparation   1   2   3   4

Areas for family food storage   1   2   3   4

Families are provided access to coffee/tea   1   2   3   4

Families are provided access to ice   1   2   3   4

9. **Procedure/Treatment** (1= Strongly disagree, 2= Disagree, 3= Agree, 4= Strongly agree) (Please circle)

There is adequate space for family members within the
 room during procedures.   1   2   3   4

Supplies and equipment are stored to minimize interference
 with families and patients (i.e., disturbing items are put away;
 no glass or needles are visible, etc.)   1   2   3   4

10. **Consultation/Education/Support** (1= Strongly disagree, 2= Disagree, 3= Agree, 4=Strongly agree) (Please circle)

Facility has a patient and family resource centre   1   2   3   4

Consultation rooms are readily available   1   2   3   4

There is space for spiritual support, meditation and prayer   1   2   3   4

Appendix 9

Coping Health Inventory for Parents (CHIP)

To complete this inventory you are asked to read the list of "Coping Behaviours" below, one at a time.

For each coping behaviour you use/d while your child is in hospital, please record how helpful it was. Circle **one** number.

3. Extremely helpful
2. Moderately helpful
1. Minimally helpful
0. Not helpful

For each coping behaviour (CB) you did not use please record your reason by checking one of the boxes: "Chose not to use it" or "Not possible."

Please begin: Please read and record your decision for EACH and EVERY coping behaviour listed below.

		Extremely helpful	Moderately helpful	Minimally helpful	Not helpful	CB not used reasons	
						Chose not to	Not possible
1.	Believing that my child (ren) will get better	3	2	1	0	☐	☐
2.	Investing myself in my children.	3	2	1	0	☐	☐
3.	Doing things with my children.	3	2	1	0	☐	☐
4.	Believing that things will always work out.	3	2	1	0	☐	☐
5.	Telling myself that I have many things I should be thankful for	3	2	1	0	☐	☐
6.	Building a closer relationship with my spouse.	3	2	1	0	☐	☐
7.	Talking over personal feelings and concerns with spouse	3	2	1	0	☐	☐

8.	Doing things with family relatives.	3	2	1	0	☐	☐
9.	Believing in God.	3	2	1	0	☐	☐
10.	Taking good care of all the medical equipment at home.	3	2	1	0	☐	☐
11.	Believing that my child is getting the best medical care possible	3	2	1	0	☐	☐
12.	Trying to maintain family stability.	3	2	1	0	☐	☐
13.	Doing things together as a family (involving all member of the family).	3	2	1	0	☐	☐
14.	Trusting my spouse (or former spouse) to help support me and my child(ren).	3	2	1	0	☐	☐
15.	Showing that I am strong.	3	2	1	0	☐	☐
16.	Getting other members of the family to help with chores and tasks at home.	3	2	1	0	☐	☐
17.	Having my child with the medical condition seen at the clinic/hospital on a regular basis.	3	2	1	0	☐	☐
18.	Believing that the medical centre/hospital has my family's best interest in mind.	3	2	1	0	☐	☐
19.	Encouraging child(ren) with medical condition to be more independent.	3	2	1	0	☐	☐
20.	Involvement in social activities (parties, etc.) with friends.	3	2	1	0	☐	☐
21.	Being able to get away from the home care tasks and responsibilities for some relief.	3	2	1	0	☐	☐
22.	Getting away by myself.	3	2	1	0	☐	☐

23.	Eating.	3	2	1	0	☐	☐
24.	Sleeping.	3	2	1	0	☐	☐
25.	Allowing myself to get angry.	3	2	1	0	☐	☐
26.	Purchasing gifts for myself and /or other family members.	3	2	1	0	☐	☐
27.	Concentrating on hobbies (art, music, jogging, etc.).	3	2	1	0	☐	☐
28.	Working, outside employment.	3	2	1	0	☐	☐
29.	Becoming more self-reliant and independent.	3	2	1	0	☐	☐
30.	Keeping myself in shape and well-groomed.	3	2	1	0	☐	☐
31.	Talking to someone (not professional counsellor/doctor) about how I feel.	3	2	1	0	☐	☐
32.	Engaging in relationships and friendships which help me to feel important and appreciated.	3	2	1	0	☐	☐
33.	Entertaining friends in our home.	3	2	1	0	☐	☐
34.	Investing time and energy in my job.	3	2	1	0	☐	☐
35.	Going out with my spouse on a regular basis.	3	2	1	0	☐	☐
36.	Building close relationships with people.	3	2	1	0	☐	☐
37.	Developing myself as a person.	3	2	1	0	☐	☐
38.	Talking with other parents in the same type of situation and learning about their experiences.	3	2	1	0	☐	☐
39.	Talking with the medical staff (nurses, social worker, etc.) when we visit the medical centre.	3	2	1	0	☐	☐

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40. Reading about how other persons in my situation handle things.	3	2	1	0	☐	☐
41. Reading more about the medical problem which concerns me.	3	2	1	0	☐	☐
42. Explaining our family situation to friends and neighbours so they will understand.	3	2	1	0	☐	☐
43. Being sure prescribed medical treatments for child(ren) are carried out at home on a daily basis.	3	2	1	0	☐	☐
44. Talking with other individuals/parents in my same situation.	3	2	1	0	☐	☐
45. Talking with the doctor about my concerns about my child(ren) with the medical condition.	3	2	1	0	☐	☐

Appendix 10

NPQ- Needs of parents questionnaire
Instructions to parents

Please read the following instructions thoroughly. They tell you how to answer the questionnaires.

There are two different questionnaires in this package: One that includes questions to respond to according to different statements and another that includes direct questions concerning the questionnaire and questions for additional information about you and your child's hospitalisation.

When answering the multiple choice questions you put an "x" in the appropriate box or line to your choice of answer. The open ended questions you answer in your own words. <u>Please notice there are no right or wrong answers to the questions.</u> Kindly answer each question honestly and wholeheartedly.

Following are examples of multiple choice questions and answers.

Examples:

Questions	**A.** How important do you perceive the following statements are for you in relation to your child's Hospitalisation?	**B.** The need, concern or service presented in the statement: how well and to what extent do you feel it is being met?	**C.** Is it your opinion that the hospital should help you to fulfil the particular needs that you have perceived from this statement?

	Very important	important	Somewhat important	Not important	Does not concern me	Fully	Most often	To some extent	Seldom	Not at all	Yes	No
1. To have a outdoor swimming pool with a children's pool and whirlpool		X							X		X	
2. To have a indoor swimming pool with a children's pool and whirlpool				X								X

Please notice that to each need statement in this questionnaire there are three questions (A, B and C) and therefore three answers

Thank you for participating in this study

Questions	A. How important do you perceive the following statements are for you in relation to your child's Hospitalisation?				B. The need, concern or service presented in the statement: how well and to what extent do you feel it is being met?						C. Is it your opinion that the hospital should help you to fulfil the particular needs that you have perceived from this statement?	
	Very important	important	Somewhat important	Not important	Does not concern me	Fully	Most often	To some extent	Seldom	Not at all	Yes	No
That I get advice about the care of my child in preparation for my child's discharge												
That I be permitted to have the final decision about the treatment my child will receive after having been informed about proposed treatments by doctors and nurses												
That I be informed about all known health prognosis of my child												
To be encouraged by staff to come and stay with my child												
That a nurse assists me to recognize my own needs e.g meals, sleep												
To feel that I am trusted for the care of my child also in the hospital												
That I be informed about all treatment that my child will receive												
To have a person in the unit especially assigned to take care of the needs of my child												
That I have a place to sleep in the hospital												
That a nurse does a follow up on my child after discharge, considering health and safety in connection with previous hospitalisation												

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Questions	A. How important do you perceive the following statements are for you in relation to your child's Hospitalisation?				B. The need, concern or service presented in the statement: how well and to what extent do you feel it is being met?					C. Is it your opinion that the hospital should help you to fulfil the particular needs that you have perceived from this statement?	
	Very important	important	Somewhat important	Not important	Does not concern me	Fully	Most often	To some extent	Seldom	Not at all	Yes	No
To be able to participate in the nursing care of my child												
To learn and be informed about how illness and its treatment effects children's growth and development												
That I get assistance and support to recognize and understand my own needs, e.g anxiety, fatigue												
That I get exact information about my child's condition												
That I feel less anxious												
To feel that I am needed in the unit												
To be able to room in with my child												
That I get assistance to recognize the needs of my child.												
To be told about everything that is being done to/for my child and why												
That I can retain my hope												
That I can dine (have meals) with my child in the unit												
That on the unit there are special hygiene facilities for parents (e.g shower)												
To know that my child will get appropriate education and stimulation not to get behind in school work or development												

Questions	A. How important do you perceive the following statements are for you in relation to your child's Hospitalisation?				B. The need, concern or service presented in the statement: how well and to what extent do you feel it is being met?					C. Is it your opinion that the hospital should help you to fulfil the particular needs that you have perceived from this statement?	
	Very important	important	Somewhat important	Not important	Does not concern me	Fully	Most often	To some extent	Seldom	Not at all	Yes	No
To experience continuity in the nursing care of my child (that the same nurse take care of my child most of the time)												
That one person (a nurse) coordinates the services and the flow of information we receive in the hospital												
That I do not feel hopeless												
That a teacher helps me stimulate my child t maintain his/her development and learning												

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Date:_____.

D. 52. Did you understand the items in the questionnaire?
        All   ☐
        Most   ☐
        Some   ☐
        Few   ☐
        None   ☐

E.53. How well did the statements cover your needs as you perceive them in relation to your child's hospitalization?
        Very well   ☐
        Somewhat well   ☐
        Not too well   ☐
        Not very well at all ☐

  54. How well did the statements reflect your expectations of the hospital?
        Very well   ☐
        Somewhat well   ☐
        Not too well   ☐
        Not very well at all ☐

  55. To what extent did your answers reflect your satisfaction with the services in the hospital? How well did the extent to which you perceive your needs are met reflect your satisfaction?
        Very well   ☐
        Somewhat well   ☐
        Not too well   ☐
        Not very well at all ☐

  56. Please add anything that was not represented in the statements and you feel is important for you in connection with your child's hospitalization?

        _____

        _____

        _____

        _____

57. Please share your ideas about how to meet particular needs?

        _____

        _____

        _____

Appendix 11

Hospital Anxiety and Depression Scale (HADS)

(Zigmond & Snaith, 1983)

This questionnaire is designed to help us to know how you feel. Read each item and put an **X** in the box next to the reply which comes closest to how you have been feeling in the **past week**. Please put a cross in only **one** box for each item.

Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought out response.

1. I feel tense or 'wound' up

□ Most of the time
□ A lot of the time
□From time to time occasionally
□Not at all

2. I still enjoy the things I used to enjoy

□ Definitely
□ Not quite as much
□ Only a little

□ Hardly at all

3. I get a sort of frightened feeling as if something awful is about to happen

□ Very definitely and quite badly
□ Yes, but not too badly
□ A little, but if doesn't worry me
□ Not at all

4. I can laugh and see the funny side of things

□ As much as I always could
□ Not quite so much now
□ Definitely not so much now
□ Not at all

5. Worrying thoughts go through my mind

□ A great deal of the time
□ A lot of the time
□ From time to time but not too often
□ Only occasionally

6. I feel cheerful

□ Not at all
□ Not too often
□ Sometimes
□ Most of the time

7. I can sit at ease and feel relaxed

☐ Definitely
☐ Usually
☐ Not often
☐ Not at all

11. I feel restless as if I have to be on the move

☐ Very much indeed
☐ Quite a lot
☐ Not very much
☐ Not at all

8. I feel as if I am slowed down

☐ Nearly all the time
☐ Very often
☐ Sometimes
☐ Not at all

12. I look forward with enjoyment to things

☐ As much as I ever did
☐ Rather less than I used to
☐ Definitely less than I used to
☐ Hardly at all

9. I get a sort of frightened feeling like " butterflies" in the stomach

☐ Not at all
☐ Occasionally
☐ Quite often
☐ Very often

13. I get sudden feelings of panic

☐ Very often indeed
☐ Quite often
☐ Not very often
☐ Not at all

10. I have lost interest in my appearance

☐ Definitely
☐ I don't take so much care as I should
☐ I may not take quite as much care
☐ I take just as much care as ever

14. I can enjoy a good book or radio or T.V programme

☐ Often
☐ Sometimes
☐ Not often
☐ Very seldom

Appendix 12

Parent demographic form

Family centred care for children with a chronic respiratory illness.

<u>Parent/Caregiver Demographics</u>

1.What is your age?

☐ <20

☐ 20-30

☐ 30-40

☐ 40-50

☐ >60

Are you:

☐ Male

☐ Female

2. Which ethnic group do you belong to?

☐ New Zealand European

☐ Maori

☐ Samoan

☐ Cook Island Maori

☐ Niuean

☐ Cook Island Maori

☐ Chinese

□ Indian

□ Other- please specify below

Other :

3. Are you:

   □ Single

   □ Married

   □ Defacto

   □ Separated

   □ Divorced

4. Are you:

   □ Employed

   □ Unemployed

   □ Not in the labour force

   □ Not specified

5. If you answered employed to question 4 what is your occupation

   _____

6. What is your highest school qualification?

   _____

7. What is your highest tertiary/professional qualification?

   _____

8. How many children do you have?

    _____

9. How many children are you responsible for?

    _____

10. Do you feel that you have the support you need from friends/family
    while your child is in hospital?

    ☐ Yes
    ☐ No

11. Is your home within Christchurch
    ☐ Yes
    ☐ No

12. Is this admission with your child
    ☐ Planned
    ☐ Unplanned

13. How old is your hospitalised child?

    _____

14. What is the reason for your child's hospitalisation?

    _____

15. Once this research is finished do you wish to receive the results?

    ☐ Yes

    ☐ No

16. If you answered yes to question 15 please provide your postal address

_____

_____

_____

Thank you for taking the time to and completing this survey. Your contribution to this study is much appreciated.

Appendix 13

Qualitative questions

1. What are your child's symptoms?

2. How confident are you in managing your child's symptoms?

3. How confident are you in recognizing when you need help managing your child's condition

4. How confident are you that health professionals will listen to your concerns

5. How confident are you in your ability to engage with other health care professionals such as your GP, outreach nurse, district nurse,

6. What builds your confidence?

7. What knocks your confidence?

8. How would you describe your families' journey so far living with and managing your child's condition?

    - Impact on other siblings

    - Impact on spouse

- Impact on extended family- grandparents, aunties, uncles, cousins

Appendix 14

Information sheet for parents Stage 2

Parent/Caregiver Information sheet.

Study title: Family centered care for children with a chronic respiratory illness.

Principal Investigator: **Virginia Jones, PhD student at Otago University,**
Centre for Postgraduate Nursing studies, 72 Oxford Terrace, Christchurch.
Telephone: 03 364 3865 ext 3856

Supervisor: **Dr Lisa Whitehead, Senior Lecturer, Centre for Postgraduate Nursing Studies, 72 Oxford Terrace, Christchurch.**
Telephone: 03 364 3858.

You are invited to take part in a research study that will look at parents' needs, coping patterns, depression and anxiety levels when their child is admitted to hospital with a chronic respiratory illness. You can take your time to decide whether you want to take part as we will be recruiting parents from November 2009 to the end of May 2010. Participation is voluntary (you can choose). You do not have to take part in this study and if you decide not to take part this will not affect your child's' future care or treatment. If you do agree to participate you are free to withdraw from the study any time without having to give a reason and your child's' future health care will in no way be affected.

The study will explore levels of anxiety for parents of children hospitalized with a chronic respiratory condition and the coping strategies parents use. The researcher in consultation with the nursing staff has identified you as some one who meets the studies inclusion/exclusion criteria and therefore suitable to take part. To be included within this study your child must be diagnosed with a chronic respiratory condition and you are either the biological, step, foster or adoptive parent or caregiver. Your child has experienced a previous hospital admission prior to this acute or arranged hospital visit. You must be able to read and write English and be physically capable of independently filling out the questionnaires. Any child who is terminally ill or for palliative care is excluded from this study as is any parent that the nursing staff views as distressed.

The study will involve filling out 6 questionnaires (1 on different ways of coping, 1 on anxiety, 1 on Patient and Family Centered care, 1 on self-efficacy, 1 on depression and 1 on parental needs). You do not have to answer all the questions. Filling in the questionnaires should take no more than 1 and ½ hours. You can choose to fill these out at a location that best suits you and post them using the attached self addressed stamped envelope (needs no stamp or address) or place them in the marked box at the end of the ward or CAA. Please do not discuss these questionnaires with anyone else until you have filled them out. If you have a partner also taking part in the study, please do not discuss this with them until he or she has filled them out. However if you do not understand some of the questions or wish to get more information about this study you may contact Virginia Jones at the address and phone number over the page. You may have a friend, family or Whanau support to help you understand the risks and/or benefits of this study and any other explanation you may require.

If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact an independent Health and Disability Advocate, telephone:

- Christchurch   03 377 7501
- South Island except Christchurch   0800 377 766

If after completing the questionnaires you think you are having problems related to anxiety and or depression then you should talk with a staff member on the ward or CAA and they can refer you to someone who can help.

The study will take 24 months to complete and you will be sent information about the results if you would like to receive them. This is one of the questions asked on the demographic form. The results will be sent to you shortly after the study has finished in May 2011.

The study will contribute to knowledge around parental needs, coping behaviours, depression and anxiety when their child is in hospital. This information can assist health professionals to understand the hospital experience and provide individual support for parents.

Your confidentiality is assured and no material which could personally identify you will be used in any reports on this study. The questionnaire information will be coded and all files will be stored on a secure computer and paper copies will be stored in a locked filing cabinet in a secure office. After five years all of the data will be destroyed.

This study has received ethical approval from the Multiregional Ethics Committee.

Please feel free to contact the researchers Virginia Jones or Lisa Whitehead at the address and phone numbers given at the top of page one if you have any questions about this study.

Appendix 15

Factors impacting on family centred care for children with a chronic respiratory illness **Virginia Jones: 364 3856**	
Inclusion criteria Children between 0-17 years of age Children diagnosed with a chronic respiratory illness Biological, step, foster and adoptive parents Parents who can read and write English	
Inclusion criteria for nurse Primary nurse of recruited child with a chronic respiratory illness	
Exclusion criteria Children over the age of 17 years of age Children diagnosed with a non-respiratory chronic illness Parents who are physically incapable of independently filling out a questionnaire	
Parent name:	**Nurse name:**

Appendix 16

Family centered care for children with a chronic respiratory illness
(Individual Interview)

- I have read and I understand the information sheet dated 1st Nov, 2009 for interview participants.
- I have had the opportunity to discuss this study and I am satisfied with the answers I have been given.
- I have had the opportunity to use whanau support or a friend to help me ask questions and understand the study.
- I have had time to consider whether to take part. I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without having to give a reason.
- I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports on this study.

I know who to contact if I wish to speak with someone about
how I am feeling as a result of the interview.   **YES/NO**

I know who to contact if I wish to make a complaint   **YES/NO**

I consent to my interview being audio-taped   **YES/NO**

I wish to receive a copy of the transcription of the interview   **YES/NO**

I would like a summary of the findings from this study   **YES/NO**

_____**(full name) hereby consent to take part in this study.**

Signature _____ Date _____

Project explained by:_____   (Principal Investigator)

Signature _____   Date _____

Principal Investigator: Virginia Jones, PhD Student.

Supervisors: Dr Lisa Whitehead
                      Dr Marie Crowe, Associate Professor.