WITHIN THE WEB

The family/practitioner relationship in the context of chronic childhood illness.

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Table of Contents

Attestation of Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person nor material which to a substantial extent has been accepted for the award of any other degree or diploma or a university or other institution of higher learning, except where due acknowledgement is made in the acknowledgements.

--(signature)

Annette Robyn Dickinson

Date:

Acknowledgements

Self Portrait: Beatrice Aged 4years

Abstract

This study explores the phenomenon of the relationships between practitioners and families who have a child with a chronic illness. Using a heremeneutic phenomenological method informed by the writings of Martin Heidegger [1889-1976] and Hans-Georg Gadamer [1900-2002], this study provides an understanding of the meaning of 'being in relationship' from the perspective of both families and practitioners.

Study participants include ten family groups who have a child with a chronic illness and twelve practitioners from the disciplines of nursing, medicine, dietetics, physiotherapy and speech therapy who work with children with chronic illness. Narrative audiotaped interviewing was the means by which the participants told their stories about times that relationships worked well and when they did not. These stories uncover the every day realities of 'being in relationship' and provide another understanding of the relationship between family and practitioner.

The findings of this thesis suggest that chronic childhood illness 'throws' families and practitioners together into a web of relationships that must work for the sake of the child. The relationship is primarily conducted between adults. Children are usually excluded. In order to understand and manage the child's illness, practitioners and families 'go around' and act 'in-between' relationships. While the quality of the relationship from the family perspective is not essential to the chronic illness journey, relationships are more successful when practitioners recognise the uniqueness of each family web. The nature of the relationship is often simple, yet it co-exists with complexity. This thesis proposes that a 'companion relationship' between practitioners and family may offer a more effective and satisfying way of working. It also challenges practitioners to consider the voice of children within health care relationships.

Chapter 1

Introduction

It is the nature of beginning that something new is started which cannot be expected
from whatever may have happened before.

(Arendt, 1998, p.176)

Starting in practice

As a nurse working with families of children with chronic illness for many years I
have had numerous opportunities to learn from families about their illness experience.
Frequently while assessing a child I would ask the family "what is the hardest thing
about having a child with asthma?" I would expect a response relating to the child's
condition or treatment and I was surprised and dismayed when the response was
"working with health professionals". These families would tell me of times when
practitioners did not listen to them, when they became confused with the number of
people involved and the differing opinions they received. They would talk of times
when they became overwhelmed or confused by whom to see and when. Often it was
the practitioners' attitudes that most distressed them. They perceived some
practitioners as judgmental, dismissive, exclusive and rude. Then when I had the
opportunity to join the hospital complaints committee, I found that many of the
complaints from families originated from difficulties in relationships with health
professionals. Investigating some of these complaints, I witnessed the distress of
practitioners who were confronted with complaints from families. Many practitioners
were unaware that their relationship with the family had been failing to the point that
a formal complaint process had been initiated.

These experiences caused me to reflect on my own practice. I remembered times
when I did not listen to parent's concerns and suffered the consequence of either a
child deteriorating rapidly in my care or losing the confidence and co-operation of the

family. I also recalled times where I was so overcome by the expertise of the parents of chronically ill children, that I began to doubt my contribution to the relationship. Although my practice had never been challenged as part of a formal complaint process, I could recall times when relationships had been difficult and uncomfortable or when, as a clinical nurse specialist, I had had to mediate relationships between families and practitioners. Talking with colleagues I discovered that they had experienced similar tensions when trying to build and maintain effective relationships with families. Despite a growing belief within paediatric practice, that notions such as family centred care and partnership were assisting and promoting effective relationships between practitioners and families, this was not always evident in practice. I began to question whether these relationships based on the family and partnership did or could exist within paediatric practice. What does a partnership look like and how does it differ from other relationships? What are the rewards and tensions of relationships between practitioners and families? I became aware that health professionals understanding of what it meant to be in relationship had become hidden within the busy world of practice and it was not until something went wrong that the complexities of the relationship were revealed. It seemed to me that if practitioners and families wanted to consider the notions of family centred care and partnership as central to the care of chronically ill children, greater attention needed to be given to the experience of conducting family/practitioner relationships. It was these experiences and questions that provided the catalyst for this study.

Purpose of the study

The purpose of this study is to explore the experience of the relationship between health practitioners and families who have a child with a chronic illness. From the premise that both families and practitioners are affected by the relationship, I will examine the experience from both perspectives.

In this study practitioners are defined as New Zealand Registered Health Professionals who work on a regular basis, at least three monthly, with families who have a child with a chronic illness. The family groups participating have self selected on the basis that they identify themselves as the group who supports and cares for a chronically ill child and have at least three monthly contacts with a practitioner.

In New Zealand childhood chronic illness is defined in various, and often confusing ways. Children for example can be categorised as either "medically fragile" or "disabled" according to how their care is allocated and funded. I have avoided these rather confusing labels. For the purpose of this study, chronic illness is defined as an ongoing illness that requires the child and his/her family to have regular, a least three monthly, contact with a practitioner.

Selecting the methodology

Selecting a research methodology requires not only finding an approach compatible with the research question but also one that is philosophically congruent with the research context. I was initially drawn toward grounded theory, a method with which I had become familiar during my previous research experience (Dickinson, 1997). Grounded theory, in a highly systematic way, sets out to generate an explanatory theory about the social and psychological processes of a phenomenon (Chenitz & Swanson, 1986). Based on the theory of symbolic interaction human behaviour is viewed as a result of a process. This method focuses on uncovering processes and generating theoretical concepts and models. Grounded theory seeks to predict and explain. But I was not seeking to predict or explain the process of how relationships developed. I wanted to uncover the very nature of the experience of being in a relationship. Thus despite familiarity with the grounded theory method I recognised that it was not appropriate for use in this study.

I then considered the phenomenological approach. I had seen the power of phenomenology in uncovering the everyday world of nursing (Benner, 1984; Bishop & Scudder, 1990; Paterson & Zderad, 1988). However, as a post graduate student, I had reservations that related to the seeming complexity of its underlying philosophy and what I perceived to be a lack of a clear research process. The method did however appear to 'fit' with the question I was asking and following encouragement and coaching from my research supervisors I embarked on a hermeneutic phenomenological approach.

Hermeneutic phenomenology is both descriptive and interpretative and is particularly useful when wishing to gain a deeper understanding of everyday human experiences (van Manen, 1990). Rather than to predict and explain, hermeneutic phenomenology seeks to interpret and understand (Bergum, 1991). It allows the researcher to uncover meanings that may have become hidden or taken for granted. The relationship between health professionals and practitioners takes place within the hustle and bustle of the everyday world. I already knew that many aspects of the relationship were taken for granted and had become lost within the busyness of taking care of the child. I was also aware that to be in relationship is to be human and that each encounter reflects the nature of humanity. Hermeneutic phenomenology is a "philosophy of the personal" (van Manen, 1990, p.7) and therefore is always situated within the world of human experience. It also recognises the relationship of the researcher to the phenomenon under investigation. As a practitioner and researcher I recognised that I was already inextricably linked to the world of chronic childhood illness. I already brought with me experiences and understandings that I knew would influence and become part of my interpretation. The philosophical underpinnings of this method therefore provided a good fit not only with my research question but also the context in which the research was to be conducted.

Initially, because of my inexperience in using the method, I used the work of van Manen (1990) to guide the structure and process of the study. As I became more

familiar with the philosophical notions underpinning hermeneutic phenomenology I drew on the work of Heidegger [1889-1976] and Gadamer [1900-2002]. Their work provides the foundation for this study. Then, during the data analysis process, I became increasingly aware that other philosophical ideas could assist my interpretation of the interpersonal aspects of the relationship. This study therefore is also informed by the writings of Arendt [1907-1975] Buber [1878-1965] and Levinas [1905-1995].

Preunderstandings

One of the challenges of phenomenological inquiry "is not always that we know too little about the phenomenon we wish to investigate but we know too much" (van Manen, 1990, p.46). As I started this study I was aware that I came to it with a number of assumptions in regard to the nature of the relationship between families and practitioners. These were informed not only by my personal experiences but also the philosophies of paediatric practice. This section will examine these understandings as a way of acknowledging their influence on the study.

Preunderstandings of Paediatric Practice

The predominant espoused philosophy of paediatric practice in the last twenty years has been that of family centred care. It has influenced and shaped how paediatric practitioners have viewed their relationship with families. Arising from the consumer and family support movements in North America in the 1960's this philosophy has become synonymous with paediatric practice internationally (Johnson, 2000). There is no agreed definition for family centred care but the most frequently cited is that proposed by Shelton, Jepson and Johnson (1987) in North America and Nethercott (1993) in the United Kingdom. Shelton and Stephanek (1995) were to update and simplify the North American version and identified eight key elements. It is these that are most frequently cited. The elements include: viewing the family as the constant, exchanging complete and unbiased information, honouring the diversity of families, recognising and respecting different ways of family coping and support,

peer networking, provision of co-ordinated services and support and appreciating families as families and children as children. The United Kingdom focus was more on parental involvement and supporting the functional role of the family while in hospital (Hutchfield, 1999). Nethercott (1993) proposes that the key components of family centred care in the United Kingdom includes: family being viewed in context, enabling family participation in decisionmaking and care, promotion of usual care practices when the child is in hospital and support after discharge. While both the North American and United Kingdom literature is used in New Zealand, the New Zealand adaptation of family centred care is more closely aligned to the North American philosophy (Children's Health Liaison Group, 1993).

Despite the various attempts to articulate the philosophy most practitioners agree that there is a lack of consensus on what family centred care actually means in practice (S. Baker, 1995; Darbyshire, 1995; Espezel & Canam, 2003; Hutchfield, 1999; Letourneau & Elliott, 1996; Tomlinson, Thomlinson, Peden-McAlpine, & Kirschbaum, 2002). Although most paediatric practitioners would espouse that the philosophy of family centred care is central to paediatric practice the degree to which it is enacted in practice remains uncertain. The reasons for this has been attributed to lack of organisational support by the health care system, lack of understanding of the complexity of the relationship between families and failure of health professionals to consider a different approach to family/practitioner relationships (Ahmann & Johnson, 2000; Coleman, 2000; Darbyshire, 1995; Patterson & Hovey, 2000; Tomlinson et al., 2002).

Despite the uncertainty the philosophy of family centred care has been promoted not only amongst paediatric health professionals but also parent support groups and is the way in which practitioners and to some extent families view the relationship between families and practitioners. The values most frequently discussed and promoted are the centrality of the family to the care of sick children, parental participation,

partnership, collaboration and respect. This understanding has shaped not only my own` view of the relationship but also that of the participants in this study.

Personal Pre-understandings

To uncover my personal pre-understandings prior to starting the study I asked one of my research supervisors to interview me. Following the interview, I listened to the tape recording and made notes in my journal, recording the following pre-understandings:

Living with chronic illness is often confusing, difficult and uncertain. Families who have a child with a chronic illness want information, skills and support so that they can manage the illness themselves. The role of the practitioner is to support families in learning to 'manage it'. However equally there will be times when families will need or want health professionals or other supporters to 'manage it' for them.

The family is vital in providing care and support to children who have a chronic illness. Families have expert knowledge about their children while health professionals have expert knowledge about pathophysiology and treatment of population groups. Practitioner knowledge is usually more highly valued than family knowledge.

Families can be configured in different ways and, as practitioners, we cannot presume to know a family by our interaction with one family member. Families will have different ways of coping with the child's illness experience.

Health professionals move in and out of relationships with families. This constant movement is a point of tension for both families and practitioners.

There is a dissonance between practitioner's claims to be working in partnership and what happens in reality. The relationship between practitioners and families is centred around 'doing' or 'telling' them what to do rather than 'asking' or considering family expertise and opinions. Families desire a partnership with health professionals but it is questionable whether health professionals are committed to a similar relationship.

Journal Entry: March 2001

In addition to these pre-understandings I also bring with me my life and practice experiences. I am part of a large extended family. I have two cousins close to my own age with Cerebral Palsy. Sadly one died in early adolescence but I have lived alongside them and watched my parents and other aunts and uncles support the parents in caring for them. I have watched their struggles with disability, and seen first hand the anguish of decisions in regard to treatment and care options. Then two years prior to starting this study, I experienced what it was like to be 'on the other side' of the practitioner/family relationship. While caring for my dying mother I discovered the positive and negative aspects of being in relationship with health practitioners. I experienced the frustration of being excluded or not being given enough information, of being 'told' rather than 'asked', and of judgements being made as to how our family should act and respond to our mother's illness. I also remember the special times when practitioners shared decision-making with us, provided much needed information and support, stepping forward and back with great sensitivity. I therefore bring my own understanding of what it is to be part of a family dealing with illness and disability.

I also bring my practice experience. Prior to this study I had worked for 20 years as a nurse in both hospital and community settings nursing children with chronic illness. I have had many special opportunities to accompany children and families through the illness experience often over several years. I bring my own stories as preunderstandings as I interpret the stories of others. For example I remember Katie and her mum Tina. Katie had severe asthma and when I meet her at the age of three years she had already been admitted to hospital several times with severe life threatening attacks. When I first meet this family Tina was angry and aggressive toward me, she was clear that she did not need anyone else telling her how to care for her daughter. Over the next five years I came to know Katie, Tina and later her younger brother John, who also developed severe asthma. Visiting them at home and accompanying them through numerous hospital visits we gradually developed a special relationship. I came to admire the resiliency of this family who struggled not

only with an unpredictable and frightening illness but also the challenge of social disadvantage. They had no transport, no phone, little money and little social support yet Tina cared deeply for her children and did her very best to keep them well. Tina and her family were often judged by other health professionals as 'non compliant', 'difficult' and 'irresponsible' and I found myself frequently advocating for Tina's right to care for her children. My relationship with this family was often a stormy one. There were times when it was difficult to maintain my relationship with Tina and other times when we had a close and effective relationship. However over the years we came to know and trust each other. While I no longer care for Tina and her family we frequently meet in hospital corridors and I see the pride Tina has in her now teenage children. Experiences such as these, as well as my previous research experience (Dickinson, 1997) have significantly influenced my understanding of chronic childhood illness and the challenges and rewards of related practice.

I come to this study also recognising the very special relationship and bond that exists between a parent and their child. For the parents this is 'their' child, someone with whom they share a deep biological and/or existential connection. For the family this 'one' special relationship will influence and guide their journey through chronic illness and their subsequent relationships with health professionals. A practitioner will never share that same intimate connection with the child. For the practitioner, the child will never be 'their' child, but one child amongst the many children that the practitioner will care for in their practice day. These very different perspectives of the 'one' versus one of 'many' will influence how the relationship between family and practitioner will proceed.

Heideggerian phenomenology acknowledges the interconnectedness of the person to their world. While Hurserlian phenomenology asks the researcher to set aside or 'bracket' their previous understandings before undertaking a study, the Heideggerian approach believes that it is impossible to bracket our pre-understandings (Beck, 1999; M. Z. Cohen, Kahn, & Steeves, 2000). I therefore bring these life experiences and

pre-understandings not intending to put them aside, but as a way of acknowledging the influence they may have on how I conduct this study.

I believe the literature of child health practice simplifies what in my experience is a very complex relationship. I believe the assumptions that the child and family are the central focus of health care relationships is not always warranted. Nevertheless, I have confidence that both practitioners and families seek to do their best by each other, and yet somehow we haven't 'got it right'. Throughout this study I have been driven by the sense that something needs to change.

Structure of the thesis

This thesis is presented in ten chapters.

Chapter One, **"Introduction"** has set the scene in relation to the purpose of the study, my pre-understandings and why I selected hermeneutic phenomenology as methodology and research method.

Chapter Two, **"Between Experts: Family practitioner relationships in New Zealand"** contextualises the study by providing an historical perspective of how health care relationships have developed in New Zealand. This chapter follows the development of family/practitioner relationships from the pre-colonial period to the present day noting the tensions and struggles as both family and practitioner asserted their 'expert' role in the care of the chronically ill child.

Chapter Three, **"Standing with the tradition: A review of the literature"** considers the existing literature and its influence on how health professionals and families view the relationship. This chapter describes the differing perspectives of nursing, medicine, allied health professionals and families as revealed in the literature.

Chapter Four, **"Philosophical Foundations"** describes the philosophical ideas that have guided and provided the foundation or framework for this study. Drawing on the work of Heidegger [1889-1976], Gadamer [1900-2002], Arendt [1906-1975] Levinas [1905-1995] and Buber [1878-1965] this chapter describes how the philosophical writings of these authors have informed and guided the study.

Chapter Five, **"Method"** moves from the philosophical ideas to lay out how the research was done. It describes not only the research process but also a framework on which the trustworthiness of the study may be considered.

Chapters Six to nine presents my interpretation of the meanings of the relationship between practitioners and families. Chapter six, **"A web of relationships"** provides an interpretation that situates the relationship within the rather turbulent and complex world of chronic illness and provides the backdrop for chapters seven to nine.

Chapter Seven, **"Being In-between"** uncovers one of the ways in which families and practitioners experience the relationship as they journey admist the vast array of relationships that accompany a journey with chronic illness. This chapter describes the tensions and challenges for families and practitioners as they operate 'in-between' the various relationships they encounter.

Chapter Eight, **"Going around"** describes the meanings of moving around relationships. This chapter uncovers the two very different perspectives of family and practitioner as encountered in relationships.

Chapter Nine, **"Working in the web: Fiona's Story"** uses one practitioner's story as a way of bringing the interpretations of chapters six, seven and eight together to

illustrate the strength and resiliency of effective family practitioner relationships. This chapter describes the intricate balance between simplicity and complexity inherent in practitioner/family relationships.

Chapter Ten, **"Back to Practice"** brings the meanings uncovered in this study back to the world of practice. It considers what the interpretations of this study might be for the future of the relationship between family and practitioner within the context of chronic illness. Potential ways forward for strengthening the relationship between practitioner and family are suggested.

As a way of acknowledging the centrality of the children to this study I have included throughout the report pictures drawn for me by the children participating in this study. No interpretation is offered, rather they exist to remind the reader of the children's presence.

Chapter 2

'Between Experts'

Family practitioner relationships in New Zealand.

To understand the context in which this study is placed this chapter will describe how the relationship between families and practitioners has evolved in New Zealand. It is a unique story that has been influenced by the historical and cultural context, changing attitudes to childrearing and development and reform in health service delivery. The evolution of family practitioner relationships in New Zealand reflects a struggle between two groups of 'experts', the family as 'expert' in regard to the individual child and the practitioner as 'expert' in the management and treatment of chronic illness. It is a struggle that continues to this day as families, and practitioners seek to find common ground and a way forward in creating successful working relationships.

There have been four distinct periods that have influenced the development of the relationship between families and practitioners, pre colonisation, the colonial period, the emergence of science and specialisation in paediatrics. This chapter will use each of these periods to describe the influences on how relationships between families and health professionals have developed.

Pre Colonial New Zealand

Prior to colonisation the Maori family existed within a tribal group based around their whakapapa[1]. Family systems were upheld by tribal lore, spiritual beliefs and protocols (Cram & Pitama, 1998). They lived communally in remote rural areas where they developed horticulture and used the natural resources to ensure the

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[1] Geneology, family tree (P. M. Ryan, 1995)

physical and spiritual well being of their community (Shirley, Koopman-Boyden, Pool, & St John, 1997). Most children lived within their family and childrearing was a shared responsibility of the community. While little is known about the role and care of children in Maori society prior to colonisation, it is known that families were small, on average around four children, the birth rate was low and infant mortality was high (Durie, 1994; Trewby, 1995). The whanau[2] played an important role in the care and nurture of children.

For Maori children disease and illness was managed within the confines of the whanau using traditional remedies and healers (Tohunga). Maori communities recognised the close and intimate relationship between people and the natural environment. Theories relating to causation of disease and illness included wider spiritual and environmental events. Illness was attributed to an infringement of Tapu. Tapu is a sacred state or condition, which is set aside in dedication to the Gods. It could be applied to people, places, animals, plants, events and social relationships. Contact with an object or activity which was Tapu could be unsafe from a spiritual and physical perspective. Illness was attributed to a breach of Tapu (Durie, 1994; Gluckman, 1976). The fear of Tapu and the implications of desecrating the house by having someone ill within it meant that a person who was ill would be separated out from the community. Gluckman (1976) has suggested that because of the fear of Tapu, sick or deformed children often died soon after birth from death or exposure.

It is difficult to determine what diseases affected the children although oral histories suggest that gastroenteritis and pneumonia occurred, however there is no evidence to suggest that chronic illnesses such as tuberculosis and leprosy which were later to ravage the Maori population were present prior to colonisation (Lange, 1999). The Tohunga played an important role in care of the sick. As a learned man who acted as a medium between the people and the Gods he would be called upon to identify the avenging spirit and coax it out of the body of the person affected (Lange, 1999).

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[2] Extended Family (P. M. Ryan, 1995)

Prior to colonisation the Maori community were accustomed to consulting a health care expert about the care of the sick. However unlike the later western models this consultation integrated both the spiritual and physical dimensions of health (Durie, 1994).

The colonial period

The colonial period is defined differently within New Zealand literature, however for the purpose of this discussion I will confine it to the period of large scale settlement by Europeans in New Zealand, around the late 1830's until 1907. This was a period in New Zealand's history where western medicine was introduced and was to emerge as the dominant health care system for the country.

The child and their family

The pioneer families of New Zealand came from the United Kingdom and brought with them the structures and values of their homeland. Families were nuclear in structure and in keeping within their Christian values unions between parents were formalised in a legal marriage. Children were cared for by their biological parents, the only difference between the early colonial families and their United Kingdom relatives being that marriage was almost universal and life expectancy and fertility was higher (Pool, Jackson, & Dickson, 1998; Shirley et al., 1997). In nineteenth century New Zealand children were legal chattels of their parents (Toynbee, 1995). It was expected that children would become a productive member of the family, working on the farm or in the family business. Millen (1984) describes how children were given jobs according to their age and size and would "do everything from milking the cow to breaking horses" (p.98). Authority within the family was patriarchal and parents had considerable control over children's use of time (Toynbee, 1995). Toynbee, who interviewed New Zealand men and women brought up in the later part of this period, noted that all her respondents commented on the "strictness of their upbringing" (p.173). While some respondents feared their parents

others recognised the need for such discipline to help the family survive the pioneer life.

Most Maori families in this period continued to live within their traditional villages. Apart for some changes in diet, clothing and housing materials introduced by the Europeans, for most life continued to reflect the communal traditions of the previous period. Maori children, like their European counterparts were also expected to be productive members of their community, however the presence of toys and games suggests that Maori children did have time to themselves (Trewby, 1995). Orbell (1978) describes how some European settlers reported that Maori "were very fond of their children" (p.113). She notes that "boys of good birth were seldom punished" (p.113) which she attributes to the Maori belief that punishment could break or weaken the spirit of the child and affect their future as a warrior.

Childhood illness

Because of the lack of formalised health services in the country at this time it is difficult to get an accurate picture of childhood illness or the presence of chronic illness within the population. What is known is that the introduction of European diseases, especially infectious diseases, was to have a devastating effect on the Maori population with fears that that the Maori race would die (Durie, 1994; Lange, 1999; Shirley et al., 1997). For children it appears that respiratory disease was the greatest cause of illness, or death. Lange (1999) describes how bronchitis and pneumonia were common, often associated with subsequent tuberculosis infections. Scarlet fever, measles, and whopping cough epidemics also swept the country and had a serious impact on the health of New Zealand children (Lange, 1999; Webster, 1995). Gastrointestinal disorders were common within the Maori population and Lange concludes that it is likely that respiratory and gastrointestinal disorders were the major contributors to the increased infant mortality in Maori populations.

While it appears that these diseases had the greatest impact on Maori children Pakeha[3] children were also affected. Although Pakeha families reported that their children were much healthier in New Zealand "than they would have been back 'home'"(Millen, 1984, p.97), there is no doubt that the ravages of these diseases did result in some long-term illness for children. Webster (1995), when examining the health reports of the nineteeneth century Lush family, notes that Charles Lush who had Scarlet fever as a child, was never completely healthy and writes of "being ill for an hour or two, once a week at least" (p.186). This was accepted by the family as being beyond their or his control, therefore care was taken by the family to "protect him from too much excitement" (p.186).

The care of sick children

Prior to the 19th century, sick children in New Zealand were cared for at home by their families. For the pakeha family, this care was generally given by the mother who utilised the expertise and wisdom of family members and where available lay practitioners, doctors or pharmacists. There were few medical practitioners and considerable blurring of roles between pharmacist, doctor and lay practitioner. Western medical care was provided by missionaries a small number of colonial surgeons, civilian doctors and pharmacists. Up until the 1870's "the medical market was confused and divided among a limited number of groups" (Belgrave, 1991, p.12). In most instances isolation from medical assistance meant that families were reliant on their own resources to care for their sick child. There was a general acceptance that high infant and child mortality were part of life. The role of the health practitioner was consultative and not generally used until family treatment had failed. Webster describes this in an extract from the diary of Charles Lush. Reporting on the recovery of his daughter from measles during the epidemic of 1875 Charles reports:

> "Anne is in some respects decidedly better. Her appetite has improved and she does not seem so languid and weak – the only thing about her which still

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[3] Non Maori, European, Caucasian (P. M. Ryan, 1995)

troubles her is her cough. If Mama fails in subduing it I shall ask Dr Fox to
see her."

(Webster, 1995, p.185)

It is difficult to know exactly what the relationship between families and health
practitioners was like during this period. However it appears that although the
doctor's view was often respected, this was not the only opinion sought or valued. A
range of remedies and treatments was available from a wide range of practitioners
including grocers, travelling salesmen and mail order catalogues (Belgrave, 1991).
Evidence in the Lush family diaries reveals that medical advice and opinions from
doctors was not always accepted and sometimes even described as being "alarmist"
(Webster, 1995, p.188).

Maori families' first contact with western medicine came with the arrival of the
missionaries. Despite their lack of medical training, the early missionaries were
enthusiastic about providing western medical services. Increasing concern for the
health of Maori families' lead in 1850 to the provision of government subsidised
Native Medical Health Officers who were paid to provide medical care to the Maori
population (Dow, 1999). However health officers were not widely available and
most Maori lived beyond the range of western medical services. For Maori families
regular access to western health care was via the teachers through native schools.
Teachers, especially those in isolated areas, were supplied with simple medicines,
which they administered as required. Dow suggests that the teachers efforts were
much more effective than the irregular visits of the Native Medical Officers (Dow
1999). Seeking help from a pakeha doctor required extra effort. Not only did the
family have to overcome the difficulties of travel but also there was then the issue of
paying the doctor's fee and travelling costs (Lange, 1999). Even when Maori
families did make the effort Pakeha doctors made few attempts to make the
relationship comfortable for the Maori. Apart from the obvious language difficulties
Pakeha doctors were often intolerant and scornful of Maori values and beliefs (Dow,

1999; Lange, 1999). From the Maori perspective the Pakeha doctors did not pay enough attention to the spiritual sphere of health and their failure to observe Maori practices especially those associated with tapu, lead to a distrustful relationship between doctors and Maori families (Durie, 1994). Thus the Tohunga remained the first person to be consulted by Maori families when a child became ill. Western doctors or nurses were only called when his treatment failed.

In 1907 the passing of the Tohunga Suppression Act signalled a change in how health care would be viewed and delivered in New Zealand. Increasing concern, particularly by the missionaries and the coroner's juries, that the practices of the Tohunga, were having a negative impact on the health and spiritual wellbeing of Maori people lead to the passing of legislation to prohibit the Tohunga to operate within the community (Durie, 1994; Lange, 1999). The legislation was directed against any person

> "who gathers Maoris around him by practising on their superstition or credulity, or who misleads or attempts to mislead any Maori by professing supernatural powers in the treatment or cure of any disease, or in the fore-telling of future events, or otherwise"
> (Lange, 1999, p.249)

While the legislation proved ineffective in suppressing the work of the Tohunga, which just moved underground, it sent a clear signal that all future health care services "would be firmly based on western concepts and methods" (Durie, 1994, p.44).

Science and the arrival of the child care experts

Following the establishment of western medicine in New Zealand, the next period of significance in regard to the development of the relationship between families and health professionals was the emergence of science and the child care expert. This period (1900-1940) saw advances in medical science and changing views toward

children and child rearing. There was a marked rise in the number of health professions and significant changes in who was considered 'expert' in the care and nurture of children.

'Children's Health the Nations Wealth': Children as social capital

In the early twentieth century New Zealand, fertility was decreasing and infant mortality was high. As mentioned in the previous section, foreign diseases had devastated the Maori population and there was a real fear that the country would not have sufficient population for development of the new colony or to meet its obligations to the British Empire. Hence the notion of eugenics became popular and was promoted by many politicians and medical personnel. A social philosophy which derived from Darwinism, eugenics, focused on the importance of improving the racial stock of the country (Tennant, 1994). This, along with the declining population, prompted the development of programmes that would reduce infant mortality and improve the health of New Zealand children. Slogans such as 'children's health, the nations wealth' focused national attention on the importance of good child rearing for the future of the country (Bryder, 2003; Olssen & Levesque, 1978). To ensure a healthy and prosperous future for the new colony, significant state investment was made in the care and welfare of children. Between 1900 and 1938 legislation was introduced in New Zealand that ensured compulsory education of children, a public health system and financial support of families through the provision of a family benefit (Shirley et al., 1997). Not only did the responsibility of child welfare move from the family to the state but motherhood was also deemed to be of utmost importance. The medical profession provided 'scientific' justification to support this ideology explaining that while women were biologically programmed to have children and manage households, they required training by 'experts' to ensure healthy children for the nations future (Olssen & Levesque, 1978). Thus failure to produce healthy children was not a failure of a natural or spiritual nature, but rather failure in terms of the mother's training or inability to strictly follow the advice of the 'experts'. The ideology of trained motherhood was further reinforced by the introduction of compulsory domestic science classes for schoolgirls in 1918 and in

the area of health, the Plunket Society[4] and School Medical Service[5] (Bryder, 2003; Olssen & Levesque, 1978; Tennant, 1991). The focus of both the Plunket Society and School Medical Service was on health surveillance and health promotion. Although these services were not providers of care to sick children, their regular interface with the family provided the basis on which many families viewed and conducted their relationship with health care professionals. Certainly these experiences were most frequently recorded and, as I will show later in this chapter, provide valuable insight into how relationships between families and health professionals were conducted during this period.

Given the high social value placed on the production of a healthy and productive child, the nature of the response of families or health professionals to 'deformed' or sick child remains uncertain. But it must have been a point of tension for the family and health care professionals, when a child did not meet the 'experts' healthy criteria. Increasing institutionalisation of handicapped, children or 'sickly' children over this period suggests that families were judged to be insufficiently 'trained' to care for their child and may have experienced a sense or loss or failure in producing a weak or deformed child. I believe this issue persists in some families to this day.

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[4] Plunket Society: a voluntary organisation founded by Dr Truby King in 1907. Dr King was a close follower of the American Paediatric Societies science of infant feeding, and promoted an intricate technology of bottle feeding as well as rigid adherence to schedules for bathing, feeding and sleeping. He trained a number of Registered Nurses, Plunket Nurses, who would visit women in their homes and advise them on the 'plunket schedule' for child rearing. The Plunket Society established a network of clinics across the country. The Plunket society continues to this day and plays an important role in preschool child survallance and health promotion. However today's services are less rigid, more culturally and family focused, with home visiting, telephone advice lines, mobile clinics and Marae based services (Bryder, 2003).
[5] School Medical Service:a state run service which undertook routine medical examination of all children in schools between 1912 and 1940. The service was provided by medical officers and nurses employed by the health department. The service was also responsible for health promotion and education and instruction to children and families on health care issues (Tennant, 1991)

Care of the 'chronically ill' or 'incurable'.

In the late 19th century there was a major upheaval in medical theory and therapy. The work of Koch and Lister demonstrated that the early theory of contagion had some validity and disease-causing bacteria could be identified as the cause of disease (Cordery, 1995). The perceived benefits of isolation and aseptic techniques lead the care of the sick child away from the family home to state run institutions. While, in the United Kingdom and North America, this lead to the development of specialist Children's Hospitals (Darbyshire, 1993; Young, 1992), in New Zealand, with a smaller more geographically spread child population, children's wards or wings were developed within adult hospitals (Ludbrook, 1972). Parents and families were regarded to be a major risk to the sick child and visiting by the family was restricted to one hour once a week on a Sunday (Ludbrook, 1972; Dobbie 1990). However, suspicion and discomfort with Pakeha medical practices meant that utilisation of hospitals by Maori families during the early part of the twentieth century was low (Dow, 1999; Lange, 1999). Moreover early New Zealand hospitals imposed fees and Maori families were often not in a position to pay. For many Maori families hospitalisation was often reserved as a last resort after traditional medicine had failed (Dow, 1999). Most Maori children who were sick up until the 1920's received care within the confines of the village under the care of the Tohunga and the increasing number of visiting District Nurses (Lange, 1999). By 1940 however, following the introduction of a free public health system Maori resistance waned and more sick children were being cared for within a public hospital with a corresponding reduction in district nursing services (Dew & Kirkman, 2002; Robb, 1940; D. Scott, 1977). Care of sick children along with child rearing moved from the responsibility of the family to the responsibility of the state. In keeping with the prevailing ideology of the time, the care of sick children could no longer be entrusted to the 'untrained' family. It was now the responsibility of 'authoritative experts'.

Although it is difficult to get an exact picture of chronic illness during this time, it does appear that this was the era when the term chronic illness came into use. The

term chronic was generally designated to cases "that had been in the hospital for more than two months" (Dow, 1991, p.50). The terms 'chronic' and 'incurable' were often merged together and used indiscriminately. As in Britain, early New Zealand hospitals passed bylaws barring the admission of 'incurable' patients and, although this was not strictly enforced, it did demonstrate that these were the groupings of patients least desired by hospitals at the time. This was not only because of the costs involved but also the fact that such patients tended to reflect badly on the success of the hospital (Dow, 1991). Doctors practising in the children's wards of Auckland hospital during this period noted that, in the absence of antibiotics to manage infection, many of the children were hospitalised repeatedly and for long periods of time (Ludbrook, 1972; Moore, 1977). They report caring for many children with tubercular abscesses, osteomyelitis, nephritis, pneumonia, and rheumatism, sequalae often to tubercular or haemolytic streptococcal infections. Between the periods 1916-1948 four major epidemics of poliomyelitis occurred which, although not as severe as the 1952-53 and 1955-56 epidemics, were to bring death and disability to many New Zealand children (Cullen & Walker, 1999). Clearly many children were not developing into the healthy and productive future citizens that the nation's political and health leaders were promoting.

Advances in medical technology affected not only how disease was diagnosed and treated, but also the relationship between families and health professionals. Prior to the invention of diagnostic tools such as the stethoscope and x-ray machine, and laboratory analysis of body fluids, families could observe signs of illness equally with the doctor. Whereas diagnosis and treatment had been based on an exchange of information between the family and the doctor, the invention of medical tools gave the new medical 'experts' access to signs of illness not available to the patient or family (Dew & Kirkman, 2002). Now illness was based on something unseen and inaccessible to the family and "doctors could exercise more control over information than the patient, and could decide whether to make information available to patients or not" (Dew & Kirkman, 2002, p.156). The 'expert' status of the health professional was thus reinforced. Rapid technological development became, as it is today, one of

the most powerful influences over the distribution of power and control within the relationship between families and health professionals (Dew & Kirkman, 2002).

The relationship with the 'experts'

The early twentieth century saw the emergence of the health professions in New Zealand. Regulation of health professionals between 1900 and 1910 resulted in a "stratified, segmented and hierarchical occupational structure" (A. Ryan, Carryer, & Patterson, 2003, p.94) lead by the medical profession. Families were no longer considered to have the expertise to raise and care for children without the careful guidance of a health professional. Instead, considerable power, status and authority were given to health professionals. Tennant (1991) even suggests that doctors not only had authority over health matters but also a "moral authority which had previously been the domain of the clergy" (p.129). Health professionals could prescribe how children should be reared and treated. Particular emphasis was placed on strict routines and diet. For the sick child institutionalisation within hospitals or sanatoriums was believed to be essential, along with plenty of fresh air, physical exercise, rest and good food (Trewby, 1995).

Accounts from families and children who interacted with health professionals at this time suggest that they often felt excluded, tyrannised, intimidated, and humiliated (Bryder, 2003; Dobbie, 1990; Tennant, 1991, 1994). Dr Elizabeth Gunn a legendary School Medical Officer was described by children as "8 feet tall, with a loud, booming voice and penetrating eyes" (Tennant, 1991, p.136). Children who were judged to be "physically below par" could be brought before the class as an example of "everything that is wrong with contemporary childhood" (ibid) and the response of families to such behaviour was either to dutifully accept such pronouncements or withdraw from the relationship all together. Many families chose to withdraw their child from school rather than attend the compulsory school medical examinations of their child. These examinations were an uncomfortable experience for the parent, usually the mother, with the doctor often controlling the information that the family

received through "coded" (Tennant, 1991, p.137) comments to the accompanying school nurse. For the parent there was also the risk that during these examinations their child might be judged by the doctor as having potential defects which required removal of the child from the family to the nearest hospital or health camp[6]. Despite the authority given to health professionals there is evidence that mothers did not necessarily uncritically accept the advice of experts. In 1923, Dr Ada Paterson noted the "independent attitude of New Zealand parents compared to their British counterparts" (Tennant, 1991, p.143).

Although it seems that family/practitioner relationships were often difficult and uneasy, there is evidence that some families and health professionals benefited from a more personal and sensitive approach. Lange (1999) argues that while some Pakeha District Nurses acted insensitively to their Maori patients, others "displayed such devotion to the people's welfare and awareness of their culture that they became highly popular" (p.174). Bryder (2003) also notes that the Plunket Society reports of this period record the appreciation of families for the interest, support and dedication of the nurse caring for their family.

Not all health professionals believed in the then prevailing ideology of how health care relationships should be conducted. Drs H.P Pickerill and Cecily Pickerill who were in 1927 responsible for an eight-bed infant plastic surgery unit in Lower Hutt, believed that "to separate a baby from its mother at this tender age, when it has to undergo a series of difficult operations is seeking trouble and courting failure" (Dobbie, 1990, p.26). They therefore encouraged mothers to stay with their babies and participate in their care. The Pickerills work was internationally renowned yet their approach was not accepted and strongly opposed in New Zealand by Hospital

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[6] Health Camp: A network of permanent childrens camps established across the country. When first established children who were malnourished, in poor social circumstance or were suffering from a chronic illness were taken away for a health programme based around fresh air, exercise and healthy food. While concerns regarding institutionalized care, funding, and the cultural appropriateness of services makes the future of these camps uncertain a number still exist and continue to offer support to children with physical, social and psychological health needs (Tennant, 1994).

Boards, nurses and doctors well into the 1940's. A winning essay of the 1949 student nurses' competition provides evidence of the paternalistic and expert role of the health professional:

> "Health is every baby's birthright, and handicapped though the premature child may be, the reliability and devotion of a well trained nurse can assist less fortunate little ones to its rightful heritage".
>
> (Fraser, 1949, p.116)

Not once during the entire essay was the role of the parents or mother of the "less fortunate little one" mentioned.

This period in New Zealand's history was not only significant in relation to how power and authority over child health and welfare shifted from the family to the health professional, but also in establishing the foundation upon which current family/practitioner relationships are based. Many of the tensions between the 'experts', the expert family member and the expert practitioner, which surfaced in this period, continue through to this day. Judgements of expertise control of information and participation in decision-making and childcare all created tensions between families and health professionals.

Specialisation and the emergence of pediatrics

Since the 1940's there has been dramatic changes in New Zealand in how children are viewed within society. Consumer expectations of health services and health professionals have also altered. Alongside of these changes increasing specialisation within medicine has seen the emergence of paediatrics as a speciality and an increase in the number and range of professional experts available to families of children with chronic illness. These changes have lead to increasing tensions between families and practitioners as they attempt to work in this new environment and find a satisfactory relationship between 'experts'.

From social capital to citizen: a changing view of children and family

In post war New Zealand, like many western countries, there were significant changes in relation to how family and particularly motherhood was viewed. The rise of feminism and increasing economic pressure encouraged mothers to consider entry into the paid workforce and the development of a separate identity outside of their role as mother. However the reality for most women was that the promised support from men and the workplace never eventuated and mothers have often found themselves caught between juggling their own needs with those of their children. Motherhood for many women "became something to be survived" (May, 1992, p.311) with children increasingly becoming viewed less as a successful product of trained motherhood but as a social and financial burden. As more women returned to the workforce childcare was no longer seen as the total responsibility of the mother. Childcare had become a shared responsibility with other family members or paid carers. Health professionals who previously used the mother as the main point of contact in regard to the child now have to deal with a wider range of caregivers.

The mid-twentieth century also brought significant changes to whanau structure and function. In the 1950's increasing economic opportunities within urban areas saw accelerated movement by Maori from rural to urban areas. Maori families found themselves living outside of their traditional tribal area often isolated from the tribal system of support (Shirley et al., 1997). While for some this meant disconnection and loss of their cultural links, increased Maori initiatives in urban areas, such as Kaupapa Maori[7] and Kohunga Reo[8], enabled the whanau way to persist, be it in a contemporary form (Cram & Pitama, 1998). Although the wider community may no longer be available to Maori families on a day to day basis, communal support remains a crucial support for most Maori families particularly in relation to childrearing. The challenge for Maori families, however, is trying to maintain their cultural identity and values within an environment often based around pakeha values.

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[7] Maori strategies (P. M. Ryan, 1995)
[8] Lanugage nest, Maori pre-school (P. M. Ryan, 1995)

Moreover increased pressures by Maori and acceptance of a policy of biculturalism in the 1980's now means that the relationship between health professionals are expected to consider and include the cultural needs of Maori families (Durie, 1994).

Alongside changes in childrearing there have also been changes in how the child is viewed. The rise of psychology in the early 1950's saw the view of the child move from that of 'social capital' to what McDonald (1978) describes as that of "psychological being" (p.49). During the 1950's and 60's successful transition from child to adult was seen in psychological terms and became increasingly linked to the quality of interaction between the child and its parents and the quality of the childhood experience, particularly in the pre-school years (Bowlby, 1979; May, 1998). Increasing emphasis was placed on the environment with therapeutic psychological interventions often being used to modify or adjust the behaviour of the child. While the success of parenting continued to be measured by 'experts' in terms of the production of a good future citizen it was now increasingly being measured in psychological rather than physical terms.

However by the early 1970's there was a growing realisation that despite social policies, psychological and educational approaches not all children were experiencing a healthy life. Growing concerns regarding issues such as child abuse, poverty and neglect began "to dim the belief that New Zealand was a great place for children" (May, 1992, p.311). The community became increasingly concerned about the rights of the child, which sometimes conflicted with the rights of the family. The view of the child has moved again from that of 'psychological being' to that of "citizen" (McDonald, 1978, p.51). The passing of the Children and Young Persons Act (1974) also signified acknowledgement that children should be entitled to the same legal protection as adults (Koopman-Boyden & Scott, 1984; McDonald, 1978). Views of childhood and parenting could no longer be considered within a stereotypical pakeha way. Consideration must now be given to multiple carers, cultural identity and, for

the first time, the rights and needs of the child. The relationship between families and health professionals is now being conducted within an increasingly complex world.

A picture of chronic childhood illness

Alongside changes in parenting and childhood, advances in medical science and technology allowed a more detailed picture of chronic illness to emerge. Children in New Zealand, like those in most developed countries are less affected by chronic illness (11%) than adults (21 %) (Pink, 2002a). In adults chronic illness is limited to a few major disease groups yet, in children, over 200 different chronic conditions have been identified (Ireys & Katz, 1997). With the exception of asthma, most conditions occur infrequently with only small numbers of children being affected making accurate predictions of incidence difficult. While there has been some minor increases in the incidence of asthma, diabetes and inflammatory bowel disease, there is little evidence to suggest that the incidence of most chronic childhood diseases will increase (Cooper, 1999; Ireys & Katz, 1997; Lubkin & Larsen, 2002). However, the prevalence and the number of new and continuing cases of chronic disease in childhood, is increasing. The increased survival rate of low birth weight babies and advances in the treatment of some diseases, e.g cystic fibrosis, has meant that many children who would have previously died are now surviving into adulthood (Cooper, 1999; Ireys & Katz, 1997; Lubkin & Larsen, 2002).

It is difficult to get an accurate picture of the prevalence of chronic illness in New Zealand. A study undertaken on the Auckland population concluded that the prevalence of most chronic childhood illnesses is comparable to that of the North America and the United Kingdom (Vogel, Lennon, Ameratunga, & Holyoake, 1996). Vogel et. al (1996) identified 21 different types of chronic illness occurring in the Auckland population with the most common being asthma, mental retardation, epilepsy and congenital heart disease. While issues have been raised about diagnosis and classification of disease it appears that, compared with other OECD countries, New Zealand and Australia have higher rates of childhood asthma (Ministry of

Health, 1998a). Another difference within the New Zealand population is the impact of diseases, such as rheumatic fever, bronchiectasis and menningocccal disease. These diseases do not play a major role in the picture of chronic illness in other developed countries, however their increased incidence within New Zealand is resulting in long term illness amongst some of New Zealand's children. This impact is particularly evident in Maori and Pacific Island children (M. Baker et al., 2000; Bremner, Lennon, Martin, Baker, & Rumke, 1999; Edwards, Asher, & Brynes, 2003; Vogel et al., 1996). While increased prevalence for Maori and Pacific Island children has been found in rheumatic fever, bonchiectasis and menningococcal disease, there is no indication that the overall prevalence of other chronic diseases is higher in Maori or Pacific Island children. Maori children are however over represented in relation to disability and hospitalisation associated with chronic illness (Pink, 2002b). This has been attributed to the fact that Maori children are more likely to live in social circumstances associated with increased risk of ill health and have differential access to health care (Ministry of Health, 1998a). Thus with some exceptions, the picture of chronic illness in the New Zealand child population is similar to other western countries.

The emergence of paediatric services

Growing realisation that children were worthy of medical attention and changes in medical thinking from a more holistic approach to a body systems approach heralded the development of paediatrics as a speciality. While this occurred in the later part of the nineteenth century in North America and Britain (Darbyshire, 1993; Pawluch, 1996; Young, 1992), in New Zealand this development came much later. Children's units and wards had been established in some areas of New Zealand by the early 1920's, however it was not until the late 1940's that specialisation was being seriously considered (Ludbrook, 1968, 1972; Robb, 1940, 1947). In 1947 the Paediatric Society of New Zealand was established for doctors who had an interest in the health care of children. However not all of the doctors who joined the organisation in the beginning were practising paediatricians, even by 1972 only 38 of the 147 members were practising paediatricians (Ludbrook, 1972). Specialisation in

paediatrics within the other health professions has also been a relatively recent development. For example despite Cameron's (1953) call in the early 1950's for specialist training for nurses in paediatrics, the first post-basic qualification in paediatric nursing did not become available till 1979 (McKinlay, 1981). The development of specialist paediatric health professionals is a relatively recent development in New Zealand and for many families of children with chronic illness, access to these specialists is not always easy or guaranteed. Geographical distance and the availability of specialists usually results in an intermittent consultative arrangement with care being shared between a specialist paediatric team and a generalist health practitioner, usually the family doctor or local community nurse. Some New Zealand children still receive care from health professionals who are either generalists or adult specialists who may have limited understanding of how to meet the needs of children and their families (Dawson, 1983; McKinlay, 1981; New Zealand Paediatric Society & Health Funding Authority, 1997).

As well as inconsistencies in the type of health professionals available to families the health services for children with chronic illnesses have also developed in a rather haphazard and fragmented way. In the 1980's McKinlay's (1981) study of children's services within New Zealand hospitals described the picture as one "of fragmentation and lack of co-ordination" (p.157). During the 1990's the New Zealand health system was subject to wide-ranging and dramatic health reforms in an attempt to rationalise the services and contain the rapidly rising costs (Dew & Kirkman, 2002). The number of children with chronic illness is relatively small which, under the business model of the health reforms, makes it uneconomic for them to be given special consideration. Therefore no separate funding stream or reporting category was allocated to child health services and services to this day remain fragmented and poorly co-ordinated (N. Baker, 1999). Although the level of health professional expertise available to families may have become more paediatric focused, the organisation and inconsistencies in health care providers has meant that the relationship between health professionals and families is becoming complex and difficult to navigate.

Technology in the home

As part of the increasing complexity of child health services there have also been significant changes in relation to where the relationship between family and health professional takes place. Technological advances in the care of chronically ill children as well as increased awareness of the psychosocial needs of the child and family has lead to shorter hospital stays and more emphasis on caring for children at home. Children with quite complex chronic illness are increasingly being care for in their homes with only occasional hospitalisations during periods of acute exacerbation of the illness (Campbell, 1998; Murphy, 2001; O'Brien & Wegner, 2002; Thomsen, 1999). This has led not only to an increase in family responsibility for the care and treatment of the child but also an extension of the relationship between health professionals and families from the hospital to the home. This movement of the relationship from hospital to home is creating tensions for both families and practitioners as they adjust to changes in roles and authority (Kholen, Beier, & Danzer, 2000; Murphy, 2001; O'Brien & Wegner, 2002).

In addition to enabling care to be delivered in the home, technological advances have also given families greater access to information about the their child's illness and treatment. Parent support groups, electronic libraries and local and international web sites now provide New Zealand families with access to international and national information about their child's condition. Increasing numbers of New Zealand families have internet access (Ministry of Economic Development, 2003). This allows them almost equal access to disease information with health professionals. This means that families are now more likely to bring to the relationship information previously only available to health professionals. Greater access to information enables families to increase their knowledge in regard to the illness and to question and compare the advice of health professionals in a way not previously possible (C. M. Scott, 2003). Technological advances are therefore having a major impact on not only how the illness is managed and treated but also on how the relationship is conducted.

Developing a relationship between 'experts'

While up until the 1940's there had been a rather passive acceptance of the dominant role of the health care 'expert' from 1940 onwards families began to assert their right for inclusion within the care of the sick child. In 1949 Nancy Sutherland began a long drawn out battle to improve the care of children in hospital. Following the admission of her two-year-old daughter to hospital in Christchurch, Nancy and her husband, were appalled by the treatment they received from the hospital and health professionals. Nancy, used her writing and broadcasting skill and the backing of the newly formed Parent Centre group to campaign for better access for families to their children when in hospital. She encountered major opposition from the hospital, medical and nursing fraternity (Dobbie, 1990). It was not until 1956 that families were given regular access to children in hospital when Timaru Hospital became one of the first hospitals to introduce daily visiting and encourage parents to 'room in'. While some health professionals did promote the inclusion of parents (Cameron, 1953; Guest, McNeur, Earle, & Begg, 1960; McNeur, 1954) this practice did not become widespread until the late 1960's. The stories of children in late 1950's and 1960's tell a frightening tale of isolation and desertion;

> I can remember being admitted to Ward 20 Auckland Public Hospital late that night, a very frightened little girl put into a long dark room with what seemed like dozens of beds in it. The girl in the next bed welcomed me by telling me that a wolf came in and ate all new patients.
>
> (Butterworth & Ross, 1994, p.99)

In 1974 James and Joyce Robertson visited New Zealand and raised public and professional awareness of the effect of separation during hospitalisation (Robertson, 1952). During the visit, the then Director of Hospitals in the Ministry of Health, Dr Dickie, sent out a letter to all hospital boards urging them to adopt rooming-in policies and to investigate the possibility of nursing children at home (Zarvos, 1976). In 1975, following the example of the British National Association for the Welfare of Children in Hospital (NAWCH), the Children's Hospital Liaison Group was formed (now known as the Children's Health Liason Group). This group supported by

parents, educationalists and health professionals advocated for families' access to children in hospital. It also lobbied for the provision of educational play facilities within hospitals and domicillary nursing care for sick children (Dobbie, 1990). The focus of many of these changes reflected the psychological view of children at that time. The proximity of the family to the sick child meant that there were now more opportunities for families and health professionals to meet. Thus health professionals realised that they could no longer be ambivalent about their relationships with families. The discussion at the Paediatric Society of New Zealand's 1976 conference which supported the 'live in' policy for parents probably finally signified acceptance by health professionals that parents need to be included in care and management of sick children (Zarvos, 1976).

While the Paediatric Society discussion signified the beginning of a new relationship 'between experts' it was a relationship which needed continued development. Many health professionals and advocacy groups argued the way forward in terms of the philosophy of family centred care (Shelton et al., 1987; Shelton & Stepanek, 1995). During the 1980's family centred care was being promoted internationally as central to good paediatric care and the basis on which all practitioner/family relationship should be developed. As described in Chapter One the philosophy advocates, recognition of the special needs of children and families, collaboration between family and professionals, information sharing, services and facilities suited to the needs of children (Ahmann, 1994; Shelton et al., 1987). Several authors in North Amercia however had noted there was no common understanding of the how these concepts are applied within the practice setting (Ahmann & Johnson, 2000; Coyne, 1996; Hutchfield, 1999). Similarly in New Zealand, although the philosophy was been adapted to the New Zealand context (Children's Health Liaison Group, 1993) and included within strategic child health care documents (Ministry of Health, 1998a; New Zealand Paediatric Society & Health Funding Authority, 1997), there is still no clear indication about how it is being applied in paediatric practice. While health professionals and parent advocacy groups in New Zealand are promoting the development of effective partnerships with families, application of the model is

variable (Thomsen, 1999). Tensions persist, despite the willingness of both health professionals and families to consider a more collaborative way of working together (Carter, Stickley, Ingilis, & Laxon, 2002; Lindsay, 2000; Weaver, 1999).

Since the 1940's, under the influence of changing views of childhood and motherhood, families have begun to recognise and assert their role and right to be involved in the care of their sick child. Families have come to value their own 'expert' knowledge of the child and the limitations of the so called health care 'experts' has caused families to actively seek a more equal inclusion within the relationship. At the same time, the health care environment has become increasingly complex and specialised, so that the number of relationships in which families must engage has increased. Health professionals and families struggle to find ways forward that will allow for an alliance between experts. However, as with any struggle involving power and authority, this has been a slow and difficult process because the values, beliefs and traditions of the past, intermingle, influencing the way forward. The increasing numbers of health care expert's means that a number of views have developed in regard to how the relationship between family and practitioner should be conducted. The following chapter will consider some of these views and how they have influenced family and professional views of the relationship.

Chapter 3

Standing within the tradition- A review of the Literature

"To be situated within a tradition does not limit the freedom of knowledge but makes it possible."

(Gadamer, 1982, p.361)

Each of us comes to an understanding through the influences and traditions of our past. We each stand within the traditions of our family life, our culture, and our professions. They are part of us and influence how we come to understand the world. Gadamer (1982) suggests that these traditional influences ensure that we come to every situation with prejudices or pre-judgements based on the previous understanding or fore-meanings which have been influenced and shaped by what has been heard, read and learned within the traditions of our culture. Such prejudices generally operate unnoticed, however if full hermeneutical understanding is to be achieved, these prejudices must be surfaced. From Gadamer's perspective "historical consciousness" (p.235) must be provoked in order to situate current understandings with those from the past. Gadamer suggests it is possible to have an encounter "with a traditionary text" (p.299). The "traditionary texts" according to Gadamer are those historical ontological understandings that have been handed down to us in language and text and to which we have a connection. These texts are situated and are part of us already affecting our understanding. From a hermeneutical perspective, engagement with the literature or traditionary text, means more than going back to the past and exploring past meanings. Such meanings need then to be connected to present ideas, understandings and interpretations. It is therefore difficult to determine when and where a literature review appears within a hermeneutical report. It appears to go before as a way of provoking ones prejudices, and determining connections with the subject matter. It appears during the study in the traditions of both participants and researcher and it projects into the future as a new understanding, a

new piece of literature. Literature interpretations therefore appear at various points in this report. They situate the study, uncover prejudices, examine various meanings and connect previous with current understandings and possible future interpretations.

This chapter will reflect on the literature relating to the relationship between health professionals and families as a way of revealing the traditions that have influenced the understandings of myself as researcher and that of the research participants.

Uncovering the traditionary text

In order to examine the traditions upon which this study stands, I undertook a search using the Newzindex, CINHAL, Medline and Proquest 5000 International databases. Although literature from 1995 onwards was the focus of my search, I also reviewed significant articles that influenced and informed later studies. Many of the studies that focus on the experience of the relationship in the face of chronic childhood illness were located within the discipline of nursing with the majority describing the family response to illness. Knafl and Gilliss (2002) provide an excellent review of this body of literature. However, for the purpose of this study, I have decided to pay particular attention to studies that make connections to the relationship between health professionals and families of children with chronic illness.

It was difficult to locate a large amount of literature outside of the profession of nursing so I have also included professional literature that relates more generally to patient/practitioner relationships. The family perspective was represented in the literature of all disciplines. In most cases the perspective reflected was that of the parents (Gallo & Knafl, 1998; Gravelle, 1997; Hentinen & Kyngas, 1998; Jerrett & Costello, 1996; S. Katz, 2002; Kirk, 2001; Kirschbaum & Knafl, 1996; Stubberfield & Murray, 1999), with the mother's voice predominating (Gibson, 1995; O'Neil, Palisano, & Westcott, 2001; Swallow & Jacoby, 2001; Van Riper, 1999; Wuest, 2000). Some studies focused on individual parental perspective's (S. Katz & Krulik, 1999; Knafl & Zoeller, 2000). Others presented the perspective of child family

members (Tates, Elbers, Meeuwesen, & Bensing, 2002; van Dulmen, 1998) but only a few studies conveyed a shared family perspective (Mu & Tomlinson, 1997; Robinson, 1996). The family perspective was also located within autobiographical literature, parent handbooks and parent support group web sites. This was reviewed alongside of health professional literature.

Review of the literature reveals that each of the health professions interprets through their particular professional lens with little reference to the literature of another disciplines. Thus there were a number of traditionary texts integral to the experience of the relationship between families and practitioners yet disconnected in relation to how these texts influence and inform the understanding of each other. These include the traditionary texts of nursing, medicine, allied health professionals and the family.

The traditionary text of nursing

There are a number of studies within the nursing literature, which specifically examine the relationship between health professionals and families of children with chronic illness. The perspective taken in many of these studies appears to have been strongly influenced by family nursing theory (Gilliss, Highley, Roberts, & Martinson, 1989; Wright & Leahey, 1984), family centred care (Shelton et al., 1987) and nursing views on caring (Benner & Wrubel, 1989; Paterson & Zderad, 1988; Watson, 1988). My reading suggests that nurses view relationships in four ways: as a developmental process, a style of relating, the formation of trust, and something that needs to be managed. The following section will review each of these views.

Relationships as a developmental processes

The notion that the relationship between health professionals and families is a developmental process is a predominant theme in the nursing literature. This is related either to the length of time the family has been dealing with health professionals or to various points along the illness trajectory. This view appears to

have been largely influenced by the early works of Thorne and Robinson (1988; 1989) who, using a ground theory methodology, proposed that the relationships between health care providers and families developed over time through three distinct and predictable stages. These authors argue that family members move from a period of "naïve trusting" of all health professionals, through a phase of "disenchantment", to a final phase of "guarded alliance" (Thorne & Robinson, 1988, p.154). Trust is reconstructed to accommodate the strengths and limitations of both the medical and family perspective and while at the point of "guarded alliance", families are not entirely satisfied with their relationship with health professionals, they do become more knowledgeable and articulate. This according to Thorne and Robinson allows them to anticipate and manipulate health care encounters (Thorne & Robinson, 1988, p.298). Although the quality of Thorne and Robinson's work has been criticised because of its lack of clarity in regard to methodology (Darbyshire, 1993) the use of their work in subsequent studies is evidence that it has had a major influence on how nurses view the relationship.

While Thorne and Robinson (1988; 1989) describe the development of trust within the relationship, other authors focus on the development of power and control over the relationship. These authors place particular emphasis on the family's ability to develop trust and gain control. Perhaps because most of the studies relied on data from parents or mothers rather than health professionals, the inference appears to be that it is families who learn to manage the relationship. Gibson (1999) describes a developmental process of empowerment in mothers with chronically ill children suggesting that this is a personal process in which mothers learn to make their voices heard. Gibson suggests that frustrations with the health care system provokes families to move from "discovering their reality" to "taking charge" and finally "participatory competence" (p.1201). Participatory competence is reached when the mothers have developed a sound knowledge of their child's condition and are able to confidently communicate with health professionals. Kirk (2001) describes a similar process of taking control moving from "naïve acceptance" (p.596) to "informed assertiveness" (p.598). However, unlike the previous authors, Kirk (2001) explores

the influence of health professional behaviour. She demonstrates how the response of the health professional can become a barrier for the family in gaining control over the illness due to a lack of role negotiation. Although the focus of the study was not on the relationship with health professionals Jerrett and Costello (1996) also described how health professional behaviour influenced parents of children with asthma's progression toward control of not only their child's asthma but also their relationship with health professionals. Most of these studies link the developmental process to the family's experience with the illness over time. Swallow and Jacoby (2001) however, make the link to the illness trajectory. They suggest that prior to the diagnosis mother's seek to be taken seriously by health professionals and as they transition through to a diagnosis become confident in managing their relationship with health care professionals. Swallow and Jacoby (2001) conclude that satisfactory alliance, mutual respect and good communication early in the illness trajectory influences the family's ability to manage relationships with health care professionals. Robinson (1998) and Wuest (2000) describe a similar developmental process but take a feminist perspective emphasising the prominent role of women in the care of a chronically ill children.

Although the influence of health professional behaviour is sometimes acknowledged in these developmental studies, the reciprocal nature of the relationship is not explored. These studies have been useful for gaining a perspective on the family's' progression through the illness experience, however I do not believe they have addressed the reciprocal nature of health care relationships or the influence of the unpredictable, multiple and changing relationships in the context of chronic childhood illness. Most studies suggest that the relationship develops in a predictable and linear fashion and while some acknowledge the uncertainty of chronic illness they assume that relationships will always progress, and given time, develop into an effective be it a somewhat wary or 'guarded alliance' (Thorne & Robinson, 1989). The problem with depicting the relationships in such a linear way is that nurses have adopted these developmental processes as a way of predicting and planning their

relationships with chronically ill children and their families (McGrath, 2001) failing to acknowledge the dynamic and unique nature of each practitioner/family encounter.

Styles of relationship

Another theme prevalent in the nursing literature is that the relational style of nurses and family influence the effectiveness of family/practitioner relationships. In a phenomenological study examining parents' perceptions and expectations of health care providers during the lung transplant experience, Stubberfield and Murray (1999) suggest two types of care, which meet families' expectations of health care providers, "concerned care"(p.362) and "collaborative care" (p.365). Health care providers, who reflect "concerned care" treat each family as a unique group, become a familiar face and demonstrate that the child really matters. Families who experience "collaborative care" report that they feel that they are part of a team although some report that they often feel caught in the middle of divergent opinions. Stubberfield and Murray's use of the word 'care' to describe the relationship between practitioners and families reflects the way in which several nursing authors in the studies reviewed used the words 'care' and 'relationship' interchangeably. I believe this has been influenced by the work of humanistic nurse theorists who ascribed the word 'care' to what were theories of interpersonal relationships (Paterson & Zderad, 1988; Watson, 1988). The use of the word 'care' is problematic however, because it is often difficult to distinguish whether the authors are referring to the provision of nursing care, the tasks of nursing, or the actual interpersonal transaction between nurse and family. I believe that the provision of nursing care does not always reflect a relationship. As I will show later in this report, there are many instances where 'care' is provided by a health professionals to children and their families with minimal interaction between practitioner and family.

Although careful to separate the notions of relationship and care, Robinson (1996), like Stubberfield and Murray (1999), identifies a number of characteristics of effective nursing relationships with families. Using family accounts of therapeutic

relationships, she identifies four relational stances that a nurse can take as a way of developing effective healing relationships with families. These include nurse as a curious listener, nurse as a compassionate stranger, nurse as a non-judgmental collaborator and the nurse as a mirror of family strengths. Both of these studies were based on the experiences of parents and families and did not incorporate nurses' views or the influences of other health professionals on the relationship.

In contrast to describing the influence of the relational stance of the nurse to the family, some studies have described the influence of the family's response to the child's chronic illness. Gallo and Knafl (1998) describes three care-taking approaches taken by families, strict, flexible, and selective adherence, while Kirschbaum and Knafl (1996) identify three patterns of decision-making in families, independent, dependent or collaborative decision-makers. In both of these studies, it is suggested that the parent's response to the illness influence not only the level of parental involvement, but also their communication and level of trust with health care providers.

These studies show a closer link between the influences of the practitioner and family responses to each other than the more linear developmental studies referred to in the previous section. They suggest too that health professionals need to become aware of the differing responses and modify their approach to accommodate the families' style. While adding to the collective knowledge regarding family responses to chronic illness these studies do not address the diversity and complexity of relationships in which families and practitioners engage. I also believe that when assigning characteristics or categories as a guide for conducting relationships there is a risk of applying stereotypical labels with prescribed solutions, missing out on the unique and diverse nature of each family-practitioner encounter.

The formation of trust and respect

Some of the nursing studies have attempted to examine the characteristics of effective and ineffective relationships between health professionals and families and how they might be managed. The mixed methodologies, different population groups and the varying quality of the studies makes it difficult to bring these together in any meaningful way. However one of the themes which emerges is the notion that the formation of trust and respect results in effective relationships. Unlike the developmental studies discussed earlier, that describe a process of trust formation, these studies focus on the nature of trust and its influence over the relationship.

In one of the few studies that examines the relationship from both the perspective of the nurse and family, Kholen, Beier and Danzer (2000) show that the formation of a trusting and collaborative relationship is important when working with families caring for chronically ill children at home. By establishing a trusting relationship nurses felt that they were able to "let go" (p.367) of families at the end of the caregiving episode and both family and practitioner were able to develop personal and intimate relationships. Kholen et al (2000) suggests that continuity of the nurse family relationship enables this trusting relationship to develop over time. They also alert us to the boundary issues that may develop for nurses when involved in such an intimate relationship. Lynn-McHale and Deatrick (2000) further develop this idea of trust within the relationship in their concept analysis, suggesting that the outcome of a trusting relationship is an effective family and health care provider relationship. They suggest that the preconditions of trust are knowing each other, effective communication, negotiation, competence, respect and being trustworthy. The findings of a study by Faux and Seideman (1996) also suggest that being respected is essential. In the context of mental retardation, families commented unfavourably on professionals who they perceived were incompetent, objectified or devalued their family member, and showed lack of respect for parental knowledge and the families reaction to the illness. Good health providers took their concerns seriously, recognised parental expertise, were empathetic and caring communicated openly,

honestly and consistently and were knowledgeable about the illness (Faux & Seideman, 1996). All of these studies appear to pay attention to the influences of the environment and health professional behaviour on the relationship however the small sample of only two nurses in the Kholen study means that health professionals views and experiences are not well represented.

Managing relationships

The notion that relationships need to be managed is another strong theme in the nursing literature. Taken from the perspective of the nurse, this literature not only identifies the impact of the relationship on nurses, but also pays attention to managing boundaries and family expectations. Totka (1996) explores what paediatric nurses perceive as "crossing the line" (p.191) in relation to 'unhealthy involvement' with families. Her stories reveal that nurses often 'walk a fine line' between being nurse and friend to the families with whom they work. Boundaries are individually determined with several nurses describing how they move toward a nurse family friend relationship, particularly when they are involved with families of the chronically or terminally ill children (Totka, 1996). "Crossing the line" can be either empowering or destructive to the nurse. It can transform practice or lead to distrust and disillusionment. Nurses found the boundary, with time and experience, often learning by making mistakes. Stories of when they had 'crossed the line' were rarely shared, with nurses determining that they were often too personal and too difficult to share with colleagues. This made it difficult for them to seek and accept help during or after stressful relationships (Totka, 1996). In a slightly different context Coffman (1997) described the tensions of the family/nurse relationship when nursing technology dependent children in the home and noted the importance of determining with the family the boundaries of the relationship. Ford and Turner (2001) describe how crossing over boundaries is an important part of the "special relationships" (p.291) nurses had with families. The nurses in this study described "special relationships" as those, in which they have got to know the family, still think about them and during the course of the relationship have crossed the traditional boundary of their nursing role. The nurses in each of these studies describe special

44

relationships as an important and rewarding part of their practice. But they all recognised that they must also step back to avoid over involvement. The question of what is over involvement, or where the boundaries lie, remains unresolved. However it is clear from these studies that nurses do have special relationships with some families, which involves them crossing traditional boundaries and these relationships are not only valued but transform the practice of nurses. These studies also note that these are 'special relationships' and not one that nurses have with all the families for whom they care, the inference being that such relationships take time, energy and are very demanding on the nurse.

All of these studies were phenomenological and, while only a small part of the nursing literature, they mark an important step forward in regard to understanding the impact of the relationship on the practitioner. Studies that examine the practitioner perspective begin to address the reciprocal nature of the relationship, suggesting that it is not only the family who is affected by the relationship but also the practitioner. It is interesting to consider why this perspective is not represented more often in the literature. Perhaps it is as Totka (1996) discovered, that this is an area of nursing which is often not spoken about and remains hidden from view.

Summary

This section demonstrates that the traditionary text of nursing has been influenced and shaped by humanistic theory and interpretation of family experiences of relationships with practitioners. Because of the predominance of literature focusing on the relationship as a developmental process and the often confusing and ambiguous association with the notion of care, nurses tend to view the relationship as not only central to their practice but something which must be worked on and developed. While there is some interesting literature emerging which explores the practitioner's perspective of the relationship this knowledge is less visible within the nursing literature. Although acknowledgement is made in many of the nursing texts to the unpredictable and uncertain nature of chronic illness, the unpredictable and

uncertain nature of the number and types of health care relationships that the family must engage in is largely unexplored.

The traditionary text of medicine

As noted earlier there were few studies within the discipline of medicine that focused on the relationship between the family of a child with a chronic illness and the doctor. I was however able to locate a body of literature which focused on the doctor patient relationship in a more general sense. While some of the literature addresses this issue from a sociological and anthropological perspective I focused on the literature that examines the relationship from the medical perspective. It was interesting to note the place and form this literature took. It was mostly offered as a comment, review or instructional text rather than in research studies. The literature predominantly occurred in family practice journals or was focused on the practice of family physicians however despite this the relationship was almost exclusively discussed as a relationship between an individual patient versus the family. As with the nursing literature, the medical literature rarely made reference to the literature of other health professionals however psychology literature was frequently cited.

Following review of this literature I was able to identify three predominant themes which influence how doctors view their relationships with their patients. These themes I have named as the positivist tradition, the humanistic patient focused tradition and time and market forces.

Positivist tradition:

While there is evidence that medical profession is seeking to move away from this position, the positivist tradition still plays a major role in how doctors view their relationships with families. The positivist tradition calls the doctor to take a scientific neutral and objective view of the relationship with the family. It is a position of distance based on separateness rather than relatedness (Candib, 1995). The

relationship is totally focused on the objective examination of the child and their illness. This position has influenced how the medical profession have studied the relationship with attempts made to objectify the relationship into elements of behaviour that can be observed and counted (O'Sullivan, Mahoney, & Robinson, 1992; Tates et al., 2002; van Dulmen, 1998). Frequently the characteristics of the relationship given the most attention in the literature is the interviewing skills of the doctor with recommendations usually following as to how interviewing skills can be improved (Epstein, Campbell, Cohen-Cole, McWhinney, & Smilkstein, 1993). This suggests that many doctors view the relationship as another component of their medical practice, a skill to be mastered alongside the techniques of diagnosis and treatment. However as Arnold, Povar and Howell (1987) note competency in this area does not necessarily guarantee a successful relationship, Candib suggesting that the continued focus of contemporary medicine on the communication skills of the doctor "sidesteps the relationship" (Candib, 1995, p.213).

In keeping with the positivist view, the medical profession has been strongly influenced by psychology. This as a legacy of the influence of Freudian thought on the medical profession (Candib, 1995). Many of the traditions of psychoanalysis have been brought to the profession particularly in regard to their relationship with their patients. This is evident within the references made to psychological literature and in the writings of doctors studying the relationship using psychological models. Zinn (1990) applies the psychological framework of transference to demonstrate how the therapeutic alliance between doctor and patient can be improved. He suggests that, if doctors adapt their communication style for each individual patient, communication will be improved. He cautions however, that the "doctor should titrate the distance between themselves and patients so that patients never overstep appropriate bounds" (p.297). Shapiro (2001) applies triangulation concepts when teaching medical residents how to engage in a doctor-patient-family relationship. Shapiro describes four different triangles, the negative triangles of permanent perfect parent, dyadic enmeshment, illicit coalitions and the positive triangle. He argues that by understanding the relationship as conceptualised within triangulation models

doctors will develop a more family orientated approach. Using a behavioural approach, Tates et al (2002; 2000) suggests that a child's ability to participate in a medical interview is restricted by the behaviour of both parents and doctors. They describe that the most frequent pattern of adult behaviour during the interview was that of paternalism, where the adults dominate the interaction and treat the child as a bystander. It was interesting to note that it was the doctor rather than the parent who took the supportive role in encouraging the child's participation in the interview, especially during the medical-history taking segment. Yet, despite these efforts, most consultation still ended in a non-participatory way. While both Shapiro and Tates et al, suggest that it is the triadic interaction that determines the child's ability to participate in the medical interview, "there are still some gaps to bridge to reach the goal of talking *with* children instead of talking *to* children in medical encounters" (Tates & Meeuwesen, 2000, p.160). In my view, categorising doctor-patient-family relationships in psychological terms fails to acknowledge the impact of the environment and other health professional relationships.

Despite the limitations of the positivist approach to the relationships such studies do provide insights into doctors views of their encounters with patients and families. Although this view tends to encourage distance and separateness versus closeness and relatedness by understanding and modifying behavior in psychological terms (Candib, 1995), there is evidence that some doctors are beginning to recognise the reciprocal nature of the relationship.

Humanistic and Patient Focused Tradition

In response to increasing consumerism, and the growing evidence that effective physician patient relationship not only improves patient satisfaction, compliance, and medical outcomes, but also reduces the risks of litigation (Epstein et al., 1993; Kaplan, Greenfield, Gandek, Rogers, & Ware, 1996), a more humanistic patient focused tradition is emerging in the medical literature. It is interesting to note however, that this new tradition is still to some extent influenced by the positivist

tradition already discussed.   In many of the studies and reviews the focus on specific aspects of the relationship remains. Communication skills and participatory decision-making are emphasised and attention is not given to the diverse and multidimensional aspects of the relationship.

Epstein et al (1993) outline two approaches to doctor patient communication that incorporate a patient or family centred orientation to the relationship. In the patient-centred model the physician is called to consider not only his or her own understanding of the illness but also what the illness means to the patient. They suggest a method whereby the doctor sets aside, at least temporarily, his or her interpretative understandings of situation and opens his/herself to the patient's expression of feelings, actively listening to the patients concerns.   The authors suggest that this approach requires not only learning specific communication techniques but also a particular attitude or moral position. The second approach proposed by Epstein et al, is the family systems approach to patient care. Strongly influenced by psychoanalytical traditions it focuses on the illness experience of both patient and family and is based on what the authors describe as an integrated approach to patient care.

Studies that consider the relationship from the perspective of the patient or family are now more prevalent in the medical literature. O'Sullivan, Mahoney and Robinson (1992) conducted a survey of mothers of disabled children to obtain information about parent satisfaction with the service paediatricians provided. Results indicated that, from the perspective of these mothers, paediatricians did communicate information about their children's medical condition however they perceived that paediatricians were less helpful with psychosocial concerns or family or personal needs. It was argued that paediatricians in North America have yet to embrace the concept of family centred care (O'Sullivan et al., 1992). Van Riper (1999) surveyed the parental perceptions of the family-provider relationship in families with a child with Down Syndrome, discovering that families were less satisfied with the

relationship when their was a discrepancy between what families and health care providers wanted of the relationship. Despite this the majority of mothers in this study did report that their relationship with their primary health care provider contained some if not all of the elements of family centred care however how family centred care was defined and how it related to the tools used is unclear. In one of the few studies which examined the relationship from both doctor and parent perspective, Cohen and Wamboldt (2000), in the context of paediatric asthma care, describe how both the doctors and parents perceive negative relationships as those in which there is conflict or different ideas about illness management. The quantitative methodology used in all of these studies limits quality and depth of information about the relationship however it does indicate that the medical profession is now beginning to consider a more patient focused view of the relationship.

Although several authors have suggested that doctors need to develop a more humanistic, patient centred view of their relationship with their patients, Candib (1995) is one author who has explored what this might mean in practice. In her book, which examines a number of facets of the doctor patient relationship, she challenges doctors to reconsider their relationships with the family. She suggests that "caring-in-relation" (p.206) offers a more satisfying way for doctors and families to work together. Using powerful examples from her own family practice she illustrates a new type of relationship with families. Congruent with some of the nursing literature (Paterson & Zderad, 1988; Robinson, 1996; Stubberfield & Murray, 1999; Watson, 1988) Candib has chosen to use the word care, as a way of distinguishing the relationship from the positivist view. The term's relationship and care are used interchangeably. However Candib appears to suggest that by using the notion of relationship as care rather than as a set of communication skills the traditional medical understanding of power, respect, reassurance and relatedness is transformed. Her central thesis is that it is the relationship that is central to the clinical work of the doctor. "When we place the relationship at the centre of clinical work, caring takes on a different meaning because it emerges from the relationship" (Candib, 1995, p.225). Although this view is by no means dominant in the medical literature, there is

a suggestion that doctors are beginning to incorporate a more holistic view of the relationship both within their educational programs and within their practice.

It was interesting when reviewing this literature, to occasionally see that the call to a more patient focused relationship arises from a physician's experience of being either a patient themselves or a caregiver of a sick relative. Dubin (1997), using her experience as a doctor and parent of a young boy undergoing cancer treatment, provides her colleagues with a parent's 'wish list' for improving the parent/doctor relationships. This wish list wish includes things such as encouraging and allowing open discussions, asking about psychosocial issues and complimenting the family. She appears to echo the call of Candib (1995) for 'caring in relation'. It appears that it is often the experience of being on the other side that helps medical practitioners come to a new understanding of what the relationship between doctor and family might mean.

This movement to recognise the centrality of the family/practitioner relationship to medical practice, albeit tentative, suggests that some doctors are beginning to view the relationship as more than something that must be controlled and mastered alongside their other clinical skills. It is a view which Edsall (2000) suggests indicates that the doctor-patient relationship is finally 'growing up'. It is a view closer to that of the nursing tradition. Yet, with the exception of Candib (1995) it pays little attention to the work of nursing colleagues in this area.

Effect of time and market forces on the relationship

A theme that is dominant across the medical literature which receives minimal attention in other health disciplines is the association between time and market forces in regard to the practitioners ability to build effective relationships with patients. Many authors conclude that participatory decision-making and building effective relationships require spending more time with the patient or family. Eisenberg (1998) suggests that time should "not be measured simply by the duration of

individual visits, but by the multiple visits needed to provide continuity to establish lasting ties over the years a child develops" (p.278). However a study by Goore et al (2001), which examined parent's perception of being listened to, showed that lengthy responses by doctors did not improve parent satisfaction, suggesting that it is the quality not the quantity of communication which enhances parent satisfaction. It was interesting to note in this study that while 74% of the sample felt that having doctors listen to their views about their child's condition was important only 62% perceived that their doctor did this. This study also supported the findings of the study by O'Sullivan et al (1992) that there was increased satisfaction when doctors showed a willingness to discuss psychosocial topics not directly related to the child's medical condition.

Although I have shown the use of time within the traditionary text of nursing, particularly in relation to the development of relationships, the traditionary text of medicine draws a different association. Most of these studies regarding time are increasingly related to market forces within the health care sector. The medical literature reveals concern by medical practitioners that the recent restructuring of medical care, to incorporate cost containment may impact on their ability to have enough time to interact effectively with their patients (Clark, 2002; Kaplan et al., 1996). Given the predominance of North American literature this may reflect the current health reforms in regard to managed care in that country. However, when discussing my study with medical colleagues in New Zealand, lack of time and the impact of health restructuring was frequently raised as issue impacting on the quality of their relationships with families. The fact that this issue was rarely raised in other professional forums suggests that New Zealand doctors see time as an important influence on their relationships with families.

Summary

Review of the medical literature has enabled me to identify three different views that doctors have toward their relationships with patients/families. Doctor's

understandings are still largely influenced by their positivist traditions and as Edsall notes doctors "can't help thinking in reductionist modes that dehumanise the people we deal with to some extent and thereby hobble our dealings with them" (Edsall, 2000, p.12). Despite this there is evidence to suggest that doctors are beginning to consider the centrality of the relationship to their practice. However, in an even more egocentric way than nursing, the traditionary text of medicine remains almost exclusively focused on the relationship between doctor and patient with little consideration or understanding of the influence of other health professionals or the illness trajectory. In comparison to the large amount of treatment focused medical literature within the journals and medical texts, the literature relating to the doctor patient relationship is minimal.

The traditonary text of allied[9] health professionals

This review has been confined to the traditionary texts originating from the allied health professionals who participated in this study and those who family participants regularly encountered in their illness experience. On reviewing this literature I discovered that while a number of studies had identified the importance of the relationship (Ekenberg, 2001; Jensen, Gwyer, Shepard, & Hack, 2000; Maquis & Gayraud, 2002; Prigg, 2002), there were few studies which examined the relationship between allied health professionals and families who have a chronically ill child. When broadening my search to include literature that examined the relationship between therapists and patients in a more general sense I still was unable to locate an extensive body of literature. The difficulties locating the literature was confirmed by allied health professional colleagues who agreed that literature within their own disciplines in this area was sparse (R. Ackroyd, dietician, personal communication, June, 2003; P. Neads, physiotherapist, personal communication, June, 2003; A. Paddy, occupational therapist, personal communication, June, 2003). These colleagues reported that when allied health professionals in New Zealand want to

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[9] Allied Health Professionals – includes all health care disciplines other than medicine and nursing.

explore relationship issues they tend to draw on the literature of nursing. This perhaps reflects the interdisciplinary nature of allied health professional education in New Zealand where, for example at the Auckland University of Technology, nurses teach interpersonal skills and relationship skills across disciplines. I was able to capture some of the aspects of the traditionary text of the allied health professionals by including literature which, while not specifically addressing the relationship, has in some way made comment on the relationship between allied health professionals and their patients. The themes that appeared were collaboration and clinical decisionmaking and the relationship as expert practice.

Collaboration and Clinical Decision-making

Physiotherapy has been strongly influenced by the work of Jensen, Lorish and Shepard (1997) who outlined a model of patient/physiotherapist collaboration. This model is closely linked to clinical practice and proposes four activities: establishing a therapeutic relationship, diagnosing through mutual inquiry, finding common ground through negotiation, intervening and following up. Barr and Threlkeld (2000) applied this model in an adult setting and claimed that not only did it improve patient outcomes but it also assisted the physiotherapist in focusing on the issues important to the patient. This model emphasises the role and skill of the therapist in leading the relationship but only superficially considers the reciprocal nature of the relationship or the impact of environmental factors.

In paediatrics, Embrey, Guthrie, White and Dietz (1996) examined the clinical decision-making of physiotherapists working with children. While the study did not specifically examine the relationship between children and physiotherapists, it did discover the importance of practitioners attending to both the physical and social and emotional needs of children. The authors identified the importance of social reciprocity when working with children but the methodology did not facilitate examination of the relationship between children and physiotherapists. O'Neil (2000) examined physical therapists attitudes toward family centred care and clinical

decision-making and concluded that physical therapists believed strongly in a family centred care or systems approach. It was acknowledged however that the study reported attitudes rather than actual behaviour. Another study by O'Neil, Palisano and Westcott (2001) focused on the experience of relationship from both the mother and therapist perspective. The findings revealed that mother's perceive that physical therapists are using family-centred behaviours however the definition of family centred care was not explained and the quantitative questionnaire design of the study restricted mothers responses and did not allow for in-depth analysis of this relationship. Hanna and Rodger (2002), in a review of parent-therapist collaboration in occupational therapy practice, noted the growing recognition of the importance of the relationship between parent and therapist. They noted that within the occupational therapy literature there is increased understanding of the diverse nature of family perspectives and the contribution of family knowledge to children's' therapy. Hanna and Rodger describe a positive attitude toward parents expressed as sensitivity to parental concerns, providing information and options, and treating parents as friends resulted in supportive partnerships. These were seen to promote supportive partnerships, while parents and professionals not following through on agreed activities or parents felt that their concerns were ignored resulted in negative partnerships. The emphasis in this review, like the physiotherapy studies, was also closely aligned to clinical practice and the notions of collaboration and clinical decision-making. However despite increasing awareness of the family perspective, "the 'therapist as expert' view still persists in many systems and services for children with disabilities, even those which claim to be family centred in their approach" (Hanna & Rodger, 2002, p.19). Most of the literature in the allied health professions presents the relationship between practitioner and family from the perspective of patient outcomes and mutual goal setting, without considering a broader, more holistic view.

'Good relationships' reflect expert practice

Another theme evident within the traditionary text of allied health professionals suggests that the ability to develop effective and satisfying relationships with patients

is a manifestation of expert practice. Again, utilising the work of Jensen et al (2000; Jensen et al., 1997) and to some extent Benner (1984), the traditionary text of allied health suggests that a characteristic of expert practice is the demonstration of effective therapist-patient relationships. Jensen et al (2000) argue that expert practitioners who demonstrate the skills of active listening, go beyond discussing the movement problem and injury to focusing on the psychosocial issues. One of the characteristics of the expert practitioner is their ability to interact with the patient in a way that indicates that the patient is a person rather than an injury to be treated. Gyllensten, Gard, Salford and Ekdahl (1999) identifies a number of prerequisite and interactional characteristics which enable effective relationships to develop. They suggest that it is not only internal characteristics of the therapist such as theoretical competence, personal qualities, life and practice experience, but also external quality of working effectively within a team. With regard to the actual interaction between therapist and patient Glyllensten et al suggest that empathy, respect, engagement, sensitivity and the ability to listen leads to the development of a constructive dialogue. It is in the experience of interacting and the subsequent reflection on practice that therapists learn and develop their relational skills. When examining parents' perspective of expert physiotherapy practice Jackson (2001) identified a positive therapeutic partnership between therapist and parent as being essential. What appears to be largely unexplored in allied health literature, however, is the relationship between families and inexperienced practitioners.

Summary

The traditionary text of allied health professionals reveals that the relationship between therapist and family has yet to be fully examined. However there is increasing recognition by allied health professionals of the importance of exploring the relationship further. Texts that have addressed the relationship in some way have tended to take a narrow focus from the perspective of how relationships assist the processes of clinical decision-making and goal setting. Because of the quantitative nature of most studies, the reciprocal and dynamic nature of practitioner/family relationships has yet to be explored. It is interesting to note the close association

drawn by allied health professionals between effective relationships and experience or expert practice. This may relate to the literature I used to uncover the traditionary text of allied health professionals. It is also possible however, that allied health professionals believe that effective relationships only develop with time and experience. In comparison with the literature of other professions, the text of allied health draws more on the work of other disciplines, particularly nursing and medicine. This probably reflects the lack of research available within allied health however it does demonstrate that allied health professionals are more likely to incorporate knowledge from other disciplines when considering the relationship between therapist and family.

The traditionary text of the family

To uncover the traditionary text of the family I reviewed literature that was written by families' about their experiences of working with health professionals. Because of the unique context of the New Zealand health system, I used the New Zealand literature as a starting point, expanding then into the international and professional literature. The majority of the literature written by parents discussed the illness experience and only paid minimal attention to the relationship between health professionals and families. However, interaction with the health care 'system' was frequently mentioned with little reference to the people who make up 'the system'. Steele (2002) reports that when families only have brief encounters with the health providers they view them as an extension of the health care system. When the relationship is significant, intimate and ongoing, the relationship was commented on and included in family stories. Although this may be the case in North America, I sensed a caution on the part of New Zealand families when commenting on health professional relationships. Perhaps the families perceive that there are risks in upsetting the delicate balance of health care relationships if comments are made in a more specific way. It may be easier to see it as a 'system' problem rather than risk upsetting the health professionals on which you rely. New Zealand also has a

relatively small population that makes it difficult to maintain anonymity, and families may believe that maintaining silence is a safer path.

The themes within the traditionary text of families include the complex and confusing nature of health care relationships, professional disbelief and conditional trust, and taking control. The child's relationship with health professionals is rarely mentioned in the family literature so I will conclude this section with a brief review of the few studies that sought children's perspective.

The complex and confusing

One of the themes common within family stories is the confusing and complex nature of the health care system in which they must work. Weaver's (1999) synthesis of New Zealand families' experiences notes that, at least initially, there is little choice as to the relationships formed. Families cannot choose the relationships they have and suddenly discover that they have to interact with a complex system where roles and functions are difficult to understand. Commenting from personal experience, Weaver states "I know that, for me, trying to cope with the web of systems at the same time as parenting Saffron was almost impossible" (p.131). In a parent support group newsletter, Akasha's mother also recalls that dealing with the multiple health professionals which entered her life was one of the "the hardest things to get through…I had so many people visiting. I didn't know if I was coming or going" (Anonymous, 2000). Not only are the systems and relationships confusing but the family also discovers that the interface between the various health professionals is poor. They have learnt that they cannot expect that the different practitioners will communicate well with each other. Lindsay (2000) in a newspaper report of a mother's account of trying to care for her son with multiple disabilities, described how more than 100 people had been involved in one little boy's care. In this case, the mother believed that the 'system' had failed her because, despite the large number of professionals involved, she did not get the service she required and her son died. As Lindsay reports, in an independent review following the boys death, while their was

no evidence of unethical behaviour by health professionals there was "a lack of communication between the various agencies" (p.4). Weaver suggests to, that New Zealand parents often find they must take up the role of "team leader" (p.136) because of the lack of a team concept between health professionals involved in their child's care. She attributes this to the fact that New Zealand does not have the co-ordinated managed care systems available in North America. However Steele (2002), suggests that families of children who have a prolonged terminal illness in North America also have to find out about health care systems and their place within it, learning how to mobilise multiple health care providers to get the best care for their child. It is interesting that the traditionary text of the family pays more attention to the complex and diverse nature of family practitioner relationships and the need to work with the family than that of the of health professional literature. I believe this indicates the centrality of the family within the health care systems surrounding a child with a chronic illness. They are like the hub in the centre of a wheel. It is the family who interacts with all the professionals and has a view of the whole. Their view allows them to see the complexity, ambiguity and confusion that exist between the various health care providers. Learning to operate within such a complex system is one of the many tasks that families must face when they have a child with chronic illness and this appears to add to the burden of caring for the child.

Professional disbelief and conditional trust

Another theme is the perception that health professionals do not believe family reports of their child's illness experience. Weaver (1999) describes this as "professional disbelief" (p.151). She notes, using the stories of a number of New Zealand families that it is often difficult for the family to articulate what they are going through and what they observe. When they do articulate their concerns "instead of being taken seriously we can find ourselves being pitied or seen as troublesome, ignorant individuals" (p.151). Thomlinson (2002), in a phenomenological study which focused on the experiences of families who had children with failure to thrive, reports that families perceive that practitioners often negate or minimise their experience through the use of "trite comments" (p.541)

which devalue the intimate family knowledge. Even when doctors and nurses persistently told the families that there was nothing wrong with their child the family persisted in seeking help from health professionals. This meant that the families had to tell and retell their story many times thus it may take years before the families concerns are heard (Turner & Shanks, 1996).

In a similar way to the traditionary text of nursing, the issue of 'being trusted' and deciding whom you can trust is evident in the text of the family. The family literature describes the difficulties inherent in trusting health professionals, who withhold or limit the information the family receives, communicate poorly and do not value the family's knowledge about the child and his/her illness. Families, like nurses, are selective about who they trust. Trust remains conditional on the practitioners' ability to continue to demonstrate their competence, educate and empower, and value the opinions of families (Steele, 2002; Thomlinson, 2002; Turner & Shanks, 1996; Weaver, 1999). The close connection between the traditionary text of nursing and that of the family probably reflects how nursing has utilised the experiences of families to inform its understanding.

Taking control

The need to take control of their relationships with health professionals is also evident. This appears to take time and relies on experience of working with practitioners. Realisation of the need to take control appears because families discover the complexity, confusion and uncertainty which exists within health care relationships. One way of coping with uncertainty is to take control over the number of relationships and conditions under which they will operate. Moreover there is recognition that health professionals are human and have the same human failings as families. Molly's mother describes "I've learnt that Doctors aren't Gods. In fact a well informed parent, dealing with a chronic condition day in and day out, can come close to being equal in their child's care" (Anonymous, 2003). It is the realisation of their own expertise that allows families to begin to take control of their relationships

(Steele, 2002; Thomlinson, 2002). Taking control of the relationship depends on recognition by the family that they have expertise and the right to take control. Kelly Turner's mother recalls:

> "I knew that when it came to my daughter, I was the expert. I knew her better than anyone else in the world; my instincts had never been wrong and I must continue to listen to them. I would work alongside the medical people and trust them when they earned it, but I would have my concerns listened to."
>
> (Turner & Shanks, 1996, p.60).

It was this recognition of her own expertise that she describes as a turning point in her life journey with her daughter's illness. Weaver (1999) suggests that families need to recognise their right to decide what they need, to ask and get help, to express feelings, say 'no' without feeling guilty, to be treated as an adult and choose the professionals with whom they work. To do this the traditionary text of the family frequently describes how you must learn the language, so that you can effectively communicate (Thomlinson, 2002; Weaver, 1999). It appears discovering that they can choose relationships that work for them and disposing of others is part of the process of taking control. The mother of a surviving premature twin recalled that, following a threat from a specialist that he would put her baby back in hospital, that she took control back. "I wasn't having it. The feeling that she belonged to those in hospital were still there. I refused to see the specialist again" (Anonymous, 2000). Weaver advises families to keep relationships where health professionals share power, listen, explain, acknowledge their expertise and ultimate power over decision-making. However she also explains relationships maintained may not necessarily relate to the communication skills of the practitioner. She describe how her family have "stuck with a paediatrician who is abrupt and unapproachable because his other qualities are more important to us – he is clever, dedicated, investigative, honest and finds answers" (Weaver, 1999, p.139). There is also recognition that there are risks in taking control. Families describe how by doing so there is a risk that they will be labelled as a "bolshy mother" (Anonymous, 2003) and in some instances relationships will be lost because family and practitioner can no longer work together.

A child's view

The children's view of the relationship between themselves and health professionals is rarely mentioned, although a few studies have attempted this. Sallfors, Fasth and Hallberg (2002) spoke to children living with juvenile chronic arthritis and found that children did not perceive that health professionals and school staff trusted their reporting of their illness experience. The children expressed readiness to participate in the relationship and felt able to ask questions however they did not often feel supported in doing so. The children in this study were very aware of the misunderstandings that existed between school and health professionals about their illness and the authors concluded that this often led to feelings of despair in the children. While only described in one study, it does show that children, like their parents, have a perception of the complex and confusing world in which they must exist. In another study of children suffering from Cystic Fibrosis, Angst and Deatrick (1996) report that children are rarely involved in planning and decision-making relating to their care. The children in this study perceived that questions from health professionals were always directed to their parents. In contrast to the previous study more of the children in Angst and Deatrick's study were comfortable about not being involved in decision-making. While the limited number of studies and the different methodologies used makes it difficult to really uncover the traditionary text of children, there is a suggestion that children do not perceive that they are included within the relationship. To be included requires courage and determination. Sharon, a young New Zealand girl with Cystic Fibrosis, reflects this in an extract from a poem about her illness experience: "Courage, stamina and stubbornness too. Help us do what we must do. These special people, these quiet ones" (Hauschild, 1996, p.20).

Summary

The traditionary text of the family suggests that family, and children with chronic illness, recognise the complex and ambiguous world in which they exist. It appears that their central role within the illness experience allows them greater insights into the complexity of health care relationships. The literature suggests that families prefer to describe managing the illness experience rather than talking about

relationships with health care professionals. This may relate to the fact that managing the illness occupies more of their time than their interaction with health professionals, but I believe also indicates the fragile and sensitive nature of the relationships. The traditionary text of the family suggests that despite the complexity and professional distrust families learn the importance of taking control of their relationships with health professionals. Families recognise the pivotal nature of their relationship between health professionals in getting the care they require for their child. Sadly, the voice of the child suffering the chronic illness is small and quiet.

The encounter with the traditionary text

By exploring what Gadamer (1982) calls the "traditionary text" I have discovered multiple traditions and understandings of the experience of being in relationship. The traditionary texts of health professionals have, to some extent, all been influenced by the experiences of families, however the interpretative lens of each profession influences understanding of the relationship. Nursing has based its understandings on the experience of families' development through the illness experience and nurses views on humanistic caring. In contrast, doctors and allied health professionals have sought to understand the relationship by examining the practice of practitioners in interacting or negotiating care with families. Doctor's views are more focused and perhaps reflect the greater positivist influences on this profession. Each of the professions appears to partially recognise the centrality of the relationship to clinical practice, however the literature of the family suggests that the way in which this is revealed in practice varies. The professions have yet to examine the reciprocal nature of the relationship and the families' influence on their practice in any depth. They have not considered how their relationships with other professionals may and can influence individual relationships with the family. It is only within the traditionary text of the family that the complex and dynamic nature of the relationship is revealed although this is limited because of the apparent reluctance of families to express their views and the near absence of children's views.

Revealing the traditionary texts of the participants in this study has enabled me to situate my research. It has also identified the diversity of meanings and thus provokes questions about how these traditions have and will influence this study. In the following chapter I will articulate the philosophical notions that have informed this study.

Chapter 4

Philosophical Foundations

Phenomenological research is inextricably linked to the philosophy from which it originates. To present a phenomenological study without reference to the philosophy which informs it not only fails to acknowledge the embedded nature of the philosophy within the inquiry process but, as Koch (1996) suggests, does not provide the soundness for the methodology used. However as many other nurse researchers have noted, journeying into the foundational philosophy of phenomenology is not easy (Caelli, 2001; M. Z. Cohen et al., 2000; Koch, 1996). Like other phenomenological researchers my journey was a challenging one, struggling with translated texts and new words, as I sought to uncover the philosophical notions which would provide both a foundation for the study and the scaffolding around which it could be built. This chapter will describe my journey into the philosophy and introduce the philosophical notions that guide and direct the study.

Finding Heidegger

Kant first used the term phenomenology in a scientific form in 1786, and while the beginnings of the phenomenological movement have been attributed to Franc Brentano [1838-1917] and Carl Stumpf [1848-1936], it was one of their students Edmund Husserl [1859-1939] who is most often referred to as the founder of phenomenological method (M. Z. Cohen, 1987). Reacting to the positivist paradigm Hurserl believed that science needed a philosophy that related more closely to human concerns. His call "to the things themselves" signified an important movement toward viewing the "things" as they appeared rather than the Cartesian view of viewing 'things' as isolated objective facts with no connection with the world. It was this inseparable connectedness of human beings to their world and the notion of intentionality, that human beings always come to a situation conscious of something,

which were to become the foundational tenets of phenomenology. Although I was aware of the significance of Husserl's work, his insistence that the researcher must "bracket" their own view and describe the lived experience as a detached observer, did not fit comfortably with how I experience the world. Heidegger [1889-1976], a student of Husserl, while agreeing that the world must be described as lived, noted in his description of "being-in-the-world" (Heidegger, 1996, p.49) the inseparable and intimate connection between the person and his/her world. From Heidegger's perspective human beings cannot be uninterested bystanders. We are always actively engaged in our world. This interconnected and engaged relationship appears closer to how I experience the world and how I wish to act as researcher.

While Husserl believed that it was possible to describe the phenomena without interpretation by taking the correct "transcendental" attitude, Heidegger insisted that that we always interpret the world and therefore interpretation is inherent in any phenomenological description (Burns, 2000). Heidegger's (1985) focus was on the uncovering of meaning, of moving beyond straight description to "analytic description" (p.78) which laid open the meanings which may be hidden within the experience. This notion also seemed to fit closely with the type of phenomenological approach I wished to take. This study therefore is philosophically grounded within the work of Heidegger.

As I began to understand the complex writings of Heidegger I also needed to convince myself of the trustworthiness of Heidegger the man. I was challenged by Heidegger's association with the Nazi party. Heidegger joined the Nazi party in 1933 and, while his official activity within the movement only lasted nine months, he never denounced or commented on subsequent related activities or his own involvement with Nazism (Steiner, 1987). As I read his work and the history of his involvement with the Nazi's I found myself taking a number of the positions described by Polt (1999). Firstly, I tried to separate the man from the philosophy and then I tried to find explanation within the historical context in which Heidegger was placed. But

none of these positions proved helpful or provided the reassurance or comfort I sought. So I come to this study continuing to be challenged by not only the complexities of Heidegger's writing but also the complex nature of Heidegger the man.

However within his writings I have discovered the thought provoking and revolutionary nature of Heidegger's view of the nature of being. It has challenged me to look beyond the 'taken for granted' to uncover the meanings that often lie hidden from view. It is for this reason that I chose to use Heideggerian notions to guide this study. I have also used the work of Gadamer [1900-2002] who, as a student of Heidegger, moved on to explore the development of understanding particularly as situated within language and the historical horizon. Gadamer's work provides direction in regard to analysis of the text and the use of language in this study.

Guiding philosophical notions

Discovery of phenomena

Heidegger (1996) describes phenomenology as "the science of phenomena" (p.24). He notes one of the principals of phenomenology as securing a phenomena for study and then moving on to scrutinise it (Heidegger, 1985). Heidegger suggests that we must allow the phenomenon to "show itself in itself" (Heidegger, 1996, p.28) in that it can be nothing else, it is the "being of beings" (p.31). One of the difficulties which Heidegger describes is that phenomena are often concealed from view and the challenge for the investigator is to find "access and passage through concealment" (p.l87). He suggests that the beings can show themselves in various ways. They may show themselves as a "semblance" (1996, p.25) which looks like the phenomenon but in reality is not, or as an "appearance" (p.27) which may indicate the phenomenon and relate to it but is not the phenomenon. Heidegger suggests that phenomenon can remain "concealed", can appear only to be "covered up" again or appear in a "distorted way" (p.31). The challenge of phenomenology is to find a way of accessing

and discovering the phenomena behind this concealment. Heidegger describes this as "the point of departure of analysis" (p.32) the passage through which the very being of the phenomenon can be revealed. He suggests that there is no prescribed way of doing this but that the investigator needs to find their own way depending on the phenomenon under investigation.

The phenomenon under investigation in this study is the relationship between health professionals and families who have a child with a chronic illness. Heidegger's notion of the discovery of the phenomenon challenges me to ensure that in this study I look beyond the first presentation. I need to remain wary of semblance or disguise which may hide the meaning of the relationship between families and practitioners from view. I must look for the 'passage' which allows me to reveal the relationship between families and practitioners as it is shown in its being.

The "being of beings"

Heidegger (1996) suggests that phenomenology is about the discovery of the "being of beings" (p.31). Heidegger's life's work focused upon the question of what is the meaning of being? Although he never completely answers this question he takes the reader with him on a journey of discovery, prompting us to the question in a number of new and challenging ways. He asks that 'being' be considered, not as an object or concept to be described, but rather as that which "is" the meaning of being. What is the "thatness and whatness" (p.5) in which being is found? Heidegger asks us to notice and wonder about what makes beings something rather than nothing (Polt, 1999, p.3). What makes it different? How does this make a difference to us? For Heidegger the "being of beings" exists within the very existence of people within their world. Heidegger uses the term *Dasein* as a way describing the unique and distinguishing character of people. The distinguishing characteristic of *Dasein* is not simply that it lives among others but that "it is concerned about its very being" (p.10). It has the ability to understand its being in terms of its existence. In other words we can understand because we are there in the world.   I believe what Heidegger is

suggesting is that to understand the "being of beings" we must not separate or view being as an object to be defined or conceptualised, but rather we need to discover it in its being, how it exists and is understood in its "being-in-the-world".   In this study I must therefore question what is it that makes the relationship between families and practitioners what it is? What makes it this relationship rather than another? I must as Heidegger suggests, "allow the entities to show themselves in their being" (Heidegger, 1985, p.137). I need to show what it is to 'be' in this world, to reveal the complexities and paradoxes that are revealed in the very humanity of working together.

Being-in-the-world

Being-in-the-world in its everydayness

From Heidegger's (1996) perspective human beings are inextricably connected to the world. *Dasein's* literal translation as shown by Steiner (1987) is "to be there" (p.83) and the "there" which Heidegger is referring to is the world.   Heidegger explains that it is only through "being-in-the world" that we find meaning and understanding. "*Dasein* finds 'itself' in what it does, needs, expects, has charge of, in things at hand which it initially takes care of in the surrounding world" (p.112). Heidegger suggests that meaning is found in our everyday existence of being-in-the world and within this he includes the temporal nature of everydayness. It is not the everyday of "each day" (p.338) but how the everyday stretches out from the past to the present and into the future. Heidegger also cautions that everydayness can entangle us (p.164). As we "fall prey" (p.164) to the world of everydayness our sense of what being 'is' may become lost. He describes the alluring, tranquillising and alienating effects of losing ourselves in our everydayness (p.166) misleading us into thinking that the meaning is self evident and not in need of investigation (p.110).

This paradoxical nature of this notion sets a challenge for this study. In order to find the meaning within the relationship between families and practitioners I must situate the study firmly within the 'everydayness' of their world.   I must seek out the

ordinary and routine but also recognise that perhaps in the extraordinary, meaning may also be found. I must consider the comfort with which the participants and I are encountering this world, remaining alert to the alluring and tranquillising nature of the everyday, in which meaning may be lost. I must be cautious not to accept meanings as 'self-evident' but be open to the ontological meanings that may lie hidden within the everyday.

Being-in-the-world with others

King (1964) describes Heidegger's notion of "Being-with" as the essential nature of man's existence. It is the reason for which man exists. As Heidegger (1996) shows even when we are alone or away from others it is still a mode of "being-with" (p.113). To know oneself according to Heidegger is grounded in understanding what it is to be with others or as King interprets coming to understand "the difference which separates our own possibilities from theirs" (p.112). However while Heidegger observes the centrality of this relationship he does not move on to the dynamics of "being-with" instead he then goes on to describe the influence of those with whom we are with. Heidegger describes these others as the "they" (p.118). It is the "they" who determine how *Dasein* behaves, understands and operates within the world. It is the "they" which connects us to the society in which we live and, as Heidegger describes, it is within this world that we most frequently exist. We operate within the "they when we accept the expectations and interpretations of our society and use this to structure and explain what we do. From Heidegger's perspective the 'they' poses the risk that we will lose our *Dasein* to 'they'. He goes on to describe how this happens. He suggests that in our everyday encounters with others we find that we are constantly comparing ourselves to others, trying to keep up or out-do them. Heidegger calls this "distantiality" (p.119). Another consequence of our participation in the "they" is that it creates "averageness" (p.119) in that we find ourselves conforming to what is expected, how the 'they' determine we should behave. Heidegger suggests this leads to "levelling down" which reduces our potential for being. Thus he sees inherent dangers in "being with" others, because in

the everyday public world the influence of others reduces the possibilities of our being.

Although there is a sense that Heidegger appears to miss the more positive possibilities of the relationship with others, his notion of "being with" does provide a platform to consider the relationship between families and practitioners. This very public world, which Heidegger is describing, reflects the environment in which families and practitioners interact. I will need to consider the influence of the 'they' on these relationships. How much does the need to conform influence the potential 'being' of the participants? What is the influence of the 'they' on what they choose to tell me? This notion guides me in recognising that the views of the participants and myself will be shared meanings, influenced by 'being-with' others in the world.

Taking care

Heidegger (1996) describes care as the central "character of being" (p.114). To care is inextricably linked the notion that we are 'in' the world and 'with' others' (p.180). Because we are in the world alongside others we cannot help but be concerned for or have a need to take care of others. The German word used by Heidegger *Sorge* translates to "care for" "concern for" and therefore as Steiner (1987) explains care from a Heideggerian perspective is "beyond being *Dasein*-with and *Dasein*-in - which are ineluctable modes of everyday – it must become *Dasein*-for."(p.100). Being-in-the-world and being-with-others means that we care 'for' and it is this that makes human existence meaningful. As Polt (1999) notes for Heidegger there is no way in which we can avoid care. However although Heidegger does describe two extremes of positive modes of caring "leaping in" or "leaping ahead" (p.114) his notion of care is not always the positive comfortable kind of caring often referred to by nurses. For Heidegger care is most often revealed in its deficient or indifferent modes. He notes that care is evident even when we are careless, when "we pass one another by" (p.114) or are indifferent to each other. While he notes that care is guided by considerateness and tolerance it is also revealed in intolerance and inconsiderateness.

Heidegger's notion of care is relevant within the context of this research. The notion of caring for the child is often described as central to the relationship between families and practitioners (Benner & Wrubel, 1989; Candib, 1995; Shelton & Stepanek, 1995; Stubberfield & Murray, 1999). Heidegger's notion of care prompts me to consider the interconnected nature of how 'being-in' and 'being-with' influences how the participants show 'concern for' or 'care for' each other. It challenges me to consider how care presents itself in its deficient or indifferent modes. How is care revealed in the relationship between practitioner and family?

Coming to understand

From Heidegger's perspective human beings always have an understanding of things we encounter. This Heidegger says is based on our "forehaving" our everyday interpretation, our "foresight" a definite interpretation we have in view, and our "foreconception" an interpretation we have already provisionally or finally decided on (Heidegger, 1996, p.140). We understand according to Heidegger in relation to our possibilities, of projecting available ways to be. For example the participants in my study will come to the relationship with their own "forehaving" or understanding of what it is like to have a relationship with a health professional based on their past experiences and interpretation of potential relationships. They will also understand the possibilities of such a relationship as being, for example, helpful, comfortable or daunting. It is this "forehaving" as Grondin (1994, p.92) suggests which determines the framework and parameters around which we make each interpretation of things as we encounter them in our world. From Heidegger's perspective "all interpretation is grounded in understanding" (p.144). We already come to the situation with a view and when we say we understand something we say this situation now has meaning (p.142). To understand therefore, from Heidegger's perspective, is less about a type of knowledge and more about "knowing your way around" (Grondin, 1994, p.93) because the situation has meaning. The challenge of Heideggerian phenomenology is to extend this understanding by uncovering the "forestructures" which have become covered over in our everyday understanding of the world. To do this in this study I

must become reflectively conscious of my own "forestructures" and how they have been influenced and influence my understanding. I need to remain open to extend and expand my understanding by looking "in and behind" (Grondin, 1994, p.94) what is presented to me. I already come to this study with an understanding and interpretation, the challenge is to go beyond that understanding.

Understanding revealed in the questioning

While Heidegger (1996) noted the importance of reflexivity and attention to forestructures, Gadamer (1982) went on to describe the importance of the questions we ask. He noted the important dialogical relationship and movement between question and answer that informs our understanding. From Gadamer's perspective "to ask the question means to bring into the open" (p.364). He describes the importance of the questions we ask as a way of gaining access to the knowledge we seek. For Gadamer the "art" of questioning not only maintains our "orientation toward openness" (p.367) but also allows us to ask further questions. Gadamer suggests that the questioning is the "art of thinking" (p.367). Just as Heidegger suggests we always have an interpretation or understanding of an experience, Gadamer suggests that we cannot experience the world without asking questions (p.362).

This notion highlights the importance of questioning as I carry out this study. I need to discover the questions to ask which will open the relationship between health professional and family for view. I must ask questions that maintain the direction of the study and allow myself to remain open to the possibility of new understandings. It will be in the application of the questions that my thinking and understanding will be revealed. The study will conclude with still more questions for it is the questions which lead the way forward. Answers, in contrast, close down the opportunities for new insights.

Understanding revealed through language

Heidegger (1996) describes discourse expressed through language as the way in which we show ourselves to the world (p.155). Even when we are just listening or are silent we manifest the possibility of discourse. For Heidegger language is the fundamental way in which meaning is shared, it is what makes the world intelligible to us. For this reason language, according to Heidegger, is grounded in understanding (Polt, 1999, p.154). When we speak we are already presenting our interpretation, our understanding of the world. Gadamer (1982) elaborates on this notion further by describing not only the importance of the link between language and understanding but also the importance of the dialogue between another person or a text which allows understanding to emerge. For Gadamer (1982) "language has its true being only in dialogue, in coming to an understanding" (p.446). His description of the "hermeneutical conversation" (p.387) notes the important role of both the speaker, as presented in the text, and the interpreter. For Gadamer understanding comes in the interpretation and as we proceed with the "hermeneutical conversation" the interpreter is inextricably linked with the subject matter. The interpreter's thoughts therefore will be present in the description as Gadamer states "not as a personal standpoint that he maintains or enforces, but more as an opinion and a possibility one brings into play and puts at risk" (p.388).

This notion reminds me that access to understanding the world of families and practitioners will be mediated through language. It will be not only in what is said but also in what is not said. It will be in the discourse of the interview and in the reading and interpretation of the text of these interviews that understanding will be found. However as Gadamer (1982) notes, the interpretation presented will reflect interplay between the participants' stories and my interpretation. Through my conversations with the texts new meanings and understandings will be revealed but this is not necessarily to say that this is the only meaning. However what I will present reveals another possibility open as Gadamer would say for "play" or to be "put at risk" (Gadamer, 1982, p.388).

Understanding and the hermeneutic circle

The term "hermeneutic circle" was first used by the hermeneutic scholar Schleiermacher [1768-1834] describing how understanding moves in a circular fashion between parts and whole. Although Heidegger (1996) did not describe the circle in this way he did note the importance of the circular movement of understanding as it unfolded in interpretation (Grondin, 2002). It was Gadamer (1982) who returned to Schleiermacher's description and developed the notion of the hermeneutic circle as a way of interpreting text. Gadamer noted that to understand, human beings must constantly move to "understand the whole in terms of the detail and the detail in terms of the whole" (p.291). It is important to realise that this circle does not become closed but is constantly being expanded as we come to a new understanding of the whole. Building on Heidegger's concept that every interpretation is built on the possibilities of new understandings, Gadamer sees the hermeneutic circle as "the constant revision of anticipations of understanding in the light of better and more cogent understandings of the whole" (Grondin, 2002, p.47).

This notion of the circular nature of understanding will serve to guide my interpretation in this study. As I hear and read the participants stories I must explore the details and parts of what they are telling me but also reflect on the relationship of the parts to the whole experience. I must remain alert to not getting lost in the detail so that I lose sight of the whole or vice versa. I must remain open to have my understandings expanded and revised as I uncover the meanings that lie hidden within the text.

But is Heidegger enough?

Although Heidegger's (1996) notions provide a sound framework for this study, his writings, from my interpretation, do not provide sufficient direction in regard to coming to understand the interpersonal relationships between people. Despite his descriptions of "Being-with" Polt (1999) notes Heidegger's work only "gives

promising hints of a phenomenology of human relations" (p.61). He tends to describe *Dasein* interaction with the world in either an instrumental way, as a manipulator of tools, or in a negative mode (Burns, 2000; Gordon, 2001). As Burns (2000) notes even in his descriptions of inauthenticity and authenticity Heidegger describes authenticity in a non-relational way, where *Dasein* is brought back from "falling prey" to the "they" (Heidegger, 1996, p.178). Heidegger appears to focus on the potential risks of being in relationship with others rather than the potential for the more positive modes of friendship or love. Heidegger does not provide detailed insights into the dynamics of interpersonal relationships but rather moves beyond this to examine the very nature of being. For this reason I decided to explore the work of other philosophers and have drawn upon Arendt [1906-1975] Buber [1878-1965] and Levinas [1905-1995] to guide analysis of the interpersonal aspects of the phenomenon.

To maintain philosophical congruence in my research I needed to be sure that these philosophies were compatible with Heidegger's work. In the case of Arendt and Levinas it is easy to see the connection for they were both students of Heidegger. Both remained admirers of Heidegger's work and paid tribute to it in the development of their own philosophy. Levinas was to comment in an interview with Francois Poirie (Robbins, 2001c) that "in the way in which he [Heidegger] practiced phenomenology in *Being and Time*, I knew immediately that this is one of the great philosophers in history" (p.32). While Levinas did not claim to be a disciple of Heidegger he could not deny the important part Heidegger's work played in this life (p.37). His writing makes frequent reference to the work Heidegger. Likewise, putting aside Hannah Arendt's rather notorious personal affair with Heidegger, throughout her life she admired Heidegger's work. As Wolin (2001) notes particularly in her book *"The Human Condition"* (Arendt, 1998) we see her analysis of mass society has close links to Heidegger's condemnation of everydayness described in *"Being and Time"*. However while both Ardent and Levinas remained respectful of their teacher's work, neither viewed it uncritically. Both were to comment on the limitations of Heidegger's work in regard to the relationship between

people. Levinas was critical of the anonymity and detached nature of Heidegger's "being-with-one-another". He was to comment "The Heideggerian being-with-one-another appears to me like marching together. That is not for me, there is no face there" (Robbins, 2001a, p.137). Arendt also commented that Heidegger's notion of "world" was utterly impersonal and loveless, however it appears that the nature of her critique has been somewhat confused in that it was written not long after her affair with Heidegger had ended (Wolin, 2001). Despite these criticisms Levinas and Arendt continued to acknowledge the place that Heideggerian thinking had within their own work. From my perspective their work complements that of Heidegger and therefore I believe it is compatible and appropriate to use in this study.

The relationship between Buber and Heidegger is somewhat more difficult to resolve. Buber was not a student of Heidegger nor did he make any claim to phenomenology. Both were openly critical of each other's work. Although not mentioning Buber by name, Heidegger firmly rejects the ontological basis of I-Thou. Similarly Buber rejects Heidegger's analysis of *Dasein* on the basis that it fails to address the realm of the interhuman (Buber, 2002). Gordon (2001) suggests that both were recognised existential thinkers who undertook an ontological study from different starting points. Heidegger was seeking to understand the meaning of being, while Buber was seeking to understand the significance of a dialogical life. So while Heidegger and Buber may not agree, this does not mean that some of their ideas are incompatible. I therefore support Gordon's view that they shared many perspectives. Heidegger provides direction in relation to uncovering the meaning of being in the world and Buber provides guidance in terms of interpersonal relationships.

Philosophical notions of interpersonal relationships

Arendt and The Web of Human Relationships

Arendt is generally recognised for her political philosophy, however within her writings she did explore the notion of the person as situated within both the personal

and public realm (Arendt, 1998).   Arendt argues that human affairs are always conducted within a "web of human relationships" (p.184). This is an inherent factor of human existence. The web is both context and creation (Hansen, 1993). We exist in a web of relationships shaped by those with whom we come into contact but each person is also part of creating and initiating processes that alter and shape the web. Arendt's notion of "natality" that each "newcomer possesses the capacity of beginning something anew" (p.9), is, as Canovan (1998) notes in sharp contrast to Heidegger's notion of mortality "being toward death" (Heidegger, 1996, p.235). Arendt's action focused perspective suggests that, as each person enters and acts within the web of relationships, they start a new process and from that interaction a "unique life story of the newcomer" (p.184) emerges. Arendt places great emphasis on the important role of the creation of life stories noting that it is in the telling of the story that the consequences of actions become both comprehensible and bearable (Hansen, 1993). However she notes that "nobody is the author or producer of his own life story" (p.184). It is our connectedness and our action with others which eventually produces the story. From Arendt's perspective, because of the influence and action of others, the outcome is never predictable.

The notion of the web of relationship serves as a guide in relation to the context, connectivity and creation of the relationship between families and practitioners. It challenges me to consider the impact that each participant has on the relationship as they enter the relationship. What is the interplay of actions between participants and how does that affect the new stories which emerge? It also directs me to consider that the stories that are told in this study do not just reflect the actions of the storyteller, but also those with whom the participant has come into contact with.

Levinas: The face to face encounter

While Arendt (1998) focuses on the connectivity and creation of relationships Levinas (1969) draws attention on the call and response to the relationship.   It is the "face to face" encounter that lies central to his notion of ethical relation.   It is the

"face" which "invites me to relation" (Levinas, 1969, p.198). The "face" is not some objective structural object but rather the expression of the whole human being. While Levinas does acknowledge that we may encounter the "face" in an objective and structural way, to encounter a person only in this way he believes is "defacing" (Robbins, 2001b, p.49). The "face speaks" it opens discourse before a word is uttered. The face "offers itself for my understanding" (Levinas, 1998, p.9). It is in the presentation of the "face", that human beings are exposed, "in his face, the human being is most naked" (Robbins, 2001d, p.127). However, despite its exposure, the "face" does not reveal all of the persons being. According to Levinas, in the "face to face" encounter the person maintains their "otherness" (Levinas, 1998, p.185). The person is never completely open in their being. There will always be something that remains distant or secret. It is this hidden aspect of one's being, which we cannot comprehend that Levinas calls "alterity" (Critchley, 2002, p.26). The central notion in Levinase's notion "face to face" encounter is that not only does the "face" invite me into relation but it also demands my attention. In what he was later to describe as the "epiphany of the face" (Robbins, 2001d, p.127) Levinas describes the responsibility which lies within the "face to face" encounter. My encounter with the face of the other demands a response, I have a responsibility to respond. It is this demand and my responsibility to respond which is central to Levinas notion of ethical relation.

This notion of the "face to face" encounter prompts me to consider the call of the relationship between families and practitioners. How does the "face" of each participant present itself? How do they maintain their "otherness"? How are the participants invited into relationship with each other? What is the response? It also reminds me that even in the presentation of the stories, in the exposure of the "face" there still remains the mystery of things hidden or held back.

Buber: A Life of dialogue

Buber through all of his writings carry's through the notion of a life of dialogue. For Buber, the basic movement of life is dialogue. It is "where you really have to do with those you have to do" (Buber, 2002, p.23). What goes on "between" man and man is important because it is the only way in which one can come close to an understanding of the person in their being. To really understand someone Buber believes we must enter into "genuine dialogue" (Buber, 2002, p.22) with the other person. In a similar way to Levinas (1998) Buber suggests that "genuine dialogue" requires a willingness to turn to the other and respond by "making the other present" (Friedman, 1955, p.97). However for the Buber the relationship is not driven in the ethical way described by Levinas, but by a willingness to not only understand the other but also to have your own understanding changed. For Buber "relation is reciprocity" (Buber, 1970, p.67) . "Genuine dialogue" is a mutual process of being willing to "step into relation with the other without holding back" (Kohanski, 1982, p.22), where meaning is not found in one or other partners but in the mutual interchange which goes on "between" each person. It is the deep moments of mutual understanding which come from the dialogue which Buber described as the "I-Thou" (Buber, 1970). Knowing however that it is impossible for people always to encounter each other in this way, Buber (2002) suggests that other forms of dialogue, "technical dialogue" "monologue" "debate" "conversation" and the "friendly chat", are relevant and appropriate ways to interact in the everyday world. Although none of these forms of relation provide a way of fully understanding the other.

The notion of 'life as dialogue' provides direction in this study in relation to coming to understand the different ways in which practitioners and families encounter each other in the relationship and also the degree of reciprocity inherent in the relationship. It helps explore what happens "between" families and practitioners and whether this changes their understanding of each other and the illness experiences.

Summary

In this chapter I have discussed the philosophical notions which will guide this study. The journey has taken a route through the writings of a number of philosophers. Heidegger and Gadamer anchor the philosophical approach while Arendt, Levinas and Buber provide depth to the analysis of the interpersonal relationships. While the contrasts in thinking has provided some challenges I believe they are compatible with Heideggerian philosophy and provide a strong philosophical foundation to this study. In the following chapter I will describe how I took this philosophical base forward and developed it to provide my own process of inquiry.

Chapter 5

Method

Having explored and discovered the philosophical notions that would guide the study I now need, as Heidegger (1996) describes, to find my own way of accessing and revealing the meaning of phenomenon. The phenomenon, the relationship between practitioners and families, provides what he describes as the "point of departure" (p.32) but phenomenology provides no prescribed steps for research inquiry. The challenge for me is to engage in a process of inquiry that will provide access to the phenomenon while at the same time ensuring that the methodological processes are consistent with the tenets of phenomenology. As explained in the previous chapter phenomenological philosophy is grounded in the notion of reflexivity (Grondin, 1994). The reflexive nature of the 'doing' of this study is incorporated within my research method. In this chapter I will show what I did and how the nature of the inquiry method evolved and changed as new understandings emerged.

Considering the context

Before embarking on this study I was aware of the vulnerability of the people I was asking to journey with me. New Zealand has a small population which is geographically widely spread. The number of children with chronic illness is estimated to be approximately 90,000, 11% of the total child population of New Zealand (Ministry of Health, 1998a). The number of specialist health care facilities for chronically ill children is small with only four paediatric specialist units across the country. Frequently the families of chronically ill children are well known to paediatric practitioners, as are the practitioners to families. The issue of maintaining the integrity of the participants' contribution to the study and at the same time protecting their anonymity and the family-practitioner relationship was a major issue to consider. In this study, I was examining an on-going relationship, not a relationship that started and ended with this study. The families needed to continue

to work with their practitioners and the practitioners with the families. As a practitioner myself I was aware of the vulnerability of the relationship and did not wish to do anything that would jeopardise its integrity. I knew that before undertaking this study I would need to work through issues such as anonymity until I was assured that I could undertake this study without impinging the relationship between families and practitioners.

I was also very aware of my vulnerability as researcher/practitioner. I had held a number of prominent clinical and leadership positions within one of the specialist paediatric units within New Zealand and although I had only a limited clinical practice at the time of starting this study, I recognised that the researcher/practitioner role could pose difficulties for me. I was aware that my previous positions within the health care service could cause confusion for some people as I moved from practitioner to researcher. I knew that, again because of the small population in New Zealand, there was a possibility that many of the practitioners referred to in the stories would be known to me. I recognised that it was going to be a challenge to balance my role as practitioner and colleague with that of researcher

In keeping with the reflexive stance of phenomenological research (M. Z. Cohen et al., 2000; Finlay, 2002) and, in an effort to resolve some of these issues, I decided to return to my practitioner colleagues and a small group of families of children with chronic illness with whom I was still practising. I discussed with them the study I wished to undertake. Together we wrestled with the impact of being a participant in such a study and particularly how the anonymity of participants would be maintained. We discussed the roles of practitioner, colleague and researcher and how I might deal with this. The way ahead did not always seem clear, however, throughout the discussion the resounding voice from both practitioners and families was that the experience of working together needed to be explored. I was amazed and humbled by the willingness of both families and practitioners to consider this an important enough study to not only actively encourage and support me, but also put themselves forward

or assist me in recruiting participants for the study. With this reassurance, it seemed there was no going back. The journey had begun.

Approval for the study:

New Zealand is a multi-cultural country and in considering my role as a Pakeha researcher I was aware that I may require assistance, support and cultural advice from the Maori and Pacific communities should participants identify themselves as belonging to these cultural groups. Prior to applying for approval for the study I therefore consulted with representatives of both these groups who endorsed my proposal and agreed to act as cultural advisers during the study. While the cultural advisers continued to maintain an interest in the project, no particular cultural issues arose and these advisers were not used during the study. One participating family group did identify themselves as Maori but indicated that they felt well supported during the study by their own whanau. My familiarity of practising within a bi-cultural environment also meant that I did not feel a need for additional support in my interactions with this family.

Ethical approval for the study was sought and granted by both the Auckland Ethics Committee (2000/217 October 2000) and the Auckland University of Technology Ethics Committee (01/02 April 2001). Four months into the study I recognised during the family interviews that dieticians were significant health professionals for families yet had not been included within my ethics application. I therefore returned to the approving ethics committees for approval to include dieticians. This was granted and amendment was added to the original application by the Auckland Ethics Committee (1st October 2001) and the Auckland University of Technology Ethics committee (27th September 2001).

Selection of the participants

Because I set out to explore the experience of working together from the perspective of both families and practitioners, two groups of participants were required. These included: practitioners who worked with families, who had a child with a chronic illness and families who had, within their membership, a child with a chronic illness.

Deciding to use the family unit as participant

I decided that rather than use individual family members as participants I would use the family unit in this study. I was influenced by three factors; (1) the nature of chronic illness in childhood (2) current child health care philosophies and practices and (3) the principals of phenomenological research.

The nature of chronic illness in childhood

Having a child with a chronic illness becomes a family affair. The interdependent nature of children and their family members is magnified when the child has a chronic illness. Because of the constant and complex care requirements of the child, care-giving duties are often shared quite widely amongst family members. Families of children with chronic illness are much more dependent on wider social organisations, especially health care services, to support them. This means that they must develop multiple relationships with health professionals and health care providers. This relationship between family and health professional is rarely conducted between one family member. As care-giving duties change so too do the family members who may find themselves in relationship with a health professional. There is a constantly moving interaction between health professionals, individual family members and the family. A number of studies have reported the influence of chronic illness on the family and its individual members. It is now recognised that children with chronic illness can only be considered within the context of their family (Holaday, 1989). It had also been my experience during a previous study (Dickinson, 1997), that if the mother is the only informant, there are some experiences that cannot be fully explored because another family member takes over the care of the child

during particular incidents. I believed the presence of a wider group of family members would allow a richer family description of the incident.

Another influencing factor was the lack of family perspective present in the current research regarding chronically ill children and their families. Many studies assume that the views of a single family member represent the views of the whole family. Often the views of siblings, fathers and particularly children are ignored or inferred (Hogan, Etz, & Tudge, 1999; Holaday, 1989; Sartain, Clarke, & Heyman, 2000; Whall & Fawcett, 1991). Hogan, Etz and Tudge (1999) note that the majority of research is carried out on adults as the primary source of information. They suggest that children are frequently viewed "as "becomings" rather than "beings" and this view minimises the contribution that children can make to the research study (Hogan et al., 1999, p.97) . Sartain (2000) also notes that few nurse researchers conducting research within the paediatric settings consider children to be active users of the service instead viewing them as passive recipients. I believed the family group interview would provide an opportunity for all family members including the children to contribute to the research study.

Current child healthcare philosophy and practice:
The relationship between family and health professional occurs within the wider context of the health care service. Because phenomenological inquiry requires consideration of the experience within the context of the wider environment it seemed appropriate that before deciding on a data collection approach, I should consider the prevailing child health care philosophies and practices. As discussed in chapter one, the most frequently posited philosophy of care referred to in child health care settings is that of 'family centred care'. While there is debate regarding whether this philosophy is actually understood or practised by health professionals (Ahmann & Johnson, 2000; Coyne, 1996; Hutchfield, 1999), nearly all strategic documents relating to child health care services in New Zealand refer to this philosophy in one form or other (Ministry of Health, 1998a, 1998b). It is clear that the family, rather than just the child, is believed to be the focus of child health care services. If this

research study was to remain situated within the context of the experience it seemed only appropriate that I consider the family as the participant.

The principals of the phenomenological inquiry

The third aspect considered before deciding to use the family unit rather than individual family members was the fit with a phenomenological inquiry. Phenomenology seeks to come to an understanding of the meaning and nature of 'being'. The aim is to come to an interpretive description of an experience which Heidegger (1925), describes as a "mode of encounter of the entities in themselves such as they show themselves" (Heidegger, 1925, p.81). Not only must the experience be described but also meanings that may be hidden in the everydayness of the experience need to be uncovered. In this study, the focus is on the experience of the family being in relationship with health professionals. This relationship, as has already been noted, does not occur outside or separate to family life. It is an integral part of the experience of being a family of a child with a chronic illness. Kellett (1997) and Plager (1994) both showed the importance of the contextual issues as they related to how a family participates in health care settings. The experience of interacting with health professionals and the health care system brings the family to a shared understanding of the experience and it was this shared understanding that I wished to capture in the study. Webb and Kevern (2001) argue that a group interview is incompatible with phenomenological research. They state that phenomenology is an individualistic approach where data must be collected in an "uncontaminated" way. Differentiating between a focus group interview and a family interview is therefore important. Unlike the focus group interview, a family group interview involves a group of people already closely tied by emotional bonds who are sharing the same everyday experience (Astedt-Kurki & Hopia, 1996). This means that families are already contaminated with their everyday experience of being together as a family. They will have already shared and discussed the experience of interacting with health professionals and in doing so, while there may be some diversity amongst family members, the family will have developed a shared view of the experience. Several studies have clearly demonstrated that this is indeed the case

(Astedt-Kurki & Hopia, 1996; Knafl & Zoeller, 2000; Racher, Kaufert, & Havens, 2000). I believe that that the family group interview is compatible with phenomenological enquiry and is the most appropriate entry point to the experience.

Individual versus Focus group interviews for practitioners.

Having decided to use family group interviews, why did I decide to stay with individual interviews for the practitioner participants? As a nurse in this area I was very aware that I was asking practitioners to share a very intimate part of their practice. Being a participant in this study would require them to discuss relationships that were usually hidden from the gaze and scrutiny of their colleagues. Because I wanted to collect stories that reflected the reality of their experience I needed to create an environment which was safe and comfortable. Again, using my own experience and the early discussions with colleagues about the study, I decided that a private individual interview would provide a comfortable environment in which practitioners could share their stories without having to expose themselves to the scrutiny of their colleagues. I also recognised that the encounter between families and practitioners is most often made on an individual basis. While more than one family member may be present only very occasionally is more than one practitioner present during the interaction.

I believed that by selecting family groups and a range of professionals from various disciplines I would not only capture the experience from a number of perspectives, but in keeping with the trustworthiness criteria of understandability and appreciability (see p.102), allow many voices to be heard within the study.

Recruiting the participants

Participants were recruited through professional networks. I visited a number of professional meetings and introduced the study to practitioners. During the meeting, information sheets (Appendix 1,2) were distributed and questions answered. Several practitioners also offered to distribute information sheets to families whom they felt may be interested in participating or to parent support networks with whom they had

contact. It was agreed that participants could either contact me directly or, if they preferred, give permission to a practitioner or colleague to pass their contact details on to me. On receiving potential participants contact details I would telephone them to discuss the study. In most cases potential participants had heard about the study but had not received or had mislaid the information sheet. For this reason at first contact I would post another information sheet to them and make arrangements for a follow up phone call several days later. I also offered to visit at a time convenient to discuss the research project prior to arranging an interview time.

In the case of family participants, I choose to make the follow-up phone call in the evening or weekend. A number of researchers who have used family group interviews suggest that, because the approach is usually made through one family member, the researcher is reliant on that person to relay information about the study (Astedt-Kurki & Hopia, 1996; Moriarty, 1990). This might result in the individual family member through whom the approach is made choosing to exclude family members. In an attempt to minimise this 'filtering', I telephoned at times most likely to capture more than one family member at home. Each of the participants approached at the follow up telephone call declined the offer of a discussion with me, but all clarified that opportunity would be given for individual family members to withdraw from the interview at any time. In most instances it appeared that the family had already decided who would be present and why. The reason most often given in relation to a member's absence was that the child was too young or the family member had minimal contact with practitioners. The child's father or younger children in the family were the most likely to be excluded or chose not to participate. Once a participant had agreed to participate in the study an interview time and venue was arranged.

Consent, Confidentiality and Anonymity

Prior to each interview, written consent was obtained from each participant (Appendix 3,4). In the case of the family group written consent was gained from each individual member of the family including children. If the child was developmentally unable to give written consent the parent or legal guardian granted consent on behalf of the child. It was agreed that the participants might use identifying names during the audiotaping of the interview, as it was easier to tell the story, however any identifying names or words would be removed from the transcript or a pseudonym applied. The crafted stories (Appendix 5) and the parts of the transcript from which they have been developed were returned to the participants for review at which time they could delete or amend any parts of the data.

Transcript codes known only to my supervisors and myself were assigned to all audiotapes and transcripts that were stored in a locked cabinet. All computer files were password protected.

The study participants

The study participants represented the wide range of professions and families who work together in the care of chronically ill children. As discussed earlier, the population is small and easily identifiable and, for this reason, a description of each participant will not be offered. Instead a description of each group will be given instead.

Ten family groups agreed to participate in the study. They were representative of families in New Zealand who have children with chronic illness. The children had a wide range of illness including, respiratory disease, diabetes, cardiac disease, neurological and gastrointestinal conditions and cancer. Eight of the families lived in urban areas and two in rural areas. One family identified themselves as Maori and all

other family groups identified themselves as Pakeha. The children and families managed a range of medical technologies in the home including, tracheotomies, gastrostomies, enteral feeding, central venous lines, oxygen and medication administration. The children affected by the illness ranged in age from 9 months to 14 years and the families' experience of working with practitioners in regard to chronic illness ranged from 9 months to 11 years. The practitioners that the families had most frequent contact with included, doctors, nurses, physiotherapists, dieticians and speech language therapists both in the hospital and community settings. Not all members of family agreed to be included in the study. The family groups consists of:

- 3 family groups with both parents and children
- 3 family groups with one parent and the affected child
- 1 family group with both parents
- 3 interviews with one parent

Twelve practitioners agreed to participate in the study. The practitioner group was representative of the practitioners which the families identified as being those they worked with most. For ethical reasons no attempt was made to match families with practitioners. There was, however, one occasion during the course of the interview that I recognised the story a practitioner whom I had also interviewed. I felt able to include this family because the practitioner concerned had not referred to this particular family during the interview.

The practitioner group included five nurses, two doctors, two physiotherapists, two dieticians, and one speech language therapist. The practitioners worked in both hospital and community settings and worked both within secondary and tertiary child health care services. With the exception of one nurse, all of the practitioners had been working with families with chronic illness over a number of years.

Were there sufficient participants? While I had ethical approval to recruit up to 30 participants for this study, there came a point in the research process when I believed I had enough data. Morse (2000) describes how sample size within a qualitative

study is not only determined by the scope and nature of the study but also the quality of the data. As I watched the growing pile of rich and powerful stories so willingly shared I felt it was time to move forward. I felt intensely the responsibility toward the stories to which I had been entrusted, and did not want to devalue them by having insufficient time to give them the depth of analysis they deserved. While there is no doubt that more interviews would have added to the diversity and richness of this study, I came to a point where I believe I had more than sufficient data which captured the experience from both the perspective of practitioner and family.

The other question that arose was did my participants reflect the diverse nature of practitioner family relationships? While I believe the participant group is representative in relation to the professional disciplines, family types, geographical location and the range of chronic illness children suffer, it does not reflect the ethnic diversity of New Zealand's population. Despite a number of attempts to do so I was unable to recruit a family from the Pacific Island population; this despite the fact Pacific Island children are over represented in relation to many of the chronic illnesses (Ministry of Health, 1998a). While the stories of the Pacific People are often reflected in the practitioner data, I am aware that this is an interpretation through Pakeha minds. I bring this study forward knowing that not all the voices have been heard. There are more stories to tell, another study for another time.

Collecting the data

The purpose of a phenomenological interview is to provide a way of gathering experiential descriptions of the experience. These descriptions need to be, as various other researchers have described, rich, deep and thick and to do this the researcher needs to develop a conversational relation with those being interviewed (Benner, 1994; Gehart, Ratliff, & Lyle, 2001; van Manen, 1990).

The family group interviews:

With the exception of one family group interview, which was conducted at the workplace, all interviews were conducted in the family home. Interviewing families together in their own home allowed me to develop a conversational dialogue within a comfortable and natural setting. This was the environment in which families had already shared their stories of working with health professionals and in many instances the environment in which the relationship had taken place. Having other family members present and participating together enabled me to gain further glimpses into what it is to be a family of a child with a chronic illness and added richness to the experiential descriptions gathered. I discovered that family group interviews require a reasonable amount of skill to keep the discussion focused, manage disagreement and ensure that all family members have an opportunity to contribute. The interview was largely unstructured. I opened interviews by asking each family to describe a time when a relationship with a health professional had gone really well. I was then usually able to follow the lead of the family and only occasionally had to prompt them to uncover stories of the everyday relationships and perhaps times when relationships were difficult. Although I had experienced working with family groups in the practice setting, the interviews posed some challenges. One of these challenges was coping with several family members telling the same story. Most interviews developed into a pattern of one family member starting a story that was then added to embellished or corrected by other family members. For many families this was the first opportunity they had had to share their experience with someone together as a family. They became quite excited and enthusiastic about telling it together. I often found it a challenge keeping up with the story and ensuring that important issues were clarified. There was a fine balance between allowing a story to flow and interrupting to seek clarity. I was aware that if I entered the story too early the story might be lost, however non-interrupted story telling could mean that some meanings were not fully explored. As I knew that there was within the research design the possibility of conducting a second interview, I usually let the family story flow with minimal interruption.

Another challenging issue was the presence of children within the interview. Because I wanted children to contribute their stories, families were actively encouraged to allow the children to be present during the interviews. Four of the ten families interviewed had children present and these children ranged in age from 4 to 14 years. The other six families chose not to have the children present either because the child was very young (under 2 years) or because the children were perceived by their parents to be too disruptive or would have little to offer. As a number of other researchers have noted there are considerable challenges to including children within family group interviews. It is often difficult, especially for younger children, to understand the research subject and express their feelings verbally (Astedt-Kurki & Hopia, 1996; Kennedy, Kools, & Krueger, 2001; Paavilainen & Astedt-Kurki, 1997). As a researcher one needs to be comfortable with working with children and have a repertoire of child friendly communication strategies. You must also be prepared to be flexible and patient in your approach to ensure the children's voices are heard. As a pediatric nurse I was very comfortable with conversing with children, however I also was humbled on one occasion by a 7-year-old who had to remind me that he and his 4-year-old sister had a story to tell into the tape recorder too. The subject area of the research study proved challenging for the children. In this study the younger children could relate more easily to certain environmental factors such as the presence of a television, favourite video or play activity which reflected their relationship with the health care environment rather than the relationship with people within the health care system. Children over 10 years of age, found it much easier to follow the research topic. This probably reflects their differing developmental and cognitive levels. The challenge of switching between modes of interviewing, that is interviewing adults and then children, also proved difficult at times. Another difficulty related to the eagerness with which adult family members tried to interpret the meaning or correct a child's story. Parents in particular tended to interrupt their children as they related their experience or to discount or redirect the story they were telling. I often had to diplomatically guide the family to reduce this interference and encourage the children to contribute. Astedt-Kurki, Paavilainen and Lehti (2001) have suggested that having a separate interview or part of the interview which

concentrates on the children may help overcome this problem, however I believe this would have placed even more pressure on the children, and moves away from the concept of the family group interview. Family group interviews took between 90-120 minutes and were frequently conducted alongside the everyday family tasks of feeding children, ministering treatments to the affected child answering telephones and organising family activities.

Practitioner interviews

Practitioner interviews occurred mostly in the workplace, however three practitioners chose to be interviewed at their home. In the case of the dietician participants it became difficult to arrange a time suitable for individual interviews so it was decided that they would be interviewed together. The practitioner interviews were generally much shorter, 45-60mins, and it often took longer to get the conversational dialogue under way. As with the families, the interviews were unstructured. I began by asking them to describe a relationship with a family that they felt was working really well. Practitioners looked for more direction in the way of interview questions and took more time to become relaxed about sharing stories from practice rather than analysing and rationalising how they practised. However I discovered that once I shared a story from my own practice as an example, they became more relaxed about sharing their own stories and the conversational dialogue was able to develop. My earlier concerns regarding the challenges of my role as researcher and colleague proved unwarranted and my participant colleagues appeared relaxed and comfortable with sharing their experiences. This was despite the fact that in most instances we would meet again in professional networks. In some instances the practitioners commented that my experience within their practice world assisted their participation within the interview.

Audio taping allowed me to immerse myself in the stories of the participants and be attentive and ready to seek clarification when necessary. However in most cases the interview environment was less than ideal for audio taping because of the noise and

disturbance. This reflected the reality of the participant's world and kept me close to the experience I was studying. Despite the noise and disturbance satisfactory audiotape recordings were obtained for all interviews by using two tape recorders strategically placed in different areas of the room. Following each interview I recorded some thoughts in regard to the interview environment, my observations and experience of the interview and any other details that I thought was pertinent to the interview.

Once completed the audio tapes were transcribed. While I did undertake some transcription myself most audio tapes were transcribed by a paid typist. This proved beneficial in that it allowed me more time to work with the data. Once the transcript was available I followed a process similar to that described by Caelli (2001). I began by reading the transcripts, identifying and marking the parts that described the relationship between practitioner and family and then using the participant's words wherever possible reconstructing the stories in a chronological and/or logical order. All of the transcripts contained several stories and to aid identification I gave each story a title (Appendix 5). These stories and the pieces of transcript from which they were drawn were sent back to the participants for verification, clarification, addition or if requested deletion from the study. Full transcripts were offered back to participants on request but I decided not to send these unless requested to lessen the burden of information I was asking the participants to review. The covering letter (Appendix 6) explained that if the stories were not returned within a eight week period this would indicate to me that they were comfortable with the stories being included in the data for the study. Of the ten family group interviews seven were returned with minor alterations, additions and in one case deletion of a story. Eight of the twelve practitioner transcripts were returned with minor alterations. None of the participants requested copies of the full transcript. The majority of the data collected contained participants stories of relationship however it was often difficult for participants not to include within these stories their interpretations of these experiences. These interpretations provided an important insight related to the

question of this research, and therefore the study includes some data that has more of a hermeneutic nature than phenomenological.

Having reviewed the data collected, I did not feel necessary to return for a second interview. While a second interview may had added richness and depth to the data I believed that I had captured a broad range of stories that clearly represented the relationship. I also was aware of the pressures on the time of my participants and did not wish to add to this by requesting a further interview unless absolutely necessary. However, I did have a telephone conversation with several participants clarifying how the data would be used. Several participants returned their stories with an accompanying letter to clarify some issues, but in the main they used this as a way of reiterating their continued support for the research project and the use of their data.

Working with the data

Once I had received the crafted stories back from the participants and made the requested adjustments I began to work with the stories, of each participant. I took each story and read and re-read, sometimes where phrases had been taken verbatim from the transcript listening to the audiotape, so that I could recapture the mood of the participants as they told the story.   As I read and listened I would reflect on what each story was about, what was it telling me about the relationship between practitioners and families, making notes at the end of each story to capture my tentative insights (see Appendix 7). I then read across different participant stories, looking for stories which had similar themes which I then grouped into what I called 'Clusters'. As I worked with each story new 'clusters' developed. Sometimes one story would fit within several clusters and so it was assigned to several cluster files. As I worked with the data, I made notes or drew visual diagrams in my research log about what I thought I may be uncovering. I also shared several groups of stories with my research supervisors to test my interpretation and the way in which I was working with the data. Over the ensuing months, I lived with my data, re-reading, rewriting, mapping, reorganising my clusters trying to uncover what van Manen

(1990) describes as the themes which have the "phenomenological power" (p.90). Initially I identified six themes that appeared to emerge from the participant's stories. I named these 'Being in the middle', 'Going Around', 'Making it work', 'Playing one off against another', 'Just a kid', 'Wanting to know' and 'Working together'. I began to write about these themes and, to check the trustworthiness of my interpretation. I presented these six themes with supporting data to group of practitioners and research colleagues. The critique, discussion and 'affirmatory nods', especially from the practitioners within the group, suggested that these six themes were supported within the data and worthy of further development. So I continued to write and rewrite around these themes discovering the power of writing and rewriting as a way of gaining phenomenological understanding (van Manen, 1990). Often the writing would take me down paths that appeared to lead me away from the experience of the relationship, or I would find myself lost in the detail of the story. When this happened I would walk away from the writing and give myself time for the thoughts to percolate and settle. Frequently it was during that time away from the data, as I walked the beach with the dog or spent time in the garden that new understanding came. During this time away from writing I kept my tape recorder close at hand so that I could capture my insights for later use. As I returned to my writing, I would reflect on my taped notes, sometimes mapping (see Appendix 8), at other times going directly to the writing. It was in this process of thinking, reflecting and writing that I would often discover the connection between parts and whole described by Gadamer (1982) and a new understanding would come. Through writing and reflecting that I discovered the interrelated nature of several themes, to the point where the "essential themes" (van Manen, 1990, p.107) emerged . These essential themes seemed to capture aspects of the relationship between family and practitioners that make it what it is. Thus three essential themes 'the web', 'being in-between' and 'going around' form the basis of the phenomenological description of the meaning of the relationship between practitioner and family and it is these that I will present in the following chapters.

A framework for trustworthiness:

Living through the experience of doing this research brought the daily challenge of "is what I am doing trustworthy?" Having examined a number of approaches taken by other phenomenological researchers, I decided against using trustworthiness criteria borrowed from the quantitative paradigm. I agree with other qualitative researchers that there are inherent dangers in using criteria and terminology from another paradigm of inquiry (M. Z. Cohen et al., 2000; Koch & Harrington, 1998). I have therefore selected, as more appropriate, the four criterion proposed by Annells (1999). To further increase the comprehensiveness of the framework I have also drawn on the work of other phenomenological researchers (M. Z. Cohen et al., 2000; Ironside & Diekelmann, 1998; Koch & Harrington, 1998; Sloan, 2002; Thorne, 1997; van Manen, 1997; Whittemore, Chase, & Mandle, 2001) .

Annells (1999) proposes four criteria for evaluating phenomenological research: is this an understandable and appreciable product? Is there an understandable process of inquiry? Is this a useful product? Is this an appropriate inquiry approach? Each of these became the basis for my trustworthiness framework.

Is this an understandable and appreciable product?

Annells (1999) uses this criterion to address the presentation of the findings. She suggests that the writing of the study needs to be understandable to both fellow researchers and clinicians in practice. To this criterion I have also added the four textual features described by van Manen (1997) as reflecting a good phenomenological text. Does the text have "lived thoroughness" (p.349) by placing the phenomenon concretely in the lifeworld so that the reader recognises it? Does the text have "evocation" (p.351) in that the text brings the experience vividly into the reader's presence, so that they can reflect on it? Does the text have "intensification" (p.353) with the words and silences being given their full value? Have I moved the words and silences beyond their everyday meaning to deepen meaning? Does the text have "tone" (p.357) to the extent that the words speak to the reader in a way that they are affected by it? I also believe like others (Ironside & Diekelmann, 1998; Koch &

Harrington, 1998; Whittemore et al., 2001) that if the report is to be appreciable and understandable my research must have within it many voices and not just that of the researcher. Throughout this report I have used the voices of my participants, other authors and myself to explore and describe the meaning of the relationship between practitioner and family. It is my hope that my text will allow recognition of the experience and move and challenge the reader.

Is there an understandable process of inquiry?

Annell's (1999) second criterion is met if the researcher can clearly show a "discernable trail of methodological decisions" (p.10). The report needs to show what I did, how I did it, and why I did it that way. This criterion should meet the representative credibility and analytic logic, described by (Thorne, 1997). The claims I make need to be consistent with the manner in which I studied the phenomenon and show the explicit reasoning from forestructure through to my interpretations and knowledge claims. It is within this chapter that much of this laying open of the research trail is contained. However, throughout the report, I have shown the reflective decision-making that accompanied each point of this research journey.

Is this a useful product?

In order to meet this criterion a research study must show that it has the potential to inform practice and benefit people receiving health care. Within this criteria I have included Thorne's (1997) criteria that the research has moral defensibility and disciplinary relevance in that it meets the pragmatic obligation that the findings can be considered "as if" they might be applied to practice. (p.124). Throughout this study I have remained constantly aware of the obligation to my professional colleagues and to the families to undertake a study which will provide benefit to both. This is reflected throughout the report in the decisions made about how to do the study, its interpretation and the implications for practice.

Is this an appropriate inquiry approach?

This criterion addresses the issue of whether the type of phenomenological approach I took is suitable and congruent with the questions I asked. Are the research procedures consistent with the phenomenological approach I took? Included within this must also be evidence of the reflexive stance inherent in all phenomenological work (M. Z. Cohen et al., 2000; Finlay, 2002; Koch & Harrington, 1998). I must not only declare my own pre-understandings but also show how I remained open and was challenged by new possibilities and new understandings throughout the study? The reader needs to see how my pre-understandings are revealed and the process of how I remained open to new possibilities and new understandings. The entire research report must reflect the inherent interconnection between the question, the philosophy, the method and the meanings uncovered.

In each chapter of this report I have attempted to meet each of these criteria for trustworthiness. However how can I prove that this study is trustworthy?   Cohen et.al. states that "ultimately, the findings of a hermeneutical phenomenological study can be judged only in the context of the intellectual discourse it joins and creates" (M. Z. Cohen et al., 2000, p.92). It is with this tension and uncertainty I present this research report.

My Family: by Beatrice Aged 4 years

Chapter 6

A web of relationships

"The realm of human affairs, strictly speaking, consists of the web of human relationships which exists wherever men live together."

(Arendt, 1998, p.183)

For families, entry into the world of chronic childhood illness is unplanned, uncertain and unexpected. The family has little control over when they embark on the journey, how and with whom they travel or where they are heading. All previous carefully laid plans, directions, hopes, and dreams must be reconsidered as the family embarks on a different way of being in the world. Families of children with chronic illness are suddenly thrown into a complex web of health practitioner relationships of which they have little experience and over which they have little control. Practitioners who decide to work with families of children with chronic illness also find themselves drawn, by the nature of their work, into this web of relationships. The management of chronic illness usually requires the knowledge and skills of multiple practitioners. All of the families in this study work regularly with at least four to five practitioners. For both practitioner and family the experience of working together involves working within the complexity of a web of practitioner/family relationships. While the web is flexible and supportive it is equally complex, fragile. The practice relationship exists in a dynamic world in which situations and relationships change constantly. Against such uncertainty, decisions and plans of care need to be made. Such 'is' the way of being in the world for both family and practitioner as they care for a child with a chronic illness.

This chapter will explore the complexities and contradictions inherent in the web of relationships. In much the same way as a spider constructs a web, each encounter weaves the strands into unique patterns, diverse connections which while often separate and fragile at the same time come together to provide amazing resiliency and strength for the family.

Being thrown into a web of relationships

When a family has a child diagnosed with a chronic illness, family and practitioners suddenly and unexpectedly find themselves thrown together into relationship with each other. It is not a relationship of their choosing, nor is it like any previous relationship they may have had:

> This relationship with health professionals is a forced relationship. You are forced into being in the company of people who you would not normally see socially.

> Allen Family
> Family A: 1:443

The Allen's reflect back upon their relationships with health professionals and recognise that they were forced or thrown into a relationship, which is not of their choosing. They cannot choose the practitioners with whom they work and recognise that they are forced by the circumstances of their child's illness to work with people whom they would not normally choose to relate. In contrast to professional relationships, social relationships are more enjoyable because they have chosen the company of people who share interests and with whom they can relax. From this family's perspective there is pleasure and ease of moving in and out of social relationships while health professional relationships involve the work of coming together and despite differences in style, personality and background forcing the relationship to work.

Practitioners also recognise that the circumstances of the child's illness means that the family is often thrown into a relationship with them. Brian recognises this when contrasting his work in the private and public health sector:

> In some ways it is easier in the private system because they come to you and they give you their complete trust because that is the nature of the

relationship. Whereas in the public system you are foisted on them. They can't say, "I want to go to Mr Nice Guy."

Brian
Dr B: 20:217

Brian recognises that when families come to him in his private practice they have, to some extent, chosen him as their practitioner. They have selected the relationship, trusting that this person will work with them and help them. While the child's illness has thrown them into having to develop relationships with health professionals, treatment within the private sector allows some families to maintain control over the web of relationships they develop. However for most families this is not an option and families must accept who has been "foisted" upon them. Both practitioners and families experience a loss of control, a sense of being sucked into a situation determined by others.

Families are often surprised that that they are constantly being thrown into new and unexpected relationships. Just as they think that they have settled into a new way of being in the world, they are suddenly and unexpectedly thrown again as the Davy family describe when they first took their son home from hospital:

It took me a while to warm to the idea of having community nurses come to visit me. I found their visits quite imposing when I first came home. I hadn't really expected Chris to be as sick as he was. I brought him home at 10 weeks and I thought well we have done our SCBU (Special Care Baby Unit) thing and now he is getting well I can look after him. I had brought up three other children and I thought I was quite capable of looking after him. I had brought them home and looked after them, it was a everyday sort of thing. I just felt that I wanted to be left alone to do it, I was ok. I hadn't expected to be visited by the community nurses, they were initially visiting everyday and just having them visit so often felt like an intrusion into our family.

Davy Family
Family D: 7:99

The visits of the home care nurses were unexpected and the family feels thrown yet again into a new situation, a new web of relationships. The Davy family has little

option or choice in regard to the relationship with the home care nurses.   It is something that is imposed upon them. In this situation the family is expected to accept the relationships thrust upon them by other health professionals. The family are presented with relationships that they have neither sought nor been consulted about.   The circumstances of their child's illness and the actions of health professionals are throwing them yet again into a new way of being in the world. During the interviews, as each family told their stories, I sensed their frustration at the rather paternalistic actions of the practitioners. It appeared that from the family's perspective, it was the practitioners who determined what services and relationships the family required, without any negotiation or consultation in regard to what was being offered and how it might fit with family life.   It appeared that health professionals often contributed to the rather violent and turbulent nature of the throw as the family entered each new phase of their child's illness trajectory.

Heidegger (1996) describes this "thrownness" as a mode of being in the world. He suggests that we are constantly being thrown or "delivered over" (p.127) to the world. It is a mode of being over which we have no control and in which we constantly move. Suddenly the family find themselves bounced between a number of opinions and recommendations as to how their child's care should be managed:

> We often were dealing with the phenomenal number of people. In the beginning we had six different health professionals visiting the home and then there was the GP[10] (General Practitioner) which made seven, seven health professionals altogether. I found it really difficult because of the conflicting advice we often received. I was quite surprised by the lack of understanding some disciplines had for the other when considering an issue. I found it quite bizarre that you could have a group of people looking at the same symptoms and coming to completely different conclusions and suggestions as to what to do.
>
> Gordon Family
> Family G: 13:158

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[10] The family doctor

The Gordon family have been thrown into a number of relationships with health professionals with whom they must deal, not only in the hospital and clinic setting, but also in their own home. Suddenly the previously small family network that offered opinions and advice on their child rearing practices has expanded to include a vast array of health professionals. They are surprised and confused by inconsistencies and conflicting advice.

Arendt (1998) suggests that it is part of the human condition to fall into a already existing "web of human relationships" (p.184) and that this web has within it "innumerable, conflicting wills and intentions" (p.184). Families of a child with chronic illness find themselves in a usually well established web of health professional relationships and yet, as Arendt suggests, there is an "intangible quality" (p.182) about what happens within the web as each person enters. As each person enters a new process is started a new web is formed from which Arendt (1998) suggests emerges "the unique life stories of those with whom he [the family] comes into contact" (p.184). So, while there is a sense that each practitioner/family web is thrown together, in the whirling motion or the weaving of the threads a new and unique story emerges for each participant. This is certainly evident within the stories given to me as part of this study. Each story is unique, each web of relationship different. It is this unpredictability, complexity and intangibility, which challenges both practitioners and families as they work together.

For the sake of the child

What is it that draws families and practitioners into this web of relationships? Why do they persist in working together despite the uncertainties, tensions and complexities? The overriding driver for both families and practitioners is the needs of the child.

Both practitioners and families describe how they make the relationships work for the sake of the child, even if in the process of working with each other relationships become uncomfortable or difficult to manage as Evans family describe:

> We decided right from the beginning that we didn't really care if we pissed somebody off. We wanted to make sure that we didn't regret anything we did in relation to our daughter's treatment. As long as we were doing a good job and doing the right thing nothing else mattered. Because when you look at it you know that you are not aiming to become bosom buddies with the health professionals. They are there to do a job. You are not setting out to make

them a life long friend. You are there for your daughter that was our primary objective. We would not be distracted from that.

Evans Family
Family E: 10:534

The Evan's family decide that while the circumstances of their daughters illness has thrown them into their web of relationships that is not of their choosing they will ensure that these relationships work for the sake of their daughter. They, like many families, have their daughter's interests as central to any relationships they have with practitioners. If the relationship does not assist them in "doing a good job" in managing their daughter's illness they are willing to upset practitioners to get the relationship they need. They make it work because they need to be sure they get it "right" for their child's sake.

Practitioners also describe how they work within this web of relationships for the sake of the child. However practitioners emphasise the added professional and legal tension of determining what is in the best interest of the child and who decides. For the practitioner the consequences of the relationship not working and finding themselves in the position of having to make professional and legal judgements on behalf of the child adds to the tension. Several of the practitioners in this study describe this tension and the difficulties which might arise when they are unable to make it work. Clare's story is typical of practitioners riding this tension:

> There is one particular family I am working with at the moment where it is very difficult to know where to go next. The family is a large Pacific Island family. The oldest child was diagnosed with diabetes sometime back and I followed her through until she was a teenager and went on to the adolescent clinic. She never had very good control of her diabetes and now has eye and kidney disease. Just after this child moved off the service her younger sister was diagnosed with diabetes and she also has really poor control of her diabetes. She hasn't been admitted to hospital as much as her sister, but she probably has the worst control out of all of children who come to clinic. It is really difficult to pin point what is going on. We have had someone give her injections but we still can't work out what is going on. We have brought in the Pacific Island support team to work with the family but we are still not getting anywhere. We have tried to tell her and her family that if we don't

improve things she will end up with kidney and eye disease like her sister, but even that does not seem to change things. I think the problem is that there is just too much happening in this family. It is just too hard to organise all the children and supervise them all. I know myself having a child you've got to balance your priorities. I think for some reason diabetes is not a priority for this family. I think they just accept that she has diabetes and that she will be sick. They allow her to take on the sick role and are not motivated to improve things. It is really hard to know where we go from here. The next step is probably to refer her to child protection services as the long term health of the child is at stake but that is a hard call to make when you can't definitely say this child will die without better management.

Clare
Nurse C: 9:442

Clare wants to make the relationship work with the family because she recognises the risks to the child if the family do not manage the diabetes well. She knows that if she does not make the relationship work she will be forced to make a professional judgement for the child's sake, which will have long-term consequences for the family and her relationship with them. Bringing in child protection services seems to declare to practitioners their lack of success in making the relationship work. Perhaps practitioners know that once child protection services are involved it becomes difficult for them to have an effective relationship with the family. They realise that such judgement, often against the family, may adversely affect the maintenance of an effective working relationship. Families and practitioners are therefore drawn into the web for the sake of the child and will do whatever is necessary to make the relationship work.

Heidegger (1996) suggests that our "potentiality-for-being for the sake of which" is one of the fundamental ways of "being-in-the-world" (p.181) or as King (1964) states "for the sake of is the fundamental character of existence" (p.42). It is in the throw "for the sake of" which allows us not only to understand our being as it is now but also to project ourselves forward to future possibilities. While some have interpreted this notion of Heidegger's as having goals (Guignon, 1983) or aims (King, 1964) I do not believe this captures the complexity of being in the world according to Heidegger. I agree with Dreyfus (1991) that it is not as simplistic as being goal driven. The goal

may be the welfare of the child but this alone does not capture the complex interrelationship of existing for the sake of the child.   Rather, as Dreyfus (1991) suggests, existing for the sake of "informs and orders" (p.93) our way of being in the world. It is the 'for the sake of' which that brings practitioners and families together 'in-order-to' (Heidegger, 1996, p.333) not only understand what is happening now but also what has gone before and what is possible for the child and family.   In the stories of the Evans family and Clare it is for the sake of the child that allows them to interpret and operate within their roles and relationships as parents and nurse. It is for the sake of the child that the web is woven. The child is central to a web of family and practitioner relationships, which form in the context of chronic illness.

The child within the web

Given that the relationship between families and practitioners is for the sake of the child, it would seem logical to assume that the child would be an integral and central part of the relationships between family and practitioner. However paradoxically, the stories from the participants suggest that the child is more 'presence' than 'present' in the relationship.

In most of the relationships in this study the child is excluded because practitioners and, in some instances, family members fail to acknowledge the child's presence. Even when children are included, their participation is believed to have less value or authority.   Families often appear surprised and pleased when the practitioner acknowledges the child's presence.   It is as if this was an unexpected event, something that was not part of their everyday experience of working with practitioners.   Much more commonly families can recall situations where practitioners visited and completely ignored the child's presence as the Kirk family recall:

> Doctor N is just wonderful…she has got so much warmth, when she leaves your room she acknowledges Nathan, she will touch him and talk to him like a child. Whereas other doctors who will walk in don't even look at Nathan.
>
> Kirk Family
> Family K: 17:423

For the Kirk family, Doctor N's behaviour towards the child is unusual, not something they have come to expect of the doctors who visit their son. Doctor N acknowledges the child. She reaches out and touches him. She speaks to him and recognises him as part of her relationship with the family. Other doctors are remote. They keep their distance and do not look at their son. It is as if he does not exist. The focus of their discussion is for the sake of Nathan, and yet he is not there. Candib (1995) suggests that separateness continues to underlie doctors views of caring despite a new appreciation of the patients experience. However it was not just the doctors who were referred to in this way by the families in this study. Families also told stories where dieticians, nurses and physiotherapists maintained their distance from the child. It is interesting that even during the process of interviewing, the importance to families of including the child came through. In families where children were not present during the interview I often began the interview by inquiring after the child and families eagerly seized on the opportunity to introduce their children to me. They did this either by taking me into the room where the child was sleeping or by bringing me photos to view. It appeared to be an unexpected pleasure, rather than something they expected in their relationship with practitioners.

Older children in this study related this lack of acknowledgement to the fact that practitioners and occasionally their parents perceive their opinion or inclusion as having little value. As Lynda explained:

> I find that many doctors just treat me like a kid, as if I don't know anything and it is not like that! … They treat me like I don't know anything and they don't involve me in what is happening. They just talk to my parents and they don't tell me what is happening.

Lynda
Family J: 18:119

The perceived incompetence of children to participate in their health care or in other aspects of their lives within society has been reported as a major issue for children in our society (Angst & Deatrick, 1996; Bircher, 2000; Sartain et al., 2000; Smith & Taylor, 2000; Tapp, 1998). Despite United Nations (United Nations, 1989) conventions which specifically state the child's right to be heard in matters which affect them, society continues to exclude them from participating in relationships which affect their lives often because they are not believed to be sufficiently competent to participate. As Sartain (2000) suggests "contemporary society makes a value judgement to the relative worth of knowledge and the adult 'non confused' person has the dominant voice" (p.920).

Certainly the stories of the children in this study would concur with Smith and Taylor's (2000) view that, in New Zealand society, children's voices lack "elevated status and when ascertained are usually overlaid with adult gloss" (p.13). The children in this study told a number of stories that showed that even when they do get the attention of the practitioners, they are interrupted and unable to tell their full story.

> When I talk to dieticians and start to tell them what has been going on and what I have been eating they cut me off and say "but you should not be eating some of this."

Erin
Family F: 4:513

Erin is frustrated because the dieticians do not listen to her perspective. They jump to conclusions. They anticipate what she is going to say and cut off her conversations. Like other children in this study, Erin believes that the practitioners find little value in her contribution to the relationship. She is 'just a kid.' Her opinion is not valued, and therefore she finds it difficult to be heard. While the children in this study related this experience to their relationships with practitioners it was interesting to observe during the interviews similar experiences for children within their family. Often as children began to tell me their story their parents would interrupt or stop the story-telling because they believed the child was 'being silly' or not accurately recalling the situation. Being 'cut off' or having adults 'leaping in' appears to be part of the everyday world of being a child with a chronic illness.

Heidegger (1996) suggests that "leaping in" is one of the two extreme possibilities of caring for someone. When we leap in we take care of the other but in doing so the other person is 'displaced' (p.114) with the person leaping in dominating while the person being cared for becomes dependent. Care is taken away from the person. From Heidegger's (1996) perspective this is an inauthentic way of caring, but is a very common everyday way of being in the world. Certainly, from Erin's perspective, the dietician is 'leaping in' taking care away from her. Erin feels dominated and displaced. Like many of the children even when she attempts to enter the relationship she finds her entry cut off by the adults around her. The alternative possibility according to Heidegger (1996) is to 'leap ahead' (p.114) and, rather than take care away from the person, work with them and help them see what is possible. Erin was able to show this contrast in the relationship with her new dietician:

> I have a new dietician who I really like. She listens to me and doesn't
> interrupt me when I am talking like the other dieticians. The new dietician
> doesn't do that. She listens to me tell her the whole thing and then will say
> something-nice back. She may say "oh you shouldn't be eating that" but she

says it in a nice way. She more often says "you should eat this" rather than always saying "you shouldn't eat that". She has a nicer way of speaking to me.

Erin
Family F: 11:225

In contrast to the dietician who was 'leaping in' a new dietician is willing to listen to her story and allows her time to tell the whole story uninterrupted. This dietician does not interrupt, make judgements or anticipate what Erin might want to say. She gives her the time to tell it in her own way in her own time. Erin feels comfortable in sharing honestly information about the food she is eating with the dietician, even if she knows that it is forbidden or discouraged. This dietician does not ignore these lapses in the diet but gently accepts the information and points out that this food is not acceptable. She 'leaps ahead' showing Erin the consequences and possibilities of her actions. She gives Erin back the control of her care. It is not so much the content of the dialogue rather how the dialogue is presented. Erin reflects that other dieticians have said the same thing but the tone, the mood of the conversation is different. Heidegger (1996) suggests that our mood is an integral part of being-in-the-world, we are thrown into the world in a mood which is always "directing oneself toward something" (p.129). For Heidgegger, moods are disclosive. They reveal something to us (Polt, 1999). The differing moods created by these two dieticians revealed to Erin the differing qualities of being in relationship with practitioners. However, in this study, it was rare for children to describe adults working with them in this way. They mostly described situations where the adults around them 'leapt in' and took care away from them.

It was difficult to elicit sufficient data from the children to fully understand the isolating effect of being left out of the relationship. There is a suggestion that the child may feel frustrated, isolated, frightened and not cared about.   Children with chronic illness often face frightening and acute exacerbation of their illness and are reliant on the care and protection of adults. When children are isolated and ignored, they feel vulnerable, frightened and unprotected. This is exacerbated in hospital and

several of the families expressed concern about leaving their child in the care of health professionals because practitioners had not always responded to their child's call for help or recognised the child's expertise regarding their medication or treatment. The following story is a graphic and frightening example:

> *(Erin)*
> There was one time when I was in hospital and the doctors charted me the wrong dose of insulin. They said I was to have 10 (units) and 30 (units) but I said "no that is not right that is what I have in the morning". The nurse said "this is what is charted this is what you need to give". But I said, "I am not doing that much it will give me a hypo (hypoglycaemic attack)." Fortunately Mum came in.
>
> *(Erin's Mother)*
> Yes it was lucky that I just happened to be in at the time. I dread to think what would have happened if I hadn't been there, it would have been young patient versus medical profession. They assume because she was a young girl and that she didn't know what she needed.
>
> Ford Family
> Family F: 11:168

In this situation the nurse fails to listen to the young girl's pleas. Erin's knowledge about her medication is not valued or given any authority. No one is listening to her and Erin becomes frightened, because she is unable to control the situation. From this experience Erin realises that her voice will not be heard, and that she has no power or ability to advocate or protect herself. Even when children are able to prove the value of their knowledge about their condition, there are no guarantees that their opinion will be accepted. Children often describe situations where they watched practitioners caring for them fumble over feeding pumps, treatment regimes or medications rather than take the advice of the child who in most cases had been competently managing the treatment at home for many months:

> *(Lynda's mother)*
> The last time (Lynda) was in (the hospital) she was on nasogastric feeding so they (the nurses) had to crush all her pills, they didn't actually read the labels

and they were crushing up the slow release ones. You wonder if they do have the knowledge and if you weren't around what would happen. It doesn't make me feel very confident.

(Lynda)
I knew about my medication and at first they didn't listen to me but after a while they sort of had to.

Jones Family
Family J: 18:255

Lynda has to prove her competence to the nurses, and have this validated and supported by her mother before she is heard. Now, having proved the value of her knowledge, the nurses listen to her. Like many of the children in this study she has had to prove the value of her knowledge to get herself included within the relationship. The adult tendency to devalue and ignore the experience and knowledge of children in both practice and research settings has been described by several authors (Bircher, 2000; Hogan et al., 1999; Sallfors et al., 2002; Sartain et al., 2000). As Hogan, Etz and Tudge note "adult experiences have been equated with objective reality (i.e., affording relative certainty) while children's experiences have been seen as comparatively illusory and unreliable" (p.97).

Isolation and marginalisation of the children within family practitioner relationships raises a number of issues for families of children with chronic illness who must frequently entrust the care of their children to practitioners. It raises questions for the family such as, what will happen if the family is not there? Who will advocate for the child? Who will protect them? When practitioners fail to involve the child, the child and family become frightened and vulnerable. Families often gave this as the reason for remaining vigilant and, in many instances choosing to remain with the child or maintain control of the child's medication or treatment while they were in hospital. They are aware that such a decision is not always viewed positively by practitioners but know it is necessary for the protection and security of their children. The need for families to watch over or remain vigilant in the care of chronically ill children has

been described in other studies (Burke, Kauffmann, Costello, & Dillon, 1991; M. H. Cohen, 1993; Dickinson & Dignam, 2002; Gasquoine, 1996; Horner, 1997). While remaining vigilant has been related to the expert knowledge parents have about their child, in this study the failure of health professionals to acknowledge the expertise of the child also influences the families decision to remain vigilant.

There were times that the children in this study interpreted the fact that practitioners did not listen to them as a lack of care about them. As Erin explained:

> They think we are just kids and they can just give us medicine and we will be well in a couple of weeks. It seems to me they don't really care about us.
>
> Erin
> Family F: 11:513

Frequently children described their only interaction with practitioners as being a temperature recording, the administration of medication or clinical examination. The practitioners do things to them rather than engage with them or show an interest in what really matters to them. The children recognise the practitioners focus on their illness and treatment rather than what they as individuals think, feel or hope. Lynda expressed this when describing her relationship with the dietician:

> They seem more worried about the weight chart and that is not what matters. They keep telling me to eat lots but lots of people are skinner than me. I think it is just because I have this disease… She doesn't seem to understand why I can't eat. She just thinks, "oh she is not eating properly. We will make her eat properly by following this diet plan"
>
> Lynda
> Family J: 18:142

Lynda believes that the dietician sees her only as reflected in her weight chart. From Lynda's perspective the dietician does not appear to be interested in her as a person.

Her concerns and expectations in regard to her weight are not heard or acknowledged by the dieticians. Lynda's mother validates her daughter's view of her relationship with the dieticians and is concerned in regard to the impact it will have in the future:

> It is like Lynda is four years old and doesn't have a thought in her head. I am not sure if it is because they are so used to dealing with children that they forget that they actually getting older. It really worries me about how this will effect her in the future.
>
> Jones Family
> Family J: 18:142

Lynda's mother worries about how her daughter is going to learn to work with and negotiate her health care with health professionals in the future. As the children get older, families try to promote their children's capacity to manage their illness. The families know that it is important for their child's future survival that they have a good understanding of their illness and management and can articulate and negotiate their health care needs confidently with practitioners. However the behaviour of practitioners toward their children often does little to promote this independence or allow them to come into relationship with the practitioners involved in their care.

Buber (1970) suggests that being viewed as an "I-It" (p.56) describes a basic way of experiencing the world. According to Buber it is the nature of the world that people will often encounter each other in their "thinghood" (p.69) as things and processes that can be measured and described. The world is experienced objectively, something that we view but to which we do not relate. It is a way of being which means being isolated and detached from the other. The person contemplates the other "without any feeling" (p.80) and it is this that enables him/her to find order in the world. However Buber cautions that although we will return to this "I-It" world again and again, it is not the world in which we can remain because what appears to us in this world is unreliable and lacks "density" (p.83). To really encounter the world in all its fullness we must enter the world of the "I-You" and this can only be attained "through relation" (p.80). This is a world which comes toward us and touches us but

is only possible if the person is willing to reach out and "confront each other freely in a reciprocity that is not involved in or tainted by causality" (p.100). Buber proposes that we walk freely between the worlds of "I-It" and "I You" and in doing so may encounter the "I-Thou" a deep relational understanding of the other. Lynda encounters the dietician in an "I-It" world. It is not a world of relation. The dietician views her with detachment and uses language that objectifies her as a series of weight recordings. Lynda is not able to experience the world of relation or reciprocity with this practitioner and this probably reinforces her view that other practitioners do not value or care for her. Lynda's mothers concerns seem valid. If Lynda never encounters the world of "I-You" with a practitioner she will abandon any hope of being included within health care relationships.

While a few children were able to gain entry into the relationship by proving their expertise to the practitioners, most gained entry by calling attention to themselves by not co-operating with what the practitioner or parents wanted them to do. By refusing to co-operate they found that the practitioner was no longer able to ignore them, they had to listen. This became easier to do as the child got older however it was noted by parents of children as young as four years of age. Parents recognise that even younger children can assert some control over what they will tolerate from practitioners and gain entry into the relationship. While it could be argued that the protest of young children relates more to a primordial response rather than premeditated action, young children with chronic illness learn through repeated treatment experiences that they can be included in relationships. They learn that by directing their protests and actions in specific ways they can gain some control over their situation and at least get some acknowledgement of being part of the relationship. The mother of four year old Susan explains:

> Susan has become a real expert as well and can be quite assertive about whom she likes and what they can do. I find it quite hard when she is being a madam and having an off day and she just won't let anyone do anything. But she has her favourites (practitioners).

> Brown Family
> Family B: 4:762

This was not an easy situation for Susan's mother who was often left in the position of negotiating her daughters relationship with the practitioners but Susan's mother recognised that it was her daughter's way of making herself heard and of gaining some control over her situation. Even Peter, Susan's seven-year-old brother, noticed that Susan had to protest very loudly in order to be heard.

> When Susan goes to hospital she needs this thing put into her arm. It is this thing with a needle on the end and they give her medicine through it. Susan helps the nurses by holding the little bit while they give the medicine. She doesn't like that thing in her arm though because she goes "No! No!" when they are doing it.

> Peter
> Family B: 4:1160

Peter recognises that Susan cannot always control the things that are happening to her, but she is able to get the nurses attention by protesting loudly. The nurse then recognises that Susan is not just an object to which something must be done but that she is a person with whom she must interact and negotiate care. She moves from 'working on' Susan to 'working with' Susan. Unfortunately this study suggests that even as children get older they persist in using non co-operation as an effective way of gaining entry into the relationship.   However this becomes an increasingly frustrating and unsatisfactory way to engage with practitioners as Lynda explains:

It doesn't get any easier working with the dieticians, especially when I am sick. It is getting hard for them to make me do things. She can't make me do things but she really bugs me!

Lynda
Family J: 18:142

Lynda knows that in refusing to do the things the dietician asks she will gain some control over her situation. While the relationship remains frustrating and difficult, because of the dietician's failure to acknowledge her right to participate in the relationship, her resistance at least draws the dietician's attention toward her. However from Lynda's perspective it is a frustrating and unsatisfactory way to relate to a practitioner.

This suggests that the experience of working together within the web of relationships requires that not only is the voice of the 'other' heard, but also included as a valued strand within the web. Relationships cannot exist unless both parties recognise and respond to the call of the other. By listening, recognising and responding to the call of the other the door is now open for both parties to work together, to weave a supportive network of relationships which appreciates the unique perspective of the other.

Buber (2002) suggests that the only way to enter into a relationship or dialogue with another is to turn to the other. To "become aware" (p.25) that the person is not merely an object but someone who must be responded to. Levinas (2002) develops this further in his notion of the face to face encounter. For Levinas the 'face of the other' not only is presented to us but it appeals to us. In its expression it becomes more than a mere object but something which "offers itself to my understanding" (Levinas, 2002, p.515). The face of the other demands a response, or as Waldenfels (2002) interprets it is not just "something seen, observed registered, deciphered or understood, but rather somebody to be responded to" (p.69). Both Buber and Levinas argue that it is only when we become aware and turn to the face of the other that we

can enter into dialogue and come to understand each other. In relation to the nurse patient relationship, Berman (1994) suggests that it is the face which invites us into the being of the other. We see the other "at the threshold of the door" which "may be partially ajar, beckoning us to come to enter, to come to know the person more fully" (p.12). Perhaps, in their acts of defiance and protest, Susan and Lynda are presenting their 'face' to the nurse and dietician. While the nurse takes up what Levinas would call her responsibility to come to an understanding of the other in the face to face encounter, the dietician does nothing to cross this threshold.

Practitioners and families do however recognise the importance of acknowledging the child as the centre of the relationship between practitioner and families. All of the practitioners referred to the importance of including the child.

> One thing that I always try to do when I meet a family is to make sure that the first person that I say "hello" to is the child. I get down and play with them whenever I can even if they are disabled. I will do that first and then switch to the parent. Obviously that depends on how old the child is.
>
> Angela
> Dr A: 15:542

Angela appears to be suggesting that to include the child within the relationship requires a different approach, a different language and way of relating compared to the interaction she has with adult family members. The practitioner must be responsive and adapt their approach to the developmental needs and abilities of the child, switching from one way of relating to another. They must adapt their dialogue in a way that acknowledges the unique needs of each participant. Perhaps this is what makes including children in the relationship difficult for families and practitioners. How easy is it for practitioners to constantly adapt their approach to be inclusive of children? My experience, in both practice and research, suggests that, remembering to switch the nature of the dialogue to include both child and family takes considerable effort. Perhaps, because we have forgotten the experience of being and thinking like a child, we forget how to relate to children. As adults it is easier and

more natural to talk to adults. We have forgotten the language in much the same way that practitioners often forget the everyday language when talking in medical jargon to families. Including children within the web of relationships requires recognition of the language of childhood and the ability of practitioner and adult family members to move appropriately between different dialogues and ways of relating.

Gadamer (1982) suggests that language presupposes a common world. Our experience of the world is bound to language, and therefore we each have our own language. "Children and lovers likewise have "their" language, by which they communicate with each other in a world that belongs to them alone" (p.406). This notion of language reveals the complexity and tensions of trying to communicate across the different worlds of childhood and adulthood. While we may have all experienced childhood we no longer use the language of childhood yet this does not exclude us from communicating with children. In much the same way as Gadamer suggests we approach a foreign language, we need to re-learn the language of childhood. We can enter the child's world because, while it is foreign it still is related to us. By entering their world we can come to experience and understand the world from a new perspective. The important thing is to recognise the unique world of the child and be willing to enter and experience it even if that requires the effort of re-learning the language. Barbara, a physiotherapist, described how she is able to successfully achieve this with one family:

> I have this family with whom I have a real open and honest relationship. Shane is really close to his Mum but right from the start they have both asked lots of questions and been really keen to learn as much about the disease as they can. For example, when Shane was having blood tests to measure the inflammatory markers in his blood, he asked, "what is blood made up of?" To help them get all the information they needed I put them in touch with other families with the disease and shared my knowledge with them. Time, trust and clear explanations right from the start have meant that we have established a real open relationship with each other. Shane is quite clear what he likes and dislikes and very clear and concise about how he is feeling during treatment. He will tell you when he is in pain and you can adjust your

treatment accordingly, but you always know he is going to put all of his effort into it. So when he tells you he is in pain or says he is tired you know that he is really being honest and not just putting it on, so you know to stop or modify things. He sat himself up in bed today for the first time in a few months, and that was a huge effort, and he is really pleased with himself. We work together to keep him functional and set little goals that we know are achievable. It is a real team effort and I think it works because we have had time together and through honesty have gained trust in each other.

Barbara
Physiotherapist B: 8:42

In working with this family Barbara acknowledges Shane as a participant in the relationship and values his contribution. She recognises that Shane's observations and knowledge about his illness are important and incorporates these into the relationship. Barbara responds to his questions and his need, tailoring her response to his needs and abilities. She moves comfortably between working with his mother and working with him. Barbara recognises their individual needs and modifies her response accordingly. She moves easily between the two ways of relating. She takes time to listen to Shane's story, and avoids 'leaping in'. By adapting her treatment in response to Shane, she is involving him in his care and allows him some control of how and when treatment is given. By working with Shane and his family, Barbara creates an atmosphere that allows for free, open and honest exchange of views. She encourages family members to contribute their own unique story and weave threads that add to what Arendt (1998 p.182) would call the "intangible" and "unique" character of the web.

However stories like this were relatively rare in the data I collected. It is evident that although practitioner and family may claim that the child is central to the relationship, it is much more common for children to be excluded from the relationship. It is a strange paradox that a web of relationship that exists for the sake of the child often disenfranchises and marginalises the very people for whom the web is woven.

Flexible yet fragile

The web in which families and practitioners work is very fragile, and yet at the same time is sufficiently flexible to ensure that relationships remain intact. Occasionally families and practitioners identify relationships that could be severed but in most cases there is a reluctance to allow these connections to be lost. For families in particular there is the sense that they may have to return to relationships in the future and therefore the ability to maintain relationships is important.

The Kirk family has to be flexible in regard to how their family operates to maintain their relationship with their doctor:

> There was one particular doctor who I felt used to judge us a lot but now our relationship is good. For a time though it was difficult. Mum was caring for Nathan while I went to work so he was seeing both of us. It became really difficult and Nathan had a Tracheostomy so I decided to give up work and put my time into the kids. After that the relationship improved because he only had me to deal with. However it has taken me a long time to feel comfortable with him and he would make me feel very nervous. I would go along to see him and think "oh no, what am I going to say to him today".
>
> Kirk Family
> Family K: 17:282

This family recognises that the relationship with their doctor is not working. This practitioner seems unable to cope with the way the family has chosen to share the child's care between two family members. To make their relationship with the doctor work, the family changes their way of operating. Perhaps in doing so the family concurs with the doctor's expectations in regard to how the relationship should work. Yet the mother senses that the judgement lingers and the relationship remains tense and fragile.

Practitioners also describe situations in which they find themselves needing to be extremely flexible because of the fragility of the relationship. Brian recalls how he makes a relationship work with a family despite ongoing tensions and confrontations:

> For a while there it looked like they were going to go and see another doctor. But we have hung on through it and now they continue to see me with this little boy and the two subsequent children. I find that I have to 'jolly' this mother along a bit and be a bit more careful than I would be with other people because she has deep seated anxieties about her children. For example, with her third baby she was worried because it appeared that he might have a scoliosis. The mother and the Plunket Nurse became convinced that he had asymmetry so she asked me to have a look at him. I did take a look at him and told her that I thought it was just a normal deviation and that it would come right with time. I told her I would be happy to do a x-ray but that I was sure it would show no abnormality. I think that she had really decided at that time that he was another deformed baby. He is fine now and we have forgotten all about it, in fact we don't even mention it any more. I think the success of the relationship is that the family knows that I have accepted the mother's limitations. She is really hard work and they will always stay at least half an hour over the allotted time, which keeps other people waiting. They always make a point of emphasising that they can't afford to pay for private visits so I don't charge them any more for the extra time. I think I have compromised quite a lot, but we have got through it. The success of the relationship is that we have got through it together.
>
> Brian
> Dr B: 20:8

From Brian's perspective, he is maintaining the connection with the family by being flexible in how he approaches this relationship. He must "jolly them along" recognising the anxiety of the mother. Brian also recognises that this relationship will always take time and that he needs to accommodate this within his working day. The relationship remains fragile and is pushed and pulled by the demands and anxieties of the mother, however the doctor's flexible approach allows the fragile connections to remain intact and the relationship survives.

Candib (1995) suggests that flexibility is inherent in a caring relationship. She suggests that for practitioners to have an effective relationship with a patient they

must be prepared for the "come-what-may" (p.231). Candib suggests that to 'care-in-relation' the practitioner must accept that the relationship must sustain and include uncertainty and to do this flexibility is required. The tensions created by such flexibility are evident in the stories of the Kirk family and Brian as they balance the demands of practice and family. They twist and turn to maintain the relationship and it is easy for the connections to become stretched and broken. Families and practitioners, existing within the web appear to recognise the fragility of each encounter and use their flexibility to maintain the integrity of the connections.

Discovering the simplicity within the complexity of the web

The web of relationships, which exist around a child with chronic illness, is amazingly complex, and yet it is also profoundly simple. The simplicity lies in the quality of the interaction between family and practitioner. Families often describe how one relationship between practitioner and the family can provide the crucial link which enables them to negotiate the complex web of relationships within which they exist. For the Kirk family it is their relationship with the home care nurses:

> We have been very lucky with the home care nursing service. Initially they came to see us weekly and that was probably the main thing that kept me going in the beginning. They were like my safety net my protection in those early stages. They were wonderful in helping me deal with the equipment, telling me what to do if he got sick and what were the warning signs to look for. They were really good at giving you the information you needed and just being there to give you a bit of a pat on the back and say, "you are doing a good job".

> Kirk Family
> Family K: 17:57

For the Davy family their key relationship is with the social worker:

> She lifted a lot of burdens for us by organising carer support, disability allowances and all the other financial supports we needed to look after Chris. She has become that link person for us, putting us in touch with the resources

we need, co-ordinating people and generally keeping everything stable. Many of our friends ask us how we manage and I just say, " we have this really good social worker."

Davy Family
Family D: 7:132

Inherent in the complexity and diversity of the relationships the family must negotiate with various health care providers, is a simple relationship that provides stability, support and protection. Many of the participants in this study are able to describe the stabilising influence of the simple relationship within the complex world of chronic illness. For others, this was something they were still seeking:

The health service we worked with had a team approach. The theory is that everybody on the team looks after you. On our team there were six or eight doctors and when you go to clinic you could be seen by anyone of the doctors. The theory is that they all know your case and can look after you. Well from our point of view it doesn't work. It doesn't feel comfortable that every time you go to clinic you have to go through everything with the Doctor you are seeing. They may have read your file and have had a team meeting every Friday about your case but they are not really switched on to your child's particular illness. … What you need is continuity, having the same person who knows your whole background. Too many things slipped through the cracks. We felt we were the only ones with a whole view of our child's condition and treatment and it was up to us to ensure there were no mistakes and that's pretty scary.

Evans Family
Family E: 10:678

The Evans family is seeking that simple relationship, that one person who can provide the continuity and security they need. However the service that they are working with continues to maintain a complex network of relationships for the family to negotiate. For the family this poses the risk that things may fall between the "cracks" and mistakes will be made. It leaves the family feeling frightened and vulnerable.

It would appear that acceptance of the complexity and discovery of the simplicity within the world of chronic childhood illness is an important aspect of successful practitioner family relationships. As Arendt (1998) suggests a complex "web of human relationships exists wherever men live together" (p.184) however it is the words and actions of each practitioner and family member which allows each new life story to emerge. The Davy and Kirk family found the opportunity to navigate their complex web and produce their own 'story' in the simple relationship with one key practitioner. The complexity of the web remains but the simplicity of the relationship between practitioner and family allows the opportunity to set in place actions which supports the families and allows them to 'produce' their own story (Arendt, 1998). Many of the families and practitioners in this study had discovered this simplicity and were working well together. However, there were also those like the Evans family who were still trying to find the simple connections which would help them to negotiate the complex web of relationships into which the child's illness had thrown them.

Conclusion

When a child has chronic illness families and practitioners find themselves thrown together into a web of relationships 'for the sake of the child'. Paradoxically the child may be marginalised or excluded from relationship. Yet, like the spider, he or she is an integral part of the web. As they work together, families and practitioners weave together a complex and unique web of relationships to support and protect the child. It 'is' a way of being-in-the-world, and the way in which they must journey together. Working together within the web enables both families and practitioners to discover the tensions of fragility and flexibility, complexity and simplicity. They strive to make it work 'for the sake of the child'. Families and practitioners describe how they act both 'in-between' and 'going-around' in order to maintain the integrity of the web. These two ways of working within the web will be explored in the following chapters.

Chapter 7

Being In-between

On the narrow ridge, where I and Thou meet, there is the realm of 'between'.

(Buber, 2002, p.243)

As families and practitioners journey together within the complex web of relationships, they frequently describe the experience of being 'in-between' the various relationships they encounter. For practitioners this experience most frequently relates to being 'in-between' family and practitioner relationships, while for families it is often the experience of being 'in-between' individual practitioners. Both families and practitioners describe a number of different experiences including being in-between individual family members, individual practitioners, and child welfare or education services. Sometimes practitioners or family members take this position as a way of holding things together, while at other times it facilitates the dialogue and allows different perspectives to be heard. Occasionally being 'in-between' is used as a way of managing expectations or controlling access to information or services. It can be a position of extreme discomfort and tension, while at other times it provides comfort and protection.   The experience of being 'in-between' is dynamic, placing different demands and having different meanings for the individuals depending on the context and circumstance. Being 'in-between' reflects the diversity, complexity, simplicity, and fragility which both families and practitioners experience when working within the web of relationships which surrounds a child with a chronic illness. This chapter will describe the experience of being 'in-between'.

Being 'in-between' facilitating the Dialogue

Buber (2002) described his journey through life as walking on the "narrow ridge" (p.218). He uses the analogy of the 'narrow ridge' because he does not believe it as a comfortable middle ground but a "rocky ridge between gulfs where there is no sureness of expressible knowledge but the certainty of meeting what remains, undisclosed" (p. 218). It is a place where one stands open to extreme positions and prepared to embrace the contradictions of life. As Arnett (1986) explains this is an alternative to either/or; it is a philosophical stance which requires openness to contrary statements and the capacity to balance concerns for self with concerns for others. Buber does not see it as a neutral position, but as a place where having heard views from both sides. "We must make our stand on the narrow ridge, as a company of soldiers takes up its position on an embattled hill" (Hodes, 1972, p.70). It appears that the 'in-between' position for many practitioners and families requires them to walk this 'narrow ridge'. Sometimes as will be shown they are walking amidst conflict and tension, and other times facilitating the dialogue and understanding between the family and practitioners.

Brian describes a time when he had to walk this "narrow ridge" between the family and his medical colleagues. He was acting as primary paediatrician for a child with a condition that appeared to be showing signs of deterioration:

> When I saw the family for a six monthly review I asked them how their daughter was going. They said they were having a lot of difficulty working that out because the Neurosurgeon was saying one thing and the Oncologist something else. They said they weren't sure which was right and whether they were supposed to have a say in her management or not. I then asked them what had people told them about the long-term prognosis. The parents said they were too scared to ask the Oncologist. …..I suggested that we should all have a meeting together. I wrote to the Oncologist and said that I would like to organise a meeting and that we should try really hard to co-ordinate it so that the Neurosurgeon could be there as well. I said to the parents I was happy to come along and just sit in on the meeting and that is what I did. Apparently the Oncologist was very nervous about the meeting and when we arrived I discovered that he had a medical colleague with him for support. It

was actually a very constructive meeting and I think that was the best thing that could have happened for the family at that time. They were able to air their concerns and the Oncologist his. They were able to meet somewhere in the middle and I had a feeling that this Oncologist would now be their very best support. But it was a very good experience for me to go into a meeting without the information and my usual authority, and help the family to say that as parents they wanted some say in their child's management.

Brian
Dr B: 20:254

While being 'in-between' is not a familiar experience for Brian from the 'narrow ridge' he sees the confusion and uncertainty of the family in regard to their child's condition and management. By co-ordinating a meeting he embarks on a journey along the 'narrow ridge', facilitating the dialogue, listening to the concerns of both family and practitioners. It is in the dialogue that a new understanding, a new relationship emerges between practitioners and families. From the unfamiliar "in-between", without his usual specialist knowledge and authority, Brian is able to catch a glimpse of the relationship from the family perspective.

Donna, a home care nurse, also describes a situation akin to walking the 'narrow ridge' between family and dietician:

One day when I was visiting, I asked about how the baby was feeding and the mother became quite upset. She said that although this baby was her baby, she felt that she had no control. She felt that her life was governed by appointments and by what doctors, nurses and dieticians said. She felt that her whole life was being ruined and governed by health professionals, who she felt were more against her than for her. Her greatest problem at that time appeared to be her relationship with the dietician. She felt that the formula the dietician was insisting she gave her baby contained too much fat and that is why her baby was vomiting and losing weight. She had become quite frightened of the dietician and worried what her response would be when she saw that they baby had lost weight. The mother told me that she had already brought up one healthy child and that she knew how to feed her children, but the dietician was taking over her life and constantly undermining her ability as a mother. She felt the dietician was treating her as if she was stupid. Having become aware of the mother's distress I then talked with her about the things

we could do to make her feel better. I reminded her that this was her baby and not to forget that. …..That ultimately what happens is their decision. I suggested that one of the things we could do was to have a meeting with the dietician. I said that I could be there with her as her primary nurse or she could have anybody else she chose to support her. The mother decided the meeting would be a good idea and felt that she would be able to express herself within a supportive environment.   So I organised a meeting with the dietician. The dietician was really surprised that a meeting was required and wasn't initially happy with having a meeting. However I persuaded her that it was really important that she came and got alongside the family and just heard what they had to say. I told her that I thought it was important that we try and improve the working relationship between her and the family because I knew that it would be an important relationship but at the moment it was causing a lot of stress for the family. So she rather reluctantly agreed to attend.   It was quite a long meeting and the dietician wasn't really very forthcoming. However the parents did get the opportunity to get across to her that they didn't expect the child was ever going to make "old bones" but they felt that they were just forcing food down her and making her sick.   They told her that it was not only unpleasant for the baby but also for the family. They also said that they wanted to be given some credit for being able to look after their baby. The mother told her that she felt she could manage with some good common-sense and asked that the dietician to leave them alone to care for their daughter. And that is what happened. The parents took control and felt a lot better for it, and the child did well. The relationship between the Dietician and the family became quite distant. I think the dietician couldn't be bothered with them after the meeting. She removed herself basically because they didn't want to follow her advice. She wasn't very helpful anymore but the family seemed happy with that.

Donna
Nurse D: 14:68

Being 'in-between' provides a way of giving both family and dietician the opportunity to hear and listen to each other.   Donna moves between family and dietician.   It is a delicate balancing act, listening to the perspectives of family and dietician, managing the tension, trying to facilitate dialogue and understanding. As Buber (2002) suggests walking the 'narrow ridge' is uncomfortable because it requires exposing oneself to the conflicting views and tensions. It is a place from which one must ultimately take a stand. Donna does this as she fiercely defends the family's right to be heard and make decisions in regard to their baby's care. Although the outcome of the meeting does not strengthen the relationship between family and

dietician, it allows for the family's concerns to be heard, enabling them to move on, and gain control over their baby's care.

Asking Questions

Gadamer (1982) notes "we cannot have experiences without asking questions" (p.362). Questioning, or the desire to question, Gadamer suggests, presupposes knowledge that one does not know, "where the difficulty lies in knowing what one does not know" (p.365). This is the dilemma that confronts many families as they enter into the world of chronic childhood illness.

Practitioners frequently use the 'in-between' as a way of assisting and supporting the families in their questioning of practitioners:

> Sometimes, for whatever reason, the families may have difficulty asking the questions of the doctor so I will go along to the appointment with them. I would only attend an appointment with a family where I think it is crucial for the management and ongoing development of the child or where it is quite evident that the family doesn't feel empowered to ask the questions. When the doctor sees me coming along they usually know why I am there. But even when I am there I will try not to ask the questions for them. I will ask an open question of the parents "there are several questions you want to ask" and I will make sure they go through them all before we leave.
>
> Ann
> Speech Language Therapist: 19:337

Ann identifies times when questions need to be asked and answers given but recognises that families do not always have the confidence to ask their questions of the medical staff. Rather than taking over, 'leaping in' and asking the questions for the family, she works 'in-between' to support the families questioning during the clinic appointment. Ann appears to recognise the importance of questioning in establishing the dialogue between doctor and family. Her presence calls to the attention of the doctor the importance of the questions. Aware of the fast moving interactions of the clinic visit, from the 'in-between' Ann regulates the pace of the

interaction. She holds the doctor back and makes sure time is given for the questions and answers, facilitating the dialogue through questioning.

While Ann directly facilitates and supports the family in asking the questions, practitioners more frequently do this indirectly, by coaching the family prior to an appointment, allowing them to practice their questions, and/or assisting them with developing a question list. Nurses frequently describe themselves working in this way. As Clare explains:

> Often I have found families do not want to ring the cellphone for advice in the first instance. That may be because of the cost or the time of day but often I think it relates to the fact that they don't want to trouble the doctor unless it is necessary. So what they do is the ring me and ask me the question. They will often just be checking out that they are doing the right thing and they don't want to feel stupid by asking the doctor a silly question. The families often seem to feel they can use us in this way.
>
> Clare
> Nurse C: 9:510

Clare provides a safe, protected and non-judgmental environment to ask the question, to check it out, to prepare. She gives the family the confidence to ring the doctor or to ask the question on the ward round or clinic visit. Like Anne, Clare is able to use the 'in-between' to coach the family and empower them to confidently interact with the medical practitioners.

The Brown family describes the importance of the learning to question, a skill that they discovered developed with time:

> I have seen other parents since who have questioned and asked stuff like that but it is not until you get involved over a period of time that you have the ability to ask what is going on. Like why are we doing that? Asking questions is definitely something you get better at over time. I mean I still think I probably ask some pretty inane questions of the consultant at times but I am much more confident at asking. I often ask the nurses first. I find it easier to ask the nurses things and see what they know about it and even if

they can't answer the question they can give you a little bit more information so that when you ask the Consultant and you don't feel so stupid.

Brown Family
Family B: 4:446

Like many families, the Brown's worry about asking the "stupid" question, the question that they think may reflect on their lack of knowledge regarding their child's illness. However, using the 'in-between' position of the nurse, the family prepares and becomes more confident in their questioning of the consultant. Hodgkinson (2002) also described how mother's of children with cystic fibrosis appreciated the support of a nurse in facilitating their questioning.

The ability to ask questions, particularly of medical practitioners, is not easy for families. It appears to be a skill that develops over time. This perhaps reflects to some extent that the families often do not know the questions to ask. However it also reflects the families journey to discover what Gadamer (1982, p.367) calls "the art of questioning" voicing the further questions which lead to "real dialogue". For families, having a practitioner acting 'in-between' to facilitate and guide the questioning appears to support them in their ability to establish effective dialogue with practitioners.

Transmitting information

Sometimes it is not the questions that pose the difficulty for families but rather their ability to transmit important information about their child's condition and treatment to other people. Families appreciate the support of practitioners who assist them in this task, especially early on in the child's illness. Clare, a Diabetes Nurse Specialist, describes how when working with families of children with newly diagnosed diabetes she often acts 'in-between' transmitting information between the family and the school.

When a child has diabetes the families really worry about them starting school, especially if the child is newly diagnosed or just turning five. The parents are just learning about diabetes themselves and they worry about how the teachers will manage and how they as the parents will advise them to look after their child. … Families often have quite unrealistic expectations of what they can expect from the school so I ask them to put themselves in the shoes of the teachers and remember back to when they first found out about diabetes. I remind them they didn't know everything and had to learn so they need to give the school time to learn what to do. You need to get the parents to acknowledge that it is a stressful time for the school staff as well… As the nurses involved we are available to go and talk to the teachers, and that is often quite reassuring for the family. We usually do it with the parents present so they know what was said and the staff at the school can identify the child and parent. … I think it is quite a relief to the parents that we talk to the school as particularly if the child is just diagnosed it takes the pressure off them to share all the knowledge they have just learnt about diabetes.

Clare
Nurse C: 9:306

From 'in-between' Clare not only transmits information for the family but also manages the expectations of family and school. She is aware that the expectations of the family differ from what the school can provide. Gently she assists the family in understanding the schools perspective and helps them recognise what is achievable. Clare understands that the family is not sufficiently confident in their own knowledge to be able to provide detailed information to the school. She 'leaps ahead' (Heidegger, 1996) recognising that rather than providing all the information for the family she must support and assist them in establishing a new relationship with the school. Clare facilitates the dialogue between family and school by having the family alongside. Her role is to coach them and support them in what and how information about their child's illness needs to be shared with others. For Clare this is a comfortable and transient role.

Certainly the Clark family appreciates the ability of the nurse to support them in this way.

When Andrew was first diagnosed the nurse was really helpful. At the beginning of the school year the nurse orchestrated a meeting with his teacher, the secretary, the principal and another women who is the receptionist. She got everyone involved and was able to impress upon everyone how important it is to mange Andrew's diabetes. She seemed to realise how difficult it can be for us to explain to others what it is like and that you need to be fairly vigilant. It was good that she co-ordinates it all for you and you knew that you had that professional back up.

Clark Family
Family C: 6:35

The family appreciates the nurse's ability not only to transmit the information but identifies the appropriate people with whom to communicate. The family perceives that the nurse's professional status and position gives added value and authority to the information. Perhaps like Clare, this family recognises the transitory nature of this 'in-between' role. The family realises that they soon will have the confidence and authority to negotiate this relationship themselves with "professional backup" from the nurse. As Kleibenstein and Broome (2000) note it is important that parents of children with chronic illness have the information and ability to advocate for their child within the school system. It appears that both Clare and the Clark family recognise this and that in future interactions with the school the nurse will not be 'in-between' but 'behind' supporting the family in their relationship with the school. The 'in-between' stance is transitory in nature providing support, comfort and security to the family.

However a much more frustrating and often difficult 'in-between' position described by families is when they find themselves transmitting information between various practitioners.

Our GP gets very few reports from other health professionals like speech therapists and physiotherapists. It is up to us to keep her informed. Like with the hernia. When the GP picked it up I told her that we knew that our Paediatrician was going to refer us to a paediatric neurologist and perhaps a

referral about the hernia could be done at the same time. So she spoke with our paediatrician about getting them all tied in together.   But unless I convey information, and seek out specialist help when necessary my GP, who looks after all of my family's health, does not get the information necessary to look after us.

Allen Family
Family A: 2:69

The Allen's have discovered that they cannot expect that their practitioners will communicate effectively with each other. To ensure the effective co-ordination of their child's care, families often work 'in-between' compensating for the ineffective dialogue that exists between practitioners.

Practitioners also describe how families often have to take up this role:

As a community paediatrician my role is to have an overview of the whole case and therefore I am more likely to think of everything. Whereas the sub specialists have their own particular areas of focus so that is all they see and they can't see anything else. They don't even seem to think that anybody else might be involved. That really frustrates me because what happens is there is just no communication from them to me. It really frustrates the family as well. They come to see me in clinic having seen a sub specialist two weeks before and they have to relay the information from that visit to me. I have not received or may not get any information from the sub-specialist. I don't believe it should be the parent's role to relay information between health professionals but that is often what ends up happening. It really annoys me.

Angela
Dr A: 15:282

It is interesting that while Angela is uncomfortable and annoyed by the situation she does little to relieve the family of this role and in some ways expects that the family will continue to act in this way. The experience of families transmitting information 'in-between' practitioners is described by most of the participants in this study, with a resigned acceptance that this is how relationships will be when a number of sub-specialities are involved. But what is it that allows practitioners to accept such

situations despite the obvious frustration for both family and practitioners?   It may be the concern that any action might upset the delicate balance of relationships between practitioners and families but perhaps it is more reflective of the impact of increasing sub-specialisation and fragmentation of services to chronically ill children.

Few studies have specifically examined the impact of increased fragmentation and specialisation of health services on the relationship between families and health professionals, however some authors have speculated on the effect it may be having. Veatch (1983) has suggested that the increasing trend toward specialisation in health care services has led to a model whereby the physician is a stranger to the patient. He suggests that the reality of current models of health care delivery places severe constraints on the development of what many view as the ideal model, that of a friend/physician relationship.   Veatch argues that the medical profession must accept that while the friend/physician relationship may be possible in some instances the institutional structure of health care dictates that in most instances health care will be delivered between strangers.   Clark (2002) also suggests that excessive specialisation is likely to be more fragmented and alienating for the patient, however I was unable to locate any studies which specifically examined the impact of specialisation on the practitioner family relationship. Interestingly most of the studies which address this topic focus on the impact on health care costs and the work of health care professionals (Cotton, 1997; Ferris, Chang, James, Blumenthal, & Pearson, 2002).

If as Veatch (1983) and Clark (2002) suggest, increasing specialisation of health care services has lead to increasing alienation and encounters between strangers, could this not lead practitioners toward viewing the child and family as what Buber (1970) would describe as an 'I-It' rather than an 'I-You'?   That is, the practitioners view the child as a detached isolated object, a body part or body system to be dealt with, rather than a person with whom to relate. Angela appears to be suggesting this is the case. Having dealt with their part of the child's body system the sub-specialist finds little reason to consider the 'I-You' of either the family or other practitioners involved in

the child's care. There is little time or need for the development of the relational encounter that would allow what Buber describes as entry into the "I-You" relationship. As Buber (2002) describes, life in the 'I-It' requires no relationship, or dialogue. The only connection 'in-between' each practitioner is the family. It therefore seems inevitable that the family will find themselves in the position of having to transmit information between the various practitioners. The participants in this study seemed to accept that this is part of the experience of caring for a child with a chronic illness.

The 'in-between' as a way of holding things together

As shown in Chapter 6, relationships between practitioners and families are often tenuous and fragile. It is easy for connections to be lost because of the number of people or services involved or through misunderstanding or conflict. Holding the connections together is often dependent on the skills and actions of either a family member or practitioner. Both practitioners and families describe situations where they act 'in-between' as a way of holding relationships together, managing conflict and tension or simply by providing the support and stability needed to maintain the connections.

Arendt (1998) describes the "in-between' as "something which *inter-est*, which lies between people and therefore can relate and bind them together" (p.182). She suggests that most action and speech is concerned with the 'in-between'. In most instances the 'in-between' focuses on the objective world producing tangible results because of the words or deeds of the participants. This appears to be the world in which most of the families and practitioners are operating. What 'inter-ests' them is the child's care, so they act to resolve conflict and inconsistencies to provide a comfortable and co-ordinated service for child and family. Arendt (1998) does not suggest that this is the only way in which we encounter the 'in-between'. Sometimes it is more subjective and intangible leaving behind no results or products but "for all its intangibility, this in-between is no less real than the world of things we visibly

have in common" (p.182). Occasionally practitioners and families do encounter this less tangible 'in-between' as they work together, but it is the tangible, objective 'in-between', that is more frequently encountered.

Families who have a child with a chronic illness have to access and manage a vast array of services and relationships to ensure the child's well being. Practitioners often use their position 'in-between' as a way of assisting families to connect to the services they need, as the Davy family describe:

> Pauline, she is our regular nurse, she has become the link for us with other services. For example when you had a lot of different appointments she was able to sort them out. I knew I didn't have to stress about it because Pauline would arrange it so that operations and different appointments were co-ordinated. She seemed to know everyone we needed because when you went to the appointment and mentioned her name they knew who she was. It was nice to have someone working with you who knew everything that was going on
>
> Davy Family
> Family D: 7:101

From the family's perspective Pauline is 'in-between' them and the vast array of services which they encounter. She is able to use her 'in-between' position to look both ways, surveying the needs, demands and expectations of the family and co-ordinating the array of services they require. By being 'in-between' she is able to move back and forth between family and services, making the connections and establishing the links.

Practitioners also describe how being 'in-between' allows them to take up a co-ordinating role. While other professions describe this 'in-between' role, it is the nurses in this study who most frequently describe acting in this way.

I think that as nurses we often act as "pig in the middle". It is the very nature of our work. We have quite an intimate relationship with families and they often see us as the person who negotiates and co-ordinates things for them. I think the doctors and dieticians see us that way to. We are in a position to see what is happening. We see the different perspective's, we know what the patient is saying and what the dietician is doing. We are in a position that allows us to pull it all together for example arranging a meeting to sort stuff out.

Donna
Nurse D: 14:305

Donna, believes her intimate position beside the family and her position within the health care team places her 'in-between' allowing her to see and hear varying perspectives. Her use of the expression "pig in the middle" suggests a to-and-fro movement as she pulls family and health care team together.

Bishop and Scudder (1990; 1991) argue that nurses, by the very nature of their work are "constituted by a distinctive in-between stance" (Bishop & Scudder, 1991, p.18). They believe that nurses are strategically placed between physicians, health bureaucracy and the patient. Rather than seeing this as an ambiguous position in which nurses are caught, they suggest that this is a privileged position from which nurses can advocate and make the types of decisions that a moral sense of health care requires. From an in-between position, Bishop and Scudder argue, nurses are uniquely positioned to contend for co-operation because they share not only the medical and health service perspective, but also the personal experience of the patient. While they do not suggest that this is the only stance nurses take in practice, they argue that it is a position they must take, not because it has been historically required but because it is necessary for patients health care needs to be meet. Certainly many of the stories from the nurses in this study reflected this privileged 'in-between' stance.

Practitioners from other disciplines also describe acting 'in-between' family and practitioners however for some it is a less familiar role:

I can recall a situation where I was in the middle of a conflict between a group of health professionals and the family. I didn't feel strongly one way or the other but the group of health professionals felt very strongly one way and the family felt very strongly the opposite way. There was a major conflict and every time I saw the family they would tell me about what the group of health professionals were doing and then when I would meet with the health professionals they would say "oh that family!" What I did in this situation was to call everyone together for a practice meeting where we could identify the issues and decide what we needed to do. We had some very effective practice meetings and it has been very successful in resolving the conflict.

Angela
Dr A: 15:116

Like many of the practitioners in this study Angela finds that she is listening to the perspectives of both family and practitioners. Because she had no firm view either way she is 'in-between' listening to the perspective's of both sides, recognising the conflict and tension that exists. By bringing the two groups together she is able to maintain the integrity of the connections between practitioners and family.

Managing conflict and tension

Families and Practitioners recognise that one of the greatest risks to the integrity of the web of relationships in which families and practitioners operate is conflict and tension between participants. Practitioners and family members may use their position 'in-between' to manage conflict and tension. Often this tension relates to the family receiving conflicting advice and opinions from the practitioners they are working with:

There was a time when things went quite berserk over Chris's feeding. There was so much emphasis on Chris's weight and I was quite stressed about how to get the calories into him. I was getting really conflicting advice from the various health professionals I was dealing with. On one hand they would say "don't worry too much at least he has grown a little bit" and on the other hand another person would be saying " we need to get this many calories in and he has to be growing this much every week." Then there was the concern about how much oxygen he needed to keep him growing. The whole growth thing

became a real obsession and it was becoming a real issue for me because there was so much conflicting advice between health professionals. In the end the social worker came to the party and organised a meeting in my lounge with all the five health professionals involved. It worked really well. We all came together and sat down and discussed the issue together. It was really good having them all together so they heard each other's viewpoint and we could plan together. It was so much better than what had been happening with the individual health professionals coming separately to see me. It became like a coffee morning with us together in the lounge room and Chris crawling around on the floor.

Davy Family
Family D: 7:348

Conflicting advice is adding to the tension felt by the Davy's in regard to Chris's feeding regime. Recognising the family's anxiety the social worker uses her 'in-between' role to bring people together. The social worker works to ensure that all the participants in Chris's care have the opportunity to see the others viewpoint, and to perhaps recognise the confusion and stress the conflicting advice is causing the family. It is only when the conflict is presented or shown to the practitioners that understanding comes. By stepping 'in-between' the social worker allows something which is hidden to the practitioners to be shown, and in the showing a new perspective comes to light. Often when families and practitioners work together the conflict and tension lies hidden and it is only when someone acts 'in-between' that the tension is revealed and managed.

Heidegger (1996) suggests that "beings encountered and taken care of are also pre-ontologically hidden at first in their being" (p.63) and they can only be shown to us if we reject the "interpretational tendencies crowding and accompanying us" (p.63). Using this notion of Heidegger's the tension and conflict that the family is experiencing at first remains hidden from the view of the practitioners. Perhaps because the family has not openly declared the distress they are experiencing, each practitioner has made an initial interpretation that their relationship with the family is going well. However when the social worker facilitates the meeting these initial interpretations are challenged and what "appears", the distress and confusion of the

family, is an indicator that the relationship is not as it seems. As an "appearance" the distress and confusion is, as Heidegger would say "pointing to something in which something appears" (p.26). It does not reveal the relationship itself but it points toward something that is occurring within the relationship.

Families can feel supported by practitioners who take the 'in-between' role. Yet many also describe situations in which they feel confused and frustrated by advice that conflicts:

> When we came home from hospital we were back to six feeds a day, which meant that at some stage we had to wake him through the night. It was difficult also because the respiratory team had suggested that it was important that he got a reasonable amount of sleep at night so that the growth hormone kicked in. They suggested strongly that the feeds should be in the daytime to allow the longest sleep possible at night. But the dieticians just wanted us to keep feeding him at night. It was really difficult to convey to them our problem and work out what we should do.
>
> Gordon Family
> Family G: 13:355

The Gordon family feels 'trapped' 'in-between' the contradictory advice of the practitioners with whom they work. They hear opinions that confuse and threaten their ability to care for their son. Unlike the social worker in the previous story they find it difficult to be proactive from their 'in-between' position. Perhaps this is because they are uncertain about their child's condition or management or perhaps it is because the relationship between them and the practitioners is new and fragile. For whatever reason they feel unable to express their confusion and frustration or to negotiate a way forward. The family occupies an untenable position between practitioners, being pulled to and fro by conflicting advice.

One of the most difficult 'in-between' positions for practitioners is that of being between conflict between individual family members. This is often a tense and

difficult position to be in as the practitioner walks a difficult path of maintaining his/her relationship with the family and not interfering or damaging the integrity of the family unit. The next story reflects the tension that many practitioners feel when caught 'in-between' family members. The medical staff recommends a bone marrow transplant as the best form of treatment for the child and, while the mother wishes to go ahead with this treatment, the father is opposed. The nurse finds herself caught 'in-between' the mother and the father:

> It is really difficult for you as a nurse in this situation. The medical staff only deal with it on a much more intermittent basis, they come and meet with the family for fairly brief period of time in a formal sort of way. But as the nurse, it is there in your face all the time. Every time you provide care for the child the family are there, every time you pop in to see the child and family in an informal way you are faced with the conflict. I found both parents who had equally strong views bombarded me. Each was looking for my support based on my experience. I found it difficult because I wasn't up on all the technical aspects of this kind of intervention but I could see the wider social point of view. The emotional side. What it was doing to this family.
>
> Gil
> Nurse B: 2:388

Gil's story illustrates the tension and discomfort practitioners often feel when they find themselves in the middle of conflict. As a nurse she has constant and regular interactions with the family throughout her twelve-hour shift. She is with the family for long periods of time and this allows opportunities for each parent to lobby her, to get her support, and to question her. She is bombarded, attacked from both sides, as each parent looks to her for support. She feels ill prepared to advise them yet recognises the conflict the family are experiencing. Like the Gordon family, Gil experiences the difficulty and discomfort of being caught 'in-between'. However both she and the family remain 'in-between' holding the fragile and tenuous connections together.

Providing support and protection

The other way in which practitioners and families use the 'in-between' position is to hold things together by providing support and protection to the child or family. Community practitioners in particular often describe how they act 'in-between' to protect and support the family during a hospital admission:

> While he was in hospital the family relied on me quite a lot. Because of the inconsistencies of having different people caring for them on the ward they found it difficult to keep up with things and communicate with the ward staff. So I would visit the ward every couple of days to keep them up to date and reassure them. It would be little things like making sure they knew the results of swabs that had been done or if they had any problems with what was happening in the ward giving them an opportunity to tell me about it. I would then deal directly with the Charge Nurse to make sure that they were kept safe and things were sorted out. I appreciated that they weren't an easy family for the ward nurses to care for. They were really scared, scared that they were going to lose him again and did not have English as their first language. The nurses also often expected a lot of them while he was in hospital. The parents did most of the care for their son while he was in hospital but the nurses still expected them to get up and feed him in the night two or three hourly. I had to advocate for them and say "look they are here all day and they need a break as well". I would write in the notes so that the doctors would know that I was available if they needed to make any changes that the family wasn't happy with. After a while the doctors would just end up ringing me and saying, "can you tell the parents this and this".
>
> Fiona
> Nurse E: 16:24

From an 'in-between' position Fiona appreciates the confusion and stresses the family are experiencing but she also recognises the demands and difficulties that the family pose for the health care team. She recognises the inherent risks of misunderstandings, differing expectations and conflict that could break the fragile connection between health care team and family. From the 'in-between' she works between health care team and family, sometimes transmitting information, sometimes clarifying and managing expectations while at other times advocating and intervening on the family's behalf. Fiona maintains the connections while at the same time providing support and protection for the family. While Arendt (1998) suggests that

we more frequently encounter the tangible or objective 'in-between', there is a sense in Fiona's story that the 'in-between' is intangible and not reflected in outcomes or products but rather in the less measurable qualities of security and comfort.

Family members also describe how they often use the 'in-between' position to support and protect their children. Recall in Chapter 6 how Erin's mother has to mediate for her daughter in regard to a dose of Insulin. In telling the story Erin's mother recognises that the nurse with whom they are dealing is also caught 'in-between' the family and the medical team who have charted the Insulin:

> I took it up with the nurse and she said, "this is what has been charted" I felt a bit sorry for the nurse, she was quite obliging, but she seemed to be caught in the middle. She was trying to do her job but she really needed to listen to her patients a bit more. I said to her "let me take it up with the doctors, let me go further, because this just isn't right". I caused a bit of a commotion at the time but we got it changed.
>
> Ford Family
> Family F: 11:168

While the nurse remains caught unable to respond, reluctant to advocate for the family by questioning the authority of the doctor, Erin's mothers encounter of the 'in-between' prompts her to act. For her the risks of the wrong insulin dose far outweigh the disturbance or upset she might cause the health care team. However being 'in-between' is not an easy position for families to take. It potentially upsets the fragile balance between getting the right treatment for their child and maintaining their relationship with the health professionals. The Brown family recognises that they need to move 'in-between' to protect their daughter, but find it a particularly difficult thing to do:

> One of the hardest things when we go to hospital is getting the IV (Intravenous Canula) in. You hate having to hold her down while they put it in. As a parent you don't like to do it but you know it is all for her own good in the long run. You get to know the registrars who are good at putting the IV in often by their first name, and when you get someone who you are not sure

of you want to say "Can we have Michael to insert the IV please?" But you don't say that. I have always thought I would say "ok you have had three goes that is it" but I have never had to say that because we have always managed to get it in or find another way around the problem.

Brown Family
Family B: 4:619

The Brown family describes the tension of having to balance the need for treatment against the distress and pain it will cause their daughter. Because they have been 'in-between' these relationships many times they know who can undertake the procedure easily and who cannot. They plan when they will intervene, when they will act 'in-between' for Sarah. However like many families, the Brown's recognise that moving 'in- between' is not an easy decision. They realise that while their action may provide comfort for Sarah it may also stretch and break the connection between the family and the medical team. While the 'in-between' is used by families and practitioners to hold the connections together, they discover that the ridge they walk is indeed narrow. It is a delicate balancing act that often causes tension and discomfort.

Being 'in-between' as a way of controlling access

While the 'in-between' can be used as a way of holding connections together and facilitating dialogue a number of families describe how practitioners use their 'in-between' position as a way of controlling the family's access to services and information. Most frequently this relates to use of the Emergency Departments as a way of gaining access to the practitioners who care for their child. From the families perspective Emergency Department staff often take up an 'in-between' gate-keeping role, denying them access to the practitioners they know and trust:

Sometimes having to take Susan to the Emergency Department when she is unwell is really frustrating. It is usually because she has a chest infection and by now we know what needs to be done. She needs a chest x-ray, a review by the consultant and then a decision regarding treatment. But what happens is

that you have to see the nurse, then the house surgeon and then a registrar and then yet another registrar. Sometimes you may have to see a medical student as well! They spend ages wading though her large file before they decide what to do. You feel like saying as you walk through the door "Look we are just going to have a chest x-ray and then we will come back. Can you ring one of the paediatric or ENT consultants while we are away so you know what to do."

Brown Family
Family B; 4:413

It is frustrating for the Brown family when practitioners act 'in-between' in this way because it denies them prompt access to the treatment and practitioner they wish to treat their child. It may also expose the family to the danger of people who may not understand, who may get it wrong.

Some practitioners recognise the frustration this can cause and a number of families describe ways in which they are helped to gain more direct access. The Davy family describe use of the 'open letter':

One of the things we have found really useful especially when you have to go to the Emergency Department is the 'open letter'. It is something we have that we can take along with us and gives the staff a summary of Chris's condition and treatment. The Emergency Department has a copy as well if we don't have it with us. This letter means that we can cut out the middle man in the process. It reduces the frustration of being admitted via the Emergency Department. We don't have to be seen by the various doctors in the Emergency Department but can be sent straight up to our family on the ward. That is what the ward staff become, your hospital family, the staff who really know you and can say to the Emergency Department staff "Oh yes we know Chris."

Davy Family
Family D: 7:159

The 'open letter' gives the family authority to 'cut out the middle man' to move straight into a relationship that is familiar and trusted. The Davy's refer to the ward staff as their "family" suggesting that this is a closer and more integrated relationship

than the relationship they have with other practitioners. However strategies, such as an open letter, are not available to all families and the 'in-between' gate-keeping role of staff, both within hospital and community services, often appears as a source of frustration to families of children with chronic illness.

The 'in-between' gate-keeping role does not always relate to access to practitioners. Frequently families described practitioners acting 'in-between' as a way of controlling their access to the child's clinical record. Despite legislation in New Zealand which provides consumers of health services access to clinical information ("Health Information Privacy Code," 1994), families continue to encounter difficulty when trying to access the clinical record.

> One of the ways I kept myself informed was by asking to read Nathan's notes. I would read the notes on a daily basis, each shift I would read them. Some of the nurses would say "no you can't have them" but other's would give them to me no problem. I remember one time when Nathan was in hospital and I asked the nurse for his notes. She said that we had to get permission first but I just said, "no, it is my right to read those notes". I am fairly firm about that.
>
> Kirk Family
> Family K: 17:203

In this situation the nurse attempts to come 'in-between' the family and the clinical record. Why does the nurse act in this way? Is it her belief that the clinical record belongs to the practitioners rather than the family? Perhaps she believes that the family needs to be protected from the level of detail in the clinical notes? Is she concerned about the subjective judgements that may be contained within the practitioner's notes? Whatever her reason the nurse attempts to use her 'in-between' position to deny the family access to what has become a vital source of information for the Kirk family about Nathan's progress and care.

The fact that families frequently refer to the clinical record as one of the best sources of information about their child's condition and progress raises questions about the

reluctance of practitioners to be completely open in their conversations with families, and what will happen if such information is shared? It is clear that families must become confident and assertive with practitioners if they are to overcome the gate-keeping 'in-between' role taken by some practitioners.

Conclusion

I believe these stories exemplify the complexities and contradictions of Buber's (2002) 'narrow ridge'. Sometimes the ridge is a vantage point from which to consider the various positions and possibilities, and at other times it is a place where opposing views come together. The 'narrow ridge' does not provide a comfortable middle ground for families or practitioners. It is a precarious path upon which they must carefully balance and 'take a stand' to maintain the fragile web of relationships surrounding the child with a chronic illness.

However this is not the only way in which the web of relationships is experienced. Families and practitioners also describe how they must also 'go around' the web and it is this experience which will be explored in the following chapter.

William 4 yrs 10/12

Illustration by William Age 4 years

Chapter 8

Going Around

"What is decisive is not to get out of the circle, but to get in it the right way"

(Heidegger 1996 p.143)

In the previous chapter I described how families and practitioners sometimes work together in the web of relationship from an 'in-between' position. In this chapter I will explore another aspect of working together: 'going around'. Families encounter a vast array of practitioners as they journey within the world of chronic childhood illness. They soon discover that to get the care and services they need for their child they must 'go around'. 'Going Around' means moving around each of the practitioners involved in their child's care, establishing relationships, seeking information and advice, interpreting and integrating it with what they have discovered from another practitioner. While sometimes frustrating and confusing 'going around' appears to enable families to come to an understanding about their child's illness and care. Once families have discovered the 'way around', it becomes a familiar journey, part of the everyday world of having a child with a chronic illness. 'Going Around' enables families to get the information and advice they need, make decisions about their child's care, test the strength and resiliency of relationships and to learn how to work within the health care system.

Practitioners also recognise that families' experience of their child's illness requires that they 'go around', yet they refer to it more negatively as 'playing one off against another'. Practitioners appear to believe that in the 'going around' or 'playing the game' families choose to manipulate and 'play around' with inconsistencies in practitioner advice and practice. Some perceive that families seek the outcomes they want through deliberate and careful playing of one practitioner off against the other. Practitioners suggest that the risk of families 'playing one off against the other' in this way is greater when the child has a chronic illness because the family have to 'go

around' a large number of health professionals. From the practitioner's perspective this mode of 'going around' is uncomfortable and difficult. It is something that must be intercepted and controlled. However although families describe becoming more assertive and focused in questioning and seeking information and opinions from practitioners, none of them describe this as the deliberate manipulative act described by practitioners. Is this because they do not know the rules? Perhaps they do not recognise that they are playing? The experience of 'going around' seems to have different meanings for families and practitioners, yet 'going around' appears as part of the everyday world of having a child with a chronic illness. This chapter will explore the meanings of 'going around' for practitioners and families.

The ontological structure of the circle

From Heidegger's (1996) perspective 'being-in-the world' has the ontological structure of a circle. It is in moving around the world that we reach interpretative understanding. According to Heidegger the ontological structure of the circle is not closed or vicious (p.143) but something into which we need to leap (p.291) to understand our 'being-in-the-world'. The movement within the circle is often described as centrifugal (Gadamer, 1982) or spiral (Polt, 1999) with each turn expanding previous understanding. Each turn moves toward a deeper and fuller understanding (Guignon, 1983). As Gadamer (1982) notes, what Heidegger is suggesting is that the hermeneutical circle is more than a "prescription for the practice of understanding' (p.266). Heidegger's circle is not just a way of interpreting text, but is something that has "ontologically positive significance" (p.266). It is the way of understanding, a way of being in the world. Heidegger (1996) claims that "to deny the circle, to make a secret of it or even to wish to overcome it means to anchor this misunderstanding once and for all" (p.291). Understanding of the whole requires being prepared to move around or back and forth between the parts and the whole, with each movement uncovering something more about the whole. As Heidegger (1996) states the decisive thing is "not to get out of the circle but get in it the right way" (p.143). I believe that Heidegger is suggesting that we enter open to the

possibility of new understandings. The circle that the families in this study describe as they "go around" has the same ontological significance as Heidegger's circle. It is the way in which families come to understand the world of caring for a child with a chronic illness. By 'going around' each practitioner they get another part of the knowledge and skills they need to understand and manage their child's illness. At each turn, they bring in into their understanding another part of the child's illness experience.

'Going around' to understand

Many families describe that in the 'going around' they gain a full and more comprehensive understanding of their child's illness. The most intense periods of 'going around' occur at the time of diagnosis or when the families are seeking to understand the long-term prognosis for their child. The Jones family describe the frustration of 'going around' to find a diagnosis, trying to find a practitioner who would listen to their concerns:

> It was really hard in the time leading up to them diagnosing Lynda's condition… Our GP sent us to a paediatrician whose speciality was asthma. I am not sure why he sent us there because this illness was not his field. Lynda had every test known to man and everything came back slightly abnormal and in the end Lynda was really sick and incredibly anorexic. The paediatrician was prepared to leave it because he couldn't find a diagnosis, his advice to us was to leave it and see what happened. Well Lynda just wasn't functioning so we got shunted around everybody. We couldn't get into the public hospital so we had to have all our tests done at a private hospital. During this period I didn't feel that they were really listening to us however from the moment the diagnosis was made we have had no problems in getting the doctors to listen.

> Jones Family
> Family J: 18:195

The family found it difficult to get the practitioners to listen to their concerns and they had to persistently 'go around' practitioners seeking out an answer, trying to understand what was happening to their daughter. In this situation the diagnosis

appears to bring greater understanding of the whole for both family and practitioner. While the family will continue to 'go around' they now have an understanding of the whole illness experience and this allows them to work with practitioners in a way that ensures their concerns are heard. Understanding the diagnosis provides a platform on which to work with practitioners. Now, in the 'going around', each turn expands their understanding of their daughters condition.

For many families, however, it is not just the search for a diagnosis which intensifies the 'going around' movement but the search to understand the prognosis for their child. The Allen family recall their frustration in trying to determine the prognosis in regard to their daughter's ability to speak:

> I am into the odds. Alex was an extremely difficult child who didn't appear to have a great grip on life. There was all the evidence, reports and CAT scan that said she had had cerebral bleeds, but what did this really mean? I wanted to say to these nurses, "now you've been here for 20 years and have seen children like this, what is the prognosis?" It must be one of the meanest questions nurses get asked because you know they are not in a position of authority to make predictions on prognosis and we do understand that each situation is unique. Nurses are just there to pick up the problems. … Just trying to nail people down, just to tell us. We won't hold it against them if they get it wrong. I am still trying to nail them down about her speech. We just want to know will this child ever speak? They talk in terms of "making very good progress". What does that mean? In regard to her speech it was only after I pinned down a friend who works in the special education services that I got an answer. But even then it wasn't very exact. When I asked her " will she speak" she said that she believed she would but I still don't know how well. I am not sure whether medicine is an art or a science. It doesn't seem very exact.
>
> Allen Family
> Family A: 1:97

This family wants to know whether their daughter will speak. The family understands the uncertainties and the uniqueness of their situation but they want to understand what lies ahead for their daughter. This is new and unfamiliar territory for them and they want to use the experience of the practitioners to help their

understanding. They 'go around' asking for help, looking forward to the future, trying to understand the possibilities for their daughter. However, movement within the circle is frustrating for the family because the responses are couched in vague and inexact words like "making good progress". The family moves between acceptance of the unpredictable, accepting that they may get it wrong, to seeking an exact answer. They will continue to 'go around' seeking to understand the prognosis for Alex.

Most chronic illnesses are unpredictable in their course and outcome. Practitioners recognise the frustration and difficulty their lack of certainty causes for families. They understand that because of this, families will 'go around' a number of practitioners in search of an answer. Several practitioners describe discussion of the prognosis as a 'no win' situation:

> I find it really difficult to know when is the right time to discuss with families what is the potential outcome for their child. It is hard to know when to bring it up with the family particularly when I don't have any idea or way of knowing what the outcome will be. ……I might see the child at ten and he is functioning as a six-year-old and the family wants to know what he is going to be able to do and whether he will be able to live independently. It is really difficult because it is an evolving thing; you can't put everyone in the same box. You can't say, "well they have "X" Syndrome then this is what they are or aren't going to do". You can however say that there is a range of things that Downs Syndrome children can do. I will often say "some will walk at the normal time and some will walk much later. Exactly where your child is going to fit in we don't know." Whenever possible I try and compare it to the normal population. I will tell them that there is always a great variation in what people do, for example some are good at sports and some are good at math's. It is almost like a no win situation, because if you say something really bad then you are going to be proved wrong and the parents are going to be right. If you say something really good and it doesn't happen then you are proved wrong again.
>
> Angela
> Dr A: 15:411

For Angela this is a "no win" situation because she recognises that, despite the family's expectation, she is not going to be in a position to make accurate predictions in regard to the child's future. She deals with this uncertainty by using the everyday natural variations of life to try and illustrate the variation in illness trajectory. But despite trying to manage the range of possibilities with the family in this way, Angela knows that her predictions are no more accurate than that of the family. The doctor is aware that in most instances, regardless of the advice and prediction she makes, it will be the child who will determine the outcome. The doctors discomfort appears to exist because of her inability to provide the precision, the exactness that she believes many families seek. Perhaps like the Allen family she realises that caring for children with chronic illness is as much an 'art' as it is a science. Zaner (1991) suggests that the illness experience invariably includes uncertainty and ambiguity and it is this which textures "every individual encounter between patient/client and professional" (p.48). While the illness experience provokes the need to know and understand it is this uncertainty and ambiguity which often gives the patient the feeling of "being adrift" (p.50). Angela's story suggests that the practitioners also have a sense of not being on firm ground.

It is evident in the stories of both practitioners and families that seeking to understand both the diagnosis and the prognosis of the child represents one of the most intense periods of movement within the circle. This finding is supported by other studies that have identified the pre-diagnosis and acute phases of the child's illness as being associated with the greatest levels of uncertainty (M. H. Cohen, 1993; Horner, 1997; Thomlinson, 2002). However, as Cohen (1993) demonstrated, to live with a child with chronic illness is to live with sustained uncertainty. While the level of uncertainty may recede as the child's illness stabilises a background of uncertainty remains and the stories of the families in this study would support this finding. Cohen suggests that the health professional's experience of uncertainty is different from that of the family. She suggests that diagnosis brings closure for health professionals. It also provides clear direction for subsequent decisions and actions. However this did not appear to be the experience for the practitioners in this study.

Many, like Angela, describe the uncertainties that often lie in the background of their interactions with families. But it is often difficult to determine in the stories of the practitioners the extent to which these uncertainties were shared with the family. Katz (1984a) suggests that physicians often acknowledge medicine's uncertainties in theoretical contemplation but, in their conversations with patients, they behave as if uncertainty does not exist. Although practitioner uncertainty is sometimes shared with families, I had a sense that in most instances, as Katz describes, uncertainty was suppressed or brushed aside out of a conviction that it does not belong in the practice. Certainly the tension of managing uncertainty appears in the experience of both families and practitioners as they 'go around'.

'Going Around' to get all the information

One of the reasons that families gave for using such a wide circle of practitioners or sources was their perception that practitioners were not always open and honest in their dealings with them or did not give them all the information they required. Frequently families suggested that practitioners deliberately held back information from them. Sometimes families perceived this as a protective act by the practitioners:

> When I think back, it is interesting to think how we got information about Susan. Sometimes you felt like they were protecting us. They often withheld information or gave it to us slowly when we were ready for it. I remember when I first asked about CHARGE[11]. I asked what the 'R' stood for. Someone told me that it was there to make up the word and did not represent anything. Later on I found out the 'R' stood for Retarded growth and development. I wondered if they didn't tell us that initially because they thought the word retarded might upset us. I mean when you first hear that word 'retarded' all these images come into your head. They probably thought that they would just leave that one out for a while and tell us all the other stuff.
>
> I also remember in regard to her hearing. I am sure they never told us that 80% of children with CHARGE are deaf. All they said was they were going to do a hearing test. When the result came back they said, "this is really good

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[11] CHARGE: a constellation of non-randomly associated congenital malformations that occur together in varying combinations. The malformations include *C*oloboma, *H*eart Disease, *A*tresia Choane, *R*etarded growth and development and/or central nervous system anolmalies, *G*enital abnormaltieis and *E*ar anomalies and/or deafness (Branchi, 1998).

news", but we didn't understand the significance of the test until we had got more information later on. I think that is quite a good thing though, not telling you all the negative possibilities, they waited till they got the results of the test and were able to tell us definitely that it wasn't an issue for her.

Brown Family
Family B: 4:259

Although the Brown family appears to accept the protective withholding of information by their practitioners, other families did not accept or appreciate this under any circumstance. The following story reflects the anger and frustration felt by many families when information was withheld:

It was after we had been going to clinic for a while that the dietician mentioned the Glycaemic Index. We hadn't heard about it before and did not realise that it was an important part of monitoring our son's condition. When we asked why we had not heard of it before they said it was because they didn't like to inundate us with too much information in the beginning. I don't agree with that though, because I believe it is our right to be given all the information and we can work out what we can cope with. I was really annoyed that they had withheld that information from us.

Clark Family
Family C: 6:121

The practitioners' stories talk about situations in which they deliberately withhold information in order to protect the family or time release of information to prevent information overload. As a physiotherapist, Barbara chooses to withhold certain information from families:

I probably withhold the really nasty stuff when I work with families. Things like whether they are going to be walking in 5 or 10 years time and whether they will be able to hold down a full time job. These chronically disabled children are very much mentally intact. They are very aware of what they want for the future, what they want to achieve and how they will be happy. You don't want to tell them you might need some hip replacements in a couple of years and we don't know if they will last you your whole life and you might be in a wheelchair. Many of the treatments are so new we don't know what the long-term outcome is so it is difficult to predict. I am quite

> sure I do withhold the nasty stuff; I don't even do it consciously any more, with experience of the condition and the family you just get to know what to tell them.
>
> Barbara
> Physiotherapist B: 8:334

Barbara avoids telling the family "the nasty stuff" unless they ask her directly. She believes she is protecting the family from unnecessary distress. Like many of the practitioners in this study, Barbara believes that families will ask when they are ready to hear difficult and often distressing information. So she waits until she is asked. She avoids giving information that may distress the family or child about their future. She notices that with experience this has almost become an unthinking act. She reads each individual situation and decides when and what information is appropriate to share. Barbara takes control of the information. It seems a somewhat paternalistic approach in that it does not appear to acknowledge the family's right to know, or even ascertain what they might want to know. Who determines what is the "nasty stuff"? Whose values are being placed on what is necessary and unnecessary information? The families' stories suggest that they do not always appreciate the filtering actions of the practitioners. Perhaps it is the perceived reluctance of practitioners to disclose information that prompts families to 'go around' in ever increasing circles to get the information they need to understand their child's illness?

'Going around' to participate in decision-making

'Going Around' helps families find all the information and explore the options before making informed decisions about their child's care. Being included in such decisions is extremely important:

> We wanted to be included in how the decisions were made. After all we were the ones who were going to live with it. The doctor might be able to say "oh damm, that was the wrong decision" and get it right five years later on with another child. But we will never be able to say "damm we made the wrong

decision." We have to live with it for the rest of our life. So that is why we made every effort to be involved in deciding what would happen to our daughter.

Evans Family
Family E: 10:184

The Evans family suggests that practitioners have the opportunity to improve on their performance, while for the family the decision they make will be with them for the rest of their life. 'Going Around' therefore offers the family the opportunity to be informed and to weigh up all the options before the crucial decisions are made.

In exploring the options families not only 'go around' the practitioners to whom they were referred but also seek information from sources such as local libraries and the Internet.

> When Lynda was first diagnosed we didn't really get much information from the health professionals. Because I work as a medical laboratory technician I read everything I could lay my hands on at work. I raided our pathologist's books and probably got more information than I needed to know. I used the medical school library and the Internet, everything possible to get a handle on this disease.

Jones Family
Family J: 18:221

Sometimes families seek independent advice from overseas experts:

> We decided to seek help independently so went and found a number of paediatricians who were based overseas and either spoke to them by telephone or e-mailed them. Most of the doctors were really keen to talk to us because the condition was so rare. We had also been using the services of the Family Information Centre[12] and the staff there knew what information we were looking for. Just by chance one of the staff at the Information Centre was attending a conference and she spoke to someone who said they had the ability to do some forms of treatment for our child's condition. They also said that nothing was proven and that nobody knows whether it would work or not,

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[12] Family Information Center: A national library service and information center where families can obtain information regarding their child's illness and the support services available to them.

but they can provide the treatment. So we contacted them as well as another centre in New Zealand and they confirmed what the overseas paediatricians had advised us. We now knew what you had to look at if you want to attempt to treat this particular condition.

Evans Family
Family E: 10:104

By going around the family now know what services to look for and what questions to ask. Several families in this study talked about the expense and effort required in going around and the impact this has on their lives. Many families are so busy searching and going around practitioners that the needs of their family, social life, work and personal well-being are sacrificed. Some families reflected on how fortunate they were to have the ability and resource to persistently "go around", but most believed that practitioners did not appreciate the effort and effect 'going around' had on them as a family:

I find it hard the number of clinics they expect us to attend. Nathan has to attend so many clinics and the health professionals seem to get a bit upset if we are not able to make it to clinic. They don't seem to realise how many other clinics we have to go to, it is like they think their clinic is the only clinic. If you don't come to clinic it looks bad on you.

Kirk Family
Family K: 17:110

The Kirk family describes the expectation is that you will 'go around' regardless of the pressure this places on the family. The family worries about the judgement that will be made if they fail to attend a clinic visit, if they fail to 'go around'. Although practitioners realise the pressure placed on families to 'go around' and do attempt to support families, they often feel powerless to control the practice of their colleagues:

Another thing that really annoys me is the number of clinic visits we expect families to make. I always try to work it out for the family so that they are not seeing all these blinking health professionals all the time. I will say "O.K so

you are going to respiratory clinic next month and genetics clinic in six months why don't you see me in say three or four months." I try to space it out for them. But it still amazes me how other health professionals in clinics will just say "oh we will see you in three weeks or three months" just because that is what they always do.

Angela
Dr A: 15:298

The experiences of families suggest that 'going around' requires commitment and involves sacrifice, however families believe it to be necessary in gaining full understanding of their child's illness. A number of studies have shown that persistently seeking out information and care from health professionals becomes one of the most powerful strategies for families in gaining control and managing uncertainty during the illness experience (M. H. Cohen, 1993; Dixon, 1996; Horner, 1997; Thomlinson, 2002).

As discussed in the previous chapter, the experience of having a child with a chronic illness requires families to 'leap in' to a circle of relationships and services which, at each turn, helps them uncover a greater understanding of the child's illness. 'Going around' the circle is sometimes a turbulent and confusing experience like the whirl of the centrifuge. At other times it is more like a gentle spiral that leads to deeper and fuller understanding. Although life within the circle can be uncomfortable, families come to appreciate it as a way to gain understanding of their child's illness. They appear to need to 'go around' as a way of determining all the options before making decisions. However it appears that although practitioners recognise and accept that families do 'go around', they do little to encourage or support them in the process. As will be seen in the following section, the practitioners tend to want to "overcome" the circle, which as Heidegger suggests, does little more than "anchor misunderstanding" (Heidegger, 1996, p.291) and this in turn does little to develop an effective family practitioner relationship.

Moving around the circle

Heidegger (1996) suggests the issue is not so much that the circle exists but how we get in and move around the circle. Families may initially 'leap in' confident that the people they encounter can be trusted to guide and nurture their understanding, but as they 'go around' they find that they must take up a more cautious and circumspect approach. I believe this relates closely to levels of trust and the trustworthiness of the people, information and opinions they encounter on their journey around the circle. A number of authors have suggested that trust is one of the critical elements in the patient professional relationship (Dixon, 1996; Johns, 1996; Lynn-McHale & Deatrick, 2000; Mechanic, 1998) and the data suggests that this is important for families and practitioners as they move around the various relationships. While several studies suggest that the development of trust in family health care provider relationships develops as a process over time (Burke et al., 1991; Robinson, 1996; Thorne & Robinson, 1989) the experiences of the practitioners and families in this study suggest that trust is often much more elusive and fragile. As they 'go around', the number of relationships the families have and the transitory nature of each encounter makes it difficult to decide what and who to trust. Experiences where families and practitioners have been deemed untrustworthy also influence future movement within the circle. Movement within the circle reflects spiralling possibilities toward cautious trust, or a backward turn toward mistrust. As they move within the circle, families and practitioners become increasingly cautious and careful in their dealings with each other.

Who can be trusted?

Buber (1957) claims that one of the greatest risks to genuine dialogue in modern society is our move away from trusting our fellow man to a climate of "existential mistrust" (pp.224,229). For Buber existential mistrust refers to the tendency of people to go into relationships seized with the doubt as to whether the person can be trusted. According to Buber, we increasingly operate in an atmosphere of suspicion and judgement, always looking for a hidden meaning in what people say or do (Arnett, 1986). From Buber's perspective this climate of mistrust not only destroys

our conversations with each other but also the togetherness inherent in a relationship between two persons (Friedman, 1955). While it has been suggested that trust is unavoidable in health care relationships (Pellegrino, 1991; Zaner, 1991) in that we often have to trust the treatments given, equipment used or knowledge of the health professional, increasingly a climate of distrust is growing within health care relationships. A number of reasons have been suggested for this change including the increasing commercialisation of medicine, knowledge and expectations of the patient as a health consumer, the movement from general to speciality practice and the increasing anonymity of the patient within the health care system (Pellegrino, 1991; Veatch, 1983, 1991). Whatever the reason, there is evidence to suggest that Buber's existential mistrust is increasingly present within health care relationships. In this study the level of trust significantly influences how families and practitioners move around their relationships and relate to each other.

Moving around carefully

Families initially appear to move into the circle expecting that the practitioners to whom they have been referred are knowledgeable and trustworthy. In the stories early in this chapter families expected that a diagnosis will be made, a prognosis given, and information shared so that they can be active participants in their child's care. They soon discover however, that are not always completely open with them as the Ford Family recall:

> Although families are pretty fragile at times and you don't want to hear the bad stuff I think the doctors need to be honest with us… I feel that if they don't tell us what the end result is of poor control, how are we going to teach our children about what can happen if they do not look after themselves properly. I feel most of the other doctors we deal with are not honest and up front with us. They won't come straight out and say "yes if you have poor control that can happen".

> Ford Family
> Family F: 11:5

The Ford family initially expected that health professionals would tell them everything, even the 'bad stuff', but as they travel around the circle they become less confident that they can trust practitioners to be completely open with them. Some families becoming increasingly suspicious that even when information is given it does not give the full story but supports that particular health professional's opinion:

> I think they come to a view about something and then they find us the information to justify or support their view. It is always so unequivocal, but I am not so convinced.
>
> Allen Family
> Family A: 1:263

An environment of mistrust grows, as families become suspicious of information being withheld or being presented in a filtered or biased form. But can health professionals present information without bias? Several authors would argue that if the information given is the basis for trust within family professional relationships then practitioners can never be trusted (Brock, 1991; Veatch, 1991). It is not possible for practitioners to present value-free information or opinions. Perhaps the mistrust comes from what Brock (1991) suggests is the practitioner's lack of commitment to confessing their inability to present value free facts. The practitioners fail to acknowledge the underlying belief system that influences and limits their opinion. Certainly the data in this study suggests that this lack of openness often leads to the increasingly cautious and careful movement of the family around the circle, as they become less trusting of their relationship with health professionals.

Practitioners also become careful and cautious about the way they move around the circle. Practitioners frequently describe having to be 'careful' in their dealings with families who have a child with a chronic illness.

The atmosphere of "existential mistrust" described by Buber (1957) often pervades the families and practitioners experiences of 'going around'. It appears to slow movement around the circle and hinders both the families and practitioners ability to understand and to care for the child. It can often leave both practitioner and family isolated and alone as the following story demonstrates:

> There was one family I was working with recently whose child had a condition that was incredibly rare. We had to try and reduce or eliminate fructose and sucrose from the diet. I had only encountered one or two cases of this in my entire dietetic career and had to go to great lengths to search the dietetic and medical literature and compile a diet for this child. I worked really hard to prepare information for the mother which was 100% correct. I reviewed commercial food lists, went to the supermarket and checked the lists against the labels. I really went above the call of duty for this family because I thought the child's diagnosis warranted it. I then sent the information out to the mother. The mother then wrote a letter to the hospital saying that she felt that I had not given her enough of my time and the information I had given were not what she had read in the literature or on the web. She asked that I be withdrawn from the case. I had no problems with that as I thought it was better that somebody else took over the management and requested that we transfer the families care over to another dietetic team. … Soon after transferring over the mother decided that the new team did not have the knowledge that she had hoped for and requested to be referred to a private dietician. However she discovered that she would have to pay for this service and realised that she could not afford it. The mother then started ringing other dieticians many of whom work on my team and therefore we discussed the management of this family together. The mother has now requested to come back to me but I actually don't think it is appropriate because I don't think we are going to get on particularly well. But it is quite a dilemma for me as I am very concerned about the child… It is hard not to take a formal complaint personally especially when it has been sent to management. I think it is hard not to take it personally when you have put so much into the case and have gone the extra mile but that it clearly has not been appreciated. I wonder whether I should give the family to another member of the team and subject them to similar criticism. This mother has gone to so many different people and never been satisfied with any of them.
>
> Faye
> Dietician A: 21:193

This family becomes suspicious of the opinions and advice they receive from the dieticians. So they 'go around' trying to find someone whose opinion they trust, only

to find themselves back with the practitioner they started with. When the family returns to Faye, she is not sure that she can work with the family. Faye's reaction seems to reflect that often practitioners confuse trust in the information with trust in the person. I do not believe that this family lacked trust in Faye or her colleagues, rather they lacked trust in the information they were given perhaps because it was not what they wanted to hear. After going around the family returns to the best advice on offer. However Faye has taken the family's lack of trust in her previous opinion personally and this makes her wary and suspicious. This situation appears to reflect Buber's (1957) concern, that in this atmosphere of "existential mistrust" genuine dialogue is no longer possible with the result that the family may find themselves isolated from the support and services they need to care for their child.

While this story is probably one of the most dramatic in the study, the data from both practitioners and families suggest that movement within the circle is not always easy. It is often hindered by a lack of openness about not only the way around but also a suspicion as to the meaning of each encounter. As Heidegger (1996) suggests it is not that the circle exists, but how we 'leap in' and move within the circle. For the family the circle exists, they must 'go around'. This is the way they discover how the health services are structured and come to understand how to care for their child. What poses the difficulty for families and practitioners is how they enter that circle and how their movement around the circle is facilitated or hindered by the health professionals they encounter.

'Playing' Around

Practitioners suggest that in some instances families move from a 'going around' which allows for understanding and access to services, to a 'going around' which deliberately uses the information and opinions they get from one practitioner to 'play with' the opinions and recommendations of another. Practitioners often refer to this as "playing one health professionals off against another". While practitioners

recognise and to some extent accept the need for families to 'go around', when they start to 'play around' the mood becomes more negative and the relationship becomes difficult and uncomfortable. As Fiona, a home care nurse describes:

> They were really bad at playing one health professional off against another. For example you would spend time going through tube feeding and some positioning with them and they would turn around and say "oh but the therapist said this", and you would think, "that is not what she told me." I had to be really careful that I had good line lines of communication with the other people this family was working with.
>
> Fiona
> Nurse E: 16:265

Fiona finds this experience particularly uncomfortable because the family always seems ready to find fault. The family focuses on the inconsistencies between practitioners and tries to exploit them. Fiona feels 'played with'. She knows the risks of being drawn into the game and that she may inadvertently undermine her colleagues practice and either lose her own credibility with the family or lose the relationship altogether. She responds carefully and ensures that she communicates well with her colleagues to avoid misunderstandings and inconsistencies. In keeping the lines of communication open she alerts her colleagues to the game that the family is playing.

Some practitioners believe that families 'play around' until they find the answers or opinions that they want to hear as Debra's story reflects:

> The family had a young boy who had debatable symptoms and diagnosis. The child's whole diagnosis was questionable and numerous paediatricians said there was nothing wrong with him. But the family was convinced that he had an illness and I think she just kept going around various doctors until she

found someone who agreed with them. Now it may be true that he does have an illness and that the other doctors were wrong but I would say this doctor had just given in to their pressure.

Debra
Nurse F: 3:346

Debra suggests that this family 'played around' until they got an opinion that supported their view of their child's illness. From Debra's perspective the practitioners succumbed to the pressure of the family. Debra believes that this family is successful in getting the answer they want because of the pressure they have applied while playing practitioners off against each other. Because of how the family has played with the practitioners Debra remains uncertain about the quality of the diagnosis and is cautious about her relationship with the family.

Heidegger (1996) describes "playing-in-the-world" (p.163) as an inauthentic way of being in the world. Note, this is a different slant on the notion of "play" to that described by Gadamer who suggests we are always in-the-play. According to Heidegger "playing-in-the-world" involves keeping track of the other person, looking out for what they say and how they will play. To play according to Heidegger is to act competitively, to be on guard and "be suspicious of foul play" (Nagel, 2001, p.300). From Heidegger's perspective "Under the mask of the for-one-another, the against-one-another is at play" (Heidegger, 1996, p.163). Heidegger suggests that "playing-in-the-world" is doomed to always to be an inauthentic way of existing because we are so busy watching out for the other, trying to outsmart the other, that it hinders our ability to take care of our issues. It appears that the practitioners who describe how families "play around" reflect Heidegger's notion of "playing-in-the-world". Fiona and Debra believe that practitioners must be on guard for families who 'play around'. They must watch for the counter moves and are careful of the ways in which they respond. This may preclude them from responding in ways that are beneficial to the family.

‘Playing around’ is a risky business

While practitioners recognise that ‘playing around’ may be indicative of the families’ distress and frustration, they see such actions as destructive to the family practitioner relationship:

> I am aware that families can start playing everybody off against each other. When families are really distressed and upset about what is happening to them they start to use mechanisms which are quite destructive. They start to play health professionals off against each other and start to seek opinions from everybody.
>
> Brian
> Dr B: 20:194

The suggestion from practitioners is that ‘playing around’ is a potentially dangerous and destructive act. But dangerous and destructive for whom? For the family or the practitioners? Or perhaps, as Heidegger (1996) suggests, the play takes both practitioners and families away from caring for the issues before them.

Certainly the stories of both practitioners and families suggest that if the families ‘play around’ too much they risk isolating themselves from the health professionals and services they need. Angela describes this in relation to a family with whom she is working:

> The mother has some very strong beliefs about what she needs to look after her child which is clearly more than she is able to get. … This mother chooses to battle and she has battled everybody, particularly Special Education Services. She fired four early intervention teachers, two speech language therapists and I am surprised she hasn’t fired me! It is bound to happen. It is good that she has kept fighting because she has been able to get more money in benefits than anyone for home schooling and therapy. It has been amazing. The Needs Assessor and I don’t know how she has managed to get all these benefits but it has come at a price. Now nobody in Special Education Services wants to work with her. A lot of the other health professionals involved find it difficult to work with her and her marriage is falling to bits. She is pushing everyone away. She continues to battle. It seems that for her

> this is the space she needs to be in. This is what she feels she must do at the moment.
>
> Angela
> Dr A: 15:204

From Angela's perspective, while the family has got more services for their child, they have played an aggressive and destructive game that has isolated them from a large percentage of the health care team.   Because of the mother's aggressive stance Angela becomes aware of the fragility of her own relationship with the family and wonders if it will survive. From the doctors perspective the family have 'out played' the game and it has now moved from a game to a battle. Several other practitioners recognise this movement from 'play' to 'battle' and suggest that it is at this point that the family lose the focus of who they are 'playing for':

> With some families I have worked with I have noticed that the mothers have got to the stage where they are so busy battling the system that they have lost touch with their child's needs.
>
> Debra
> Nurse F: 3:346

Gadamer (1982) suggests that when we play with "serious possibilities" (p.106) there is not only the freedom to choose but also an inherent danger that by becoming engrossed in the play we may "outplay" (p.106) the game. It is possible to become overcome or lost to the game. Like Heidegger (1996), Gadamer suggests that while we might choose to play, the inherent risk is that we might lose the very thing we set out to play for. Certainly the suggestion from the practitioners is that often this is the case when families 'play hard'. In the rigor of the game not only do they lose their relationship with practitioners, but also the focus on the very thing the family is playing for, the care and welfare of the child. Could this also not be true for the practitioners? Have they not also lost the very relationship that enables them to care for the family and child? Perhaps as Heidegger suggests it is the 'play' which hinders our ability to authentically care.

The risks of 'playing' seem to impact upon both family and practitioner. Several of the practitioners' stories suggest that being 'played with' is not only uncomfortable but also threatening and intimidating. This is particularly so for the new practitioner to the area as Donna, a new graduate nurse describes:

> I remember one family who I found it really hard to work with because they intimidated me. It was just after I had changed wards so my specialty had changed and I was not familiar with looking after children with cystic fibrosis. However it was not the fact that the family knew more about cystic fibrosis than me. The mother had great knowledge about the condition and was happy to teach me and I was happy to learn from her. I learnt a lot from her. What I found most intimidating was that she would run everybody down. It seemed that none of the staff had done anything right for her or her daughter. The young girl took it on as well and would often say "oh this one didn't do that" or "that one didn't even do". I knew a lot of the people they were talking about, nurses, doctors and registrars. I was always surprised by what they said about them, particularly the registrar because I thought he was a good doctor and would make a good paediatrician one-day. What they were saying really intimidated me and I avoided looking after them. I worried that they would pick on me and pull me to bits behind my back. When I couldn't avoiding looking after them I found myself going out of my way to please them right to cleaning her fingernails if they had asked! I would have done anything I could to keep them happy with me and not tell the next person who walked into the room how horrible I was.
>
> Donna
> Nurse D: 14:165

It is not the family's expertise that intimidates Donna, but how the family works with practitioners. From her perspective, the family is playing with their practitioners, criticising and reporting on their practice indirectly, going "behind their back". Donna believes that the family is constantly finding fault and attempting to play one practitioner off against another. She is surprised and disturbed by the criticism of respected and experienced colleagues and wonders, as a new practitioner in the area, how the family will perceive and report her practice to her colleagues. Donna finds it a difficult situation to deal with and attempts to minimise the risks by either avoiding

the relationship all together or when this is not possible going out of her way to please the family so that her practice will not be criticised. Donna tries not to play the game with the family, recognising the inherent dangers and her own vulnerability, however the discomfort and tension remains.

Setting the rules

Often the best way for practitioners to deal with the discomfort and risks of 'playing' is to attempt to gain control by setting some rules around how the family will play. Donna describes how a direct, honest approach helped her deal with a situation in which she felt she was being played:

> What I did was I decided to be direct and honest with them. I asked them to tell me direct to my face if they didn't like what I was doing or that they thought I was a "numb skull" rather than talking to the next person who walked in the room. The mother actually liked that approach and I think we were able to establish some sort of honesty between us. When she told me a story about something that had happened I was able to say "Oh come on, did it really happen that way or are you being bitchy". Or I would say "have you had a bad day and you really wanted to take it out on someone and that poor doctor just happened to be in the way." Sometimes I would have to say to her "well ok that nurse from the bureau hasn't got a lot of expertise in this area, it is not ideal that she is looking after you, but your child is the fittest patient on the ward. What harm can she possibly do because your child knows her condition better than anybody and she is going to keep an eye on her." I think that is they way I have come to work with families. I am direct and honest.
>
> Donna
> Nurse D: 14:165

Donna recognises that this family will continue to 'play around' but negotiates with the family. She accepts the game provided there are clear boundaries as to how the family will play. Other practitioners describe how they try to intervene in order to stop the game altogether as Brian describes:

> They start to play health professionals off against each other and start to seek opinions from everybody. What needs to happen is someone needs to sit

down with the family and say, "we don't want you to do that. I want you just to come and speak with me." It is an advantage if you haven't been the primary person involved because you come in from outside the situation.

Brian
Dr B: 16:477

The firm and honest approach by both practitioners suggests that if families are going to "play around" the rules governing the game need to be set. It appears that practitioners do not attempt to set the rules of engagement until they recognise that the family are 'playing'. Heidegger (1996) suggests that this is in fact how we 'play-in-the-world' that it is only in the course of the play that the rules are set and that these rules may vary within the course of the game (Inwood, 1999). Gadamer (1982) argues further that it is the evolving nature of the rules, which often catches the players unaware. Certainly this appears to be the case for the families in this study as they struggle to understand not only the meaning of their child's illness but also how to conduct their relationships with health professionals.

Are the families playing?

Questions remain: Is "playing around" a deliberate act by families to "play with" their practitioners? Do the families realise they are 'playing'? The stories of the families would suggest that they are unaware that they play. The families reflect the need to 'go around' and 'play' with the possibilities, contrasting, and comparing alternative opinions. But is this congruent with the 'playing in the world' described by Heidegger (1996)? Is this a suspicious and mistrustful encounter where each move is planned and each player tries to outplay the other? Certainly the data suggests that families can become suspicious of the opinions and information given to them by their practitioners. My sense is that having found a number of relationships to 'go around', the family sets out to utilise these relationships to develop their understanding of the child's illness so that they can take care of their child. Perhaps the difference in understanding between family and practitioner lies in the fact that the family recognises the need to move around the ontological circle while the practitioners attempt to 'deny' or control this movement. Could it be that this attempt

by practitioners to deny or overcome the circle provides the climate of misunderstanding that inhibits the development of an authentic relationship between family and practitioner?

'Going Around' is an essential part of the experience for families who have a child with a chronic illness. Families 'go around' not only because that is how the health care system is structured, but also because they discover that 'going around' allows them the opportunity to gain a fuller understanding of their child's illness and thus to participate in their child's care. While practitioners recognise the need for families to 'go around' and in some ways are essential parts of the circle, they provide little support for the family as they 'go around'. By denying or trying to overcome the circle, practitioners appear to foster a climate of mistrust so that movement for both family and practitioner becomes increasingly cautious. Both practitioner and family are unsure what move to make, what to watch out for, or what will be around the next turn. The issue appears to be not that one 'goes around' but that the way around is not negotiated. Perhaps, as Heidegger (1996) suggests, it is how we get into the circle which is important. If both practitioner and family enter the circle, seeing it as an opportunity to expand and enhance not only their understanding of the child's illness, but also in relation to the meaning of the illness experience and their relationship together, new and exciting stories will emerge. As will be seen in the following chapter, when a practitioner accepts the existence of the web, acts from 'in-between' and is prepared to assist the family as they 'go around' both family and practitioner come to a new understanding of what it means to work together. A new story emerges.

Chapter 9

Working within the Web: Fiona's Story

"Weave a window of *is* and let them see for themselves"

(Fawkes, 1999)

As has been seen from the preceding chapters the relationship between practitioners and families is conducted within a complex and fragile web which, despite its fragility and complexity, is central to the care of children with chronic illness. Families and practitioners move in and around the web in different ways, sometimes, from the 'in-between' holding things together, at other times 'going around' as a way of coming to understand the illness and options available. Sometimes the relationship threads are strong and easily traversed. At other times they are weak and fragile with both practitioner and family having to tread carefully. When one realises the intricacy and fragility of the threads, it is often difficult to imagine how relationships between practitioners and families can and do survive. If I were to remain focused on the individual threads or ways of operating I might miss the intricate and unique strength of the web.   In this chapter I will look at the web as a whole. Using one of the powerful stories given to me in this study I will demonstrate both the strength and resiliency of family-practitioner relationships and the unique and intricate manner in which families and practitioners can work together. I will also consider the qualities of practitioner practice, which develop and enhance family-practitioner relationships.

Fiona's Story:

There was a family I worked with where things were very difficult and we had to work through a number of issues. I had met this family for the first time when I was a charge nurse in the hospital. The little boy was around 6months old and had spastic quadriplegia and a lot of respiratory and feeding problems. He was in an out of hospital a lot with respiratory infections. His grandmother was caring for him at the time because his mother had disappeared and left him with the grandmother to look after.

Five years later I meet this family again when I was a community nurse and I discovered that Mum had returned and that there was a new dad on the scene. Because I had known the family before I was assigned this family. I had to do quite a lot of co-ordination with the rehabilitation service and other community groups. They needed a house and a lot of social support services and mum and dad had to learn to look after him. When I meet them again I thought they were a very caring couple and were really committed to make it work. So I thought this was my chance to help them out. However there were also a lot of health professionals involved with this family who had an attitude toward these parents and had really been gatekeepers in regard to the supports the family received. I think they had labelled the family as a 'difficult family' and felt that having abandoned this child they had no right to come back and take up caring for him again. The other health professional's attitude was almost "if you are going to make it that is fine, but we are not going to make it easy for you". However the health care team wanted him out in the community and the parents wanted to take him home so he finally did get home.

Once we got them all set up in their house my role was to support them by making sure they got all the information and supplies they needed and to educate them about looking after their son. At first I visited daily, because he was only five, tube fed and requiring frequent positioning. I needed to teach the parents how to do this. Then as they became confident in caring for him my visits became less frequent, every couple of days and then weekly. Over this period of time we built a trusting relationship and linked them in with a GP. I learnt not to try and make them 'run before they could walk' and to set clear boundaries around our relationship. I also found I would often have to repeat information several times in several different ways to ensure that they understood what they needed to do.

Then one day this little boy took a bit of a nosedive. He had been out of hospital a long time but then he just started fitting even though his anti-convulsant levels were fine. He had had a bit of a growth spurt and just went through a real fragile patch for about 6-10 months. He had one major fit that left him with a severe neurological impairment. He was really bad before this but this really turned things for the family and they lost confidence in their

ability to care for him. He had been in intensive care for a period a time and while he was in the ward the family was scared to take him home. While he was in hospital the family relied on me quite a lot. Because of the inconsistencies of having different people caring for them on the ward they found it difficult to keep up with things and communicate with the ward staff. So I would visit the ward every couple of days to keep them up to date and reassure them.

I think this family trusted me because they knew my personality. They knew that I would always be honest with them, if I didn't know something they knew that I would follow it up. When the consultant changed drugs or things like that I would explain things to them and the rationale for why the changes were made. All they wanted to know was why are things being changed? They didn't need the complex explanations just the simple stuff. I think it was that continuity where they knew me and knew that I would visit them in the community. I would always reassure them that they were doing well. I empathised with them, because it was pretty hard taking on a child like this. He was pretty much 24 hour care and at some stages he was awake in the night crying and screaming. He would have been about one of the hardest children to look after at home. They loved him to pieces and cared so much for him so I told them that they had done well. Occasionally I would have my camera with me when I went to visit so I would take a picture for them. The only pictures that family had on the wall of their home were the one's I had taken and so when we were working with the play specialist I would take a few more photos so that they would build up their own photo album. For this family a large piece was missing and it was good for them to have the photo's.

I think this family also trusted me because I was honest with them and occasionally I would have to say "look I am really worried." I remember one time when I visited that I was very concerned that the parents really didn't understand the severity of his illness. They thought that he was going to walk one day and I thought "no that is not going to happen, no miracle in the Womens Weekly is going to do that." So what I did is that I got his CT scan which had just a little bit of brain, probably about 10% of the normal brain tissue, on it. What I have noticed with Pasifika[13] families is that they are very visual, if you show them a weight gain chart or a picture they are so much more likely to understand what is happening. When I showed them the CT scan they were shocked and absolutely amazed. We talked about how his brain was a lot smaller than other people's brain and that the damage had been there since he was born. They seemed to respect me for being honest with them.

 I also needed to work with the grandparents. The grandparents thought that he was going to hospital all the time because the parents weren't looking after

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[13] Pasifika – a term used in New Zealand to refer to people whose ethnicity originates from one of the Pacific Islands.

him properly, so that had all sorts of implications for the family. So I became the parents advocate. I had seen these parents giving him very good and loving care so I went out of my way to make sure that the grandparents had the right story.

It was also the little things that made the difference. Making sure that they were OK about getting to their appointments. The parents usually kept track of what was coming up but at certain times in their lives things would go to custard and so I had to make sure that they had clear boundaries in regard to keeping appointments. I would be quite subtle in how I said it but I would say, "you need to go to that appointment".

I also worked quite well with the GP. We were on a first name basis and so I could ring him up and talk to him about things. I wrote to him a couple of times but most of our contact was verbal. The family also knew that I kept in contact with the GP. I would be able to say to the family "look you need to go and see your GP" and they would go and he would put them on antibiotics. Often he would say to me "I don't know what else to do". So I felt that I had built up trust with the family, they trusted my judgement. It was like if you say we have to go to the GP we have to go.

One day quite unexpectedly I received a bunch of flowers from this family. I discovered that they had sent my name through to a local newspaper and they gave me a bunch of flowers and I had my photo in the newspaper. It was rather sweet because this was a family who lived off the bones of their arse and didn't have any money but they had really appreciated the continuity I was able to give them. I hadn't been managing many children like this in the community at that stage so I learnt a lot from this family.

Fiona
Nurse E: 16:24

Fiona's story reveals a relationship between family and practitioner that has become successful and satisfying for both participants. Together she and the family have worked to build a unique, supportive and protective web for both child and family. A number of factors seem to have contributed to the success of this relationship.

Accepting that the web 'is'

Perhaps the relationship between Fiona and the family succeeds because both Fiona and the family have accepted that the web 'is'. Fiona acknowledges that the family

already works within an existing web of relationships: their own. She acknowledges the dynamic and complex nature of family relationships, recognising the tensions that arise, especially between the parents and grandparents. In addition to the tensions of family relationships, Fiona recognises the family has been thrown into practitioner relationships which may not be sympathetic to the family's situation. The fact that her colleagues label the family "difficult" suggests that an atmosphere of "existential mistrust" (Buber, 1957, pp.224,229) exists between the family and many of the practitioners they encounter. Yet Fiona is able to set the aside the views of her colleagues and enter the relationship with openness and a willingness to trust the family's ability to care for their child. She understands that the family will need to 'go around' and be 'in-between' a vast array of health practitioners if they are to effectively care for the child. The family's experience of "being in and out of hospital" suggests that they have already encountered the complex health care world in which they must exist. These experiences have enabled both family and practitioner to recognise the complex and dynamic nature of the child's illness. They have also experienced the atmosphere of uncertainty, of never knowing when the next "nose dive" will happen, when the next changes in treatment, will be required. Family and practitioner have discovered the sustained uncertainty described by Cohen (1993) which accompanies the journey through chronic illness.

Yet, despite this complexity and these tensions, neither practitioner nor family loose sight of the fact that the relationships exist 'for the sake of' the child. In her interactions with the family, Fiona constantly acknowledges the centrality of the child within the relationship. In working with the play specialist and by taking photographs for the photograph album, she acknowledges the importance of this child within its family. In recognising that the family "love him to pieces" and in her praise and affirmation of the family's care, she re-iterates the importance of not only of the child but also of the family within this relationship. Fiona and the family have discovered the essential nature of the "being for the sake of which" (Heidegger, 1996, p.181) that guides their journey together. Despite the complexity and demands of the

child's illness and health care world in which they exist, both family and practitioner commit to a relationship that ensures the best care for this child.

Fiona gently and patiently supports and walks alongside the family as they journey within the web. Sometimes she leads the way, sometimes she guides and directs, and at other times she just holds the connections so that the family can wend their own way around. She and the family acknowledge that the web 'is' the environment in which they must work together. Rather than attempt to deny or overcome the web of relationships they resolve to accept it, to move around the various relationships, to work together for the sake of the child.

Discovering the 'simple stuff'

Perhaps another reason why the relationship between Fiona and the family works so well is that they have discovered together the simplicity of a trusted relationship within the complexity of the web. From Fiona's perspective it has been the "simple stuff" which has lead to this successful relationship. 'Simple stuff' such as facilitating the families movement as they 'go around', ensuring the family is able to get to their appointments, facilitating their relationship with their family doctor, helping them understand the information they collect as they 'go around'. Fiona also finds herself 'going around' between practitioners, facilitating relationships, doing "a lot of co-ordination", following things up to ensure that relationships are maintained and services are delivered. Fiona discovers that in committing herself to assisting the family in their journey trust develops. She recognises that her honesty and openness facilitates the development of a relationship in what up until this time has been an untrustworthy world for this family. Perhaps as other authors have suggested, it is time which has allowed for trust to develop (Burke et al., 1991; Robinson, 1996; Thorne & Robinson, 1989). However Fiona's story suggests it is much more than this. It has been Fiona's willingness to, as Levinas (2002) would say, respond to the

"face of the other" (p.515) to be open and willing to accept and understand the family's illness experience.

Having responded and come to understand the family's perspective Fiona is able to build the family's confidence and understanding by using her 'in-between' position. She educates and explains the child's illness and changes to the family in ways that she knows they will understand. Fiona does not wait for their questions. She anticipates what they need to know, carefully pacing the amount and timing of the information given. Fiona does not expect the family to "run before they can walk". She walks the "narrow ridge" (Buber, 2002) with them, helping them understand and assimilate the different perspectives presented to them. It is not a relationship in which Fiona constantly 'leaps in' taking the child's care away from the family, but one in which she 'leaps ahead' anticipating the questions, possible options, and the ways in which the family can be strengthened and supported. By 'leaping ahead' she not only assists the family in their understanding but also helps them to weave their own unique web of relationships, which can provide support and protection to them and their child as they withstand the uncertainties of the child's illness. Perhaps Fiona has come to understand the privileged 'in-between' described by Bishop and Scudder (1990; 1991), which allows her to act because of her unique understanding of both family and practitioner? What is clear in this story is that Fiona uses her position well to facilitate the family's movement within the web.

For Fiona, this is not a nebulous relationship but a relationship that is negotiated and re-negotiated. As things change, and new people enter the web, Fiona gently but firmly sets the boundaries and expectations around the relationship not only with the family but also with her colleagues. When the child returns to hospital she renegotiates her role with the charge nurse manager, doctors and the family. When the General Practitioner enters she renegotiates the new roles, and boundaries within which she will operate. Fiona has discovered what Arendt (1998) describes as the impact of new entries into the web. As each new person enters the web they add their

own story, which will affect all those with whom they come in to contact. At each negotiation, and turn, family and practitioner colleagues come to respect Fiona's reliable and honest approach. They come to "trust her judgement" (p.184) not only in regard to the child's condition but also in how the relationships between the family and other practitioners can be developed and strengthened. The simplicity lies in Fiona being "honest with them" (p.183) and, from this honesty, trust develops. Fiona and the family have discovered the simplicity of an honest and trustworthy relationship amongst the complex and uncertain world of the child's illness.

In the complexity and simplicity a new understanding emerges

Fiona's story not only reflects the simplicity and complexity of the web but also how, through weaving new patterns, understanding emerges. Fiona recognises how she has "learnt a lot from this family", how her understanding of managing chronically ill children in the community has been influenced and changed by this experience. Likewise, in the public acknowledgement and the giving of the flowers, the family show their appreciation of how this relationship has changed and shaped their understanding and ability to care for their child, perhaps even influencing how they view other family practitioner relationships. Arendt (1998) suggests that it is the process of working in the web, in the word's and actions of the participants, that eventually new and unique life stories emerge. Fiona's story reflects the evolutionary nature of the relationship. Both family and practitioner entered the relationship with their own story, their own way of being-in-the-world. However, rather than remaining trapped within their own story, they appear to be open to the possibilities of a creating a new story. Neither family nor practitioner accepts that they have 'the answer' or 'the truth'. They remain open to discovering the possibilities that lie before them together and accept that as things change they will be changed by the experience. As they 'go around' and discover the 'in-between', new understandings, new stories, and new patterns evolve. Fiona and the family emerge with a new story and acknowledge and celebrate that together. Paradoxically the secret of a successful relationship lies not only in the "simple stuff", but also in the willingness to embrace

the complexities.   Being open to possibilities of new insights brings new understandings to the ever changing situation.

Embracing the phronesis of praxis

When reflecting upon stories like Fiona's which revealed the strength, resiliency and evolving nature of the relationship, I began to consider what was it about the practitioner's practice that enabled such relationships to develop.   I noticed a difference in the quality of relationship revealed in the stories. Some practitioners remained focused on the science of treating the child while others acted in response to both the child's illness and the situational influences. It appeared that it was when practitioners embraced what Aristotle described as the *phronesis* of *praxis* that deep and meaningful relationships developed (Aristotle, 1961)

Aristotle described the three major tasks of life as being that of *theoria, techne* and *praxis* and to each he ascribed a particular type of reasoning.   Theoria, the development of theory about substances and properties, requires *episteme*, reasoning which involves formal logic and mathematical calculation. Techne, the making of products, requires *poiesis*, the reason used to enable a person to put things together. Praxis, acting for the good of others, requires *phronesis*, practical reasoning (Polkinghorne, 2004). Both theoria and techne have an important role in life and the care of children with chronic illness, for in these lies the knowledge necessary for diagnosis and treatment. However it is in praxis, acting for the good of others, that the quality of the relationship between families and practitioners is revealed.

Gadamer (1982) provides a useful analysis of how Aristotle's notion of phronesis can be applied to hermeneutic understanding. Using his interpretation I will describe the ability of the practitioners to embrace the phronesis of praxis, I believe it is this that enables them to build and develop successful relationships with families.

Phronesis is situated and requires action.

One of the qualities of successful relationship is that it is situated both within the community of meaning and within action. As Gadamer describes "practice, as the character of being alive, stands between activity and situatedeness" (Gadamer, 1981, p.90). Phronesis according to Aristotle requires "self knowledge", the ability of the practitioner to recognise the situation in which they are placed and "employ its knowledge in the immediacy of a given situation" (Gadamer, 1982, p.322). Thus phronesis is not in opposition to techne but is something that complements and enhances techne. Flaming (2001) suggests that techne, as laid out in clinical guidelines and the techniques of practice, provides answers to the technical questions of the situation but it does not answer the practical questions. In Fiona's story it was the techne of the CT scan which provided the basis for diagnosis and treatment, but it was in the phronesis, the act of situating these results for the family, that lead to understanding.

Phronesis also requires action. Gadamer (1982), drawing from Aristotle, argues that this is one of distinctions between techne and praxis. Techne involves making while praxis involves the act of doing. Making a moral decision is the act "of doing the right thing in a particular situation" (Gadamer, 1982, p.317). This reflects the notion of phronesis. Fiona was able to make decisions regarding tube feeding and positioning based on her techne but it was in the doing, the showing and teaching of the family that she revealed her praxis. I believe that the practitioners who are able recognise and act in response to unique situations have a more successful and mutually satisfying relationship with families.

Phronesis requires 'moral reflection'

Another quality of successful relationships is the recognition that praxis is interpersonal and relational and relies on the development of sympathetic understanding for the person. Gadamer (1982) suggests the person who merely applies technical knowledge and claims to be the expert, does not necessarily develop a sympathetic understanding for that person. Sympathetic understanding comes when

"the person who is understanding does not know and judge as one who stands apart and unaffected but rather he thinks along with the other from the specific bond of belonging, as if he too was affected" (Gadamer, 1982, p.323). This sympathetic understanding develops when the person utilises the Aristotelian notion of moral reflection, the ability to consider the situation from the other person's perspective. Fiona's story illustrates that practitioners who embrace the phronesis of praxis, reflect upon what this situation might be like from the family's perspective and utilise this understanding in their interaction with the family. Fiona reflected on what it might be like to care for this child 24 hours a day, to have no photographic record of your child's development, to encounter conflicting and confusing advice from the wider family and other practitioners. Following each reflection she acted. Praxis lies not only in the phronesis of practical reasoning, but also in the action or application of this reasoning. Moral reflection in the phronesis of praxis, requires much more than empathy. It requires the practical application of this sympathetic understanding of the other to a given situation. But, as Gadamer (1981) notes, the development of understanding is not a one way process. It is a reciprocal process that involves the giving and taking of advice and counsel. It requires families and practitioners to be open and ready to respond to each other and allow new understanding to emerge. When families and practitioners remain open and responsive to the possibility of learning from each other new understandings emerge and better relationships develop.

Phronesis requires a 'moral attitude'

The final aspect of the phronesis of praxis that contributes to the effectiveness of family practitioner relationships is something that Gadamer (1982) describes as "moral knowledge" (p.91). Aristotle believes it is the application of moral knowledge that distinguishes techne from praxis (Gadamer, 1982). To practice phronetically, requires that a person is able to recognise not only the goal that is being pursued but the ability to make a distinction between what is the proper and improper in a given situation. Gadamer uses the term 'Prohairesis' from which the concept of phronesis arises to mean "preference" and "prior choice" (Gadamer, 1981, p.91).

Therefore, to do good, the practitioner must recognise that their are a number of possible alternative actions which may be taken and make a purposeful choice as to which action to follow. As Benner (2000) explains, means and ends are inextricably linked, each blending and responding to the other

Benner (2000) brings the term phronesis to nursing practice: "phronesis in nursing requires a keen understanding of the ends of nursing practice, making qualitative distinctions that guide responses, reasoning across transitions and the ability to form healing relationships" (p.13). In my study effective relationships appear to develop when practitioners utilise the moral attitude of phronesis similar to that described by Gadamer and Benner. In Fiona's story, she and the family recognised a mutual goal of getting this little boy home. Together they made a number of choices in regard to how this would be achieved through each transition of the illness experience. Fiona and the family responded to changing situations and acted in accordance with what seemed the best option at the time. The path of chronic illness is dynamic and uncertain (M. H. Cohen, 1993). The ability of the practitioner to have a moral attitude which supports and assist families in setting and re-setting goals and in making and re-making choices, always for the good of the child leads to strong and resilient relationships.

But is it really "simple stuff"?

Fiona and other families and practitioners frequently referred to good relationships being characterised by the 'simple stuff'. But is it really simple? I suggest that Fiona's story, and similar stories from other participants, reflect the complex and diverse nature of good practice. Perhaps this practice has become 'simple' to families and practitioners because it is embodied within their experience of working together? Many participants found it difficult to articulate the qualities of a good relationship. It was often when something extraordinary occurred, like the giving of flowers, that the qualities of a good relationship were revealed to the practitioner. I believe the heart of good practitioner/family relationship lies in the 'simple stuff', which translates into the ability to embrace the phronesis of praxis. Phronesis comes from

encountering the situations in which practice occurs with all its complexity and ambiguity. Benner (2000) suggests that practitioners come to understand the situation and how to act through dialogue and interaction with others. It is not hard to take a photo of a child. It is 'simple stuff'. Yet recognising the family for whom a photo would be a special gift requires 'taking notice'. It is to be attuned to the uniqueness of this family, and to take the step to respond to the call of care. It is to know that the call will be different in another family, and different for this family at another time.

The first step for both practitioners and families is to understand the existence of the web of relationships. It is the willingness of both families and practitioners to work within it that which allows them to come to a perceptive and responsive understanding of each other. Mapping out and travelling the web of relationships provides not only the foundation for relationship but also the basis on which future practice can be enhanced and developed.

Conclusion

In this chapter I have described the strength and resiliency of practitioner- family relationships as revealed in Fiona's story and the qualities that I believe contribute to the success of such relationships. Successful relationships require not only an acknowledgement of the unique nature of each illness experience, each web, but also an openness and sympathetic understanding of the other. Relationships work well when practitioners support and guide families as they build and traverse the web, acknowledging the options and choices before them so that decisions are made which will assist them in setting and reaching mutually agreed goals. It is the praxis, in the making and doing of good, for the sake of the child, that new understandings and new stories develop. Generating new insights from practice experience strengthens not only the relationship between family and practitioner but also the future practice of the practitioner. For it is in the experience, in the praxis of doing together, that the strength and resiliency of the practitioner/family relationships is revealed. The following chapter I will discuss how understanding the relationship between families

and practitioners in this way challenges and informs the practice of health practitioners.

Illustration by William Age 4 years

Chapter 10

Back to practice

"Every journey begins with but a small step.
And every day is a chance for a new, small step in the right direction."
(Stepanek, 2002, p.60)

This thesis has explored the meaning of the relationship between health professionals and families who have a child with a chronic illness. Using the stories of both practitioners and families I have sought to uncover what it is to be in relationship with each other. What is it that makes this relationship what it is? What makes it different from other relationships? I have uncovered a number of meanings which, when brought together, bring to light an understanding of the relationship between health professionals and families. To leave these understandings adrift within a piece of scholarly work would fail to acknowledge the connectedness of phenomenological study to the "being-in-the-world". This chapter therefore completes a circle by bringing my understandings back to the world of practice from whence this study arose. I recognise however that the circle is never complete and understanding will continue to evolve and develop. I bring this understanding to the practice world as a way of challenging and informing the everyday world of paediatric practice.

Being within a web of relationships

This study has shown that being in relationship within the context of chronic childhood illness involves not just one relationship but many. To obtain the best care for their child, families must weave and negotiate a unique network of relationships between practitioners from many different disciplines. This intricate web of relationships is shaped not only by the child's illness but also by each of the participants who enter into the web. My interpretations have shown that the family practitioner relationship does not develop in the predictable or linear fashion

described by other authors (see Chapter 3). It takes different twists and turns as relationships are formed, developed, withdrawn, and reformed according to the demands of the child's illness. Each web develops its own unique pattern reflecting the diverse and uncertain nature of chronic illness, uniquely woven to support the child through the illness experience. Yet amazingly, as was shown in Chapter six the child is left outside this web. The findings of this study support other studies (Bircher, 2000; Hogan et al., 1999; Sallfors et al., 2002; Sartain et al., 2000) that show the difficulties children have in being heard within health care relationships.

Because of their central position in relation to all these relationships, child and family are most likely to experience and see the complex and intricate patterns of the web. It is the family who sees the ambiguity, paradox and tensions inherent in the many relationships. As they move within the web they come to know the unpredictable and uncertain nature of not only the illness but also the practitioners with whom they work. They also discover that they are often in a position to see the whole picture, to see the gaps and identify the needs. As described in Chapter two, there is a sense that for many families the only way forward is to 'take control' of the relationships. However their ability to do this, or even to build comfortable relationships, is often frustrated by a complex and fragmented health service, practitioner behaviour and lack of information in regard to what services are available to them. No one 'shows them around'. They have to find their own way, and because of uncertainty as to which connections are important, the family often find themselves weaving an increasingly complex web that they must then negotiate.

In contrast, practitioners, busy acting on the component of the illness to which they are assigned, do not always see the intricate patterns that surround each family. In an increasingly specialised health care service where the reason for the encounter is often determined by the diagnosis, treatment offered or body part to be fixed, it is difficult for practitioners to see beyond their own sphere of expertise. Paediatric services in New Zealand are fragmented (see Chapter 2) and therefore the structure of

the encounter makes it difficult for each health professional to consider his/her relationship alongside those of other practitioners. There are few opportunities and little need to consider the worlds of the others. The practitioner concentrates on his/her practice, focusing on what they have to do and what parts of the illness they must fix or treat. This structuring of the health care relationship draws practitioners to remain in what Buber (1970) would call the world of "I-it". This is a comfortable world when life is busy. It allows for relationships to be structured and organised, fitting well in practice paradigms based on predictable and certain outcomes. To see the web and its complexity, requires practitioners to move from the world of "I-It" to "I-You" (Buber, 1970). In doing so they see the other and enter into a reciprocal relationship that is neither predictable nor certain. Leaving the "I-It" world requires practitioners to acknowledge that the way forward is not certain. This creates tensions for practitioners and families (see Chapter 8). When practitioners move to Buber's world of "I-You" they must acknowledge and attend to the other, laying open their opinions and views alongside that of the family and other practitioners. It is a messy and complicated way to work because it reveals the inconsistencies and ambiguities that lie within practice. It takes time and is not always congruent with current health care structures. While other studies have described uncertainty in chronic illness and in practice (M. H. Cohen, 1993; Horner, 1997; J. Katz, 1984b; Thomlinson, 2002), I believe this study reveals the discomfort and tensions experienced by practitioners who recognise uncertainty. When practitioners are open to seeing the other and willing to embrace uncertainty they catch a glimpse of the intricate and unique web that surrounds each family.

While I have described in Chapter three how each professional discipline comes to the relationship with a different understanding of how relationships between families should be conducted this study showed no obvious differences between the stories of the respective disciplines. It became evident during the interviews that they each brought their own understanding of the nature of a professional relationship, but often described something quite different in terms of their own practice. As they told their stories they became almost apologetic as though they did not believe that their

practice was good enough. They would often begin or end stories by saying "I know this is not how you should do it" or "I am not sure if this is how my colleagues would operate". What this study has shown is that there are many similarities in the experience of health professionals when they enter into relationships with families regardless of discipline. Thus I would be cautious in ascribing particular relational styles, attributes or roles to each profession as Bishop and Scudder (1990; 1991) seem to have done when ascribing the 'inbetween' relationship with patients to nurses. It seems to me that relationships traverse disciplinary boundaries. All health professionals experience being "inbetween', and describe experiencing rewarding and reciprocal relationships. What appears to be missing are opportunities to discuss these similarities and use the knowledge and experiences gained across disciplines to inform practice. Reflecting on practice across disciplines will, I believe, help practitioners see the web and their part within it.

The simple within the complex

The pattern of the web is complex and intricately woven. Yet inherent in this complexity lies what practitioners and families describe as "simple stuff". They are referring to relationships that support and assist families to find their way around chronic illness. Chapters six and nine have revealed the simple yet complex nature of the phenomenon. Openness and willingness to see, notice and respond to 'the face of the other' (Levinas, 2002) is essential if the uniqueness of each family and each situation is to be recognised. It is to acknowledge the complexities, ambiguities, and uncertainties that lie within each family/practitioner relationship. It is about being open to a number of views, a number of ways of moving forward together, accepting that things may not always go as planned. This requires flexibility, an ability to respond to changing situations and different styles of relating. It means considering a world outside prescribed clinical guidelines or specified communication techniques. Doing the "simple stuff" requires practitioners to be willing to guide families through the world of chronic illness, showing them all the possible options and negotiating which relationships work best for them. The "simple stuff" means letting go of

unnecessary connections that only serve to complicate and confuse. In doing the "simple stuff" practitioners help families weave a web that fits their unique needs and serves their purpose in supporting the child.

While it may sound simple the families in this study did not always encounter the simple acts of practitioners. As I have described in Chapters seven and eight families often became confused and trapped within the complexity of the web. Families discover that practitioners do not always recognise the unique needs of their child and family, their expertise and role in decision-making. Families become frustrated when practitioners do not appear to acknowledge or communicate with each other and leave families to negotiate and deal with the inconsistencies. Many families become suspicious that practitioners are using the complexity of managing chronic illness to deliberately exclude them from participating in their child's care.

This study has shown that the art of the simple lies in the ability to embrace the simple within the complex. It is to recognise that the two are inextricably linked to each other and can not be separated. The art of the simple lies in being able to move between the world of 'I-It' and 'I-You' (Buber, 1970) and to balance techne with praxis (Gadamer, 1981). Perhaps the ability of practitioner to practice the art of the simple comes as some authors suggest, with experience and the development of expert practice (Benner, 1984; Jackson, 2001; Jensen et al., 2000; Jensen et al., 1997). With one exception all of the practitioners in this study had many years experience. However the stories of both practitioners and families illustrate that being an experienced or expert practitioner does not necessarily guarantee satisfactory relationships. The art of the simple may lie to some extent in experience but it more importantly depends on the ability and willingness of the participants in the relationship to recognise the humanity of the other.

Revealing one's humanity poses challenges and risks to both practitioners and families. Revealing one's humanity in a family/practitioner relationship requires time, proximity and letting go of the perception that the practitioner is expert and will know the way forward. It involves trusting the other and taking the risk of laying oneself open to the other, revealing the hopes, dreams and uncertainties that lie within the situation. This is not an easy thing to do within the current context of brief medical encounters, where relationships change constantly. It is also difficult for practitioners to reveal their humanity when the traditional views of their professions believe that professionalism requires maintaining distance rather than closeness with the families. When practitioners in this study told stories of coming close to families, they often talked in hushed tones, as if revealing a secret. Coming close to families is not what one is 'supposed to do'. Practitioners are concerned about the risks of coming close. Just as the journey with chronic illness is difficult and emotionally taxing for families so it is for practitioners. The difference for the family is that they are taking one journey with many practitioners while each practitioner journeys with many families. Practitioners are concerned with the emotional burden of bearing many close and personal relationships. The following excerpt from a poem entitled "The Good Physician" captures the tension experienced by many practitioners in this study:

> "If I care too much,
> Yours and all the others' pains will drain, weaken and kill me.
> My love must be shallow enough
> For both of us to survive"
> (Brown, 1995, p.59).

Perhaps as Ford and Turner (2001) and Totka (1996) suggest, it is not possible for practitioners to develop a deep and meaningful relationship with every family they meet. However, as I have described in Chapter nine, it is when both practitioner and family come to know 'the face' of the other that unique, effective and satisfying relationships develop.

This study has also shown that although a successful family/practitioner relationship might ease a family's journey within the world of chronic illness the family does not always see this as essential. As is described in Chapters seven, eight and nine, families will endure difficult relationships with practitioners if they get the care they need for their child. This finding supports Weaver's (1999) assertion that it is not the quality of the relationship with the practitioner that is of primary importance but rather the commitment, and expertise of the practitioner to help them get the very best care and treatment for their child. It is Heidegger's notion of the "for sake of which" (Heidegger, 1996, p.181) that leads families in the world of chronic childhood illness. I am not suggesting that practitioners should not pay attention to their relationships with families, but rather that practitioners need to recognise that their relationship may not be seen by families as essential to the care of the child. In a paradoxical way relationships do and do not matter. Nevertheless effective relationships are treasured and have a huge impact on the illness experience.

Implications for practice

The findings of this study have important implications for clinical practice, not only in relation to how the relationship is conducted between family and practitioners but also the health care service in which the relationship occurs. This section will consider the challenges for practice particularly in relation to recognising and honouring of the expertise of all participants, and in making the web visible so that practitioners and families are able to journey together more easily and comfortably for the sake of the child.

Honouring the expertise of the other

This study has shown that each of the participants brings their own expertise to the relationship. Unfortunately the expertise of each participant is not always recognised, valued or afforded the same consideration. Expertise within the context of this discussion refers to knowledge and skill in regard to the child's illness, developed

through experience, training and practice (Higgs & Bithell, 2001). It is more than just technical knowledge and skills but engaged "know-how" (Richardson, 2001, p.44). Expertise is often equated with experts and thus is more often attributed to health professionals. Yet I believe that this study has shown that children and families also bring their own expertise to the relationship. The type of expertise each participant brings however is different. As other authors have described, doctors bring expertise in regard to the nature of disease and methods of treatment (Freidson, 1988; Sefton, 2001), the nurse saliency, observation, informed risk taking and the ability to integrate care of the family (Hardy, Garbett, Titchen, & Manley, 2002; Titchen, 2001). Allied professionals also bring their speciality knowledge and clinical reasoning, in regard to the treatment of the child within their family (Jackson, 2001; Jensen et al., 2000). This study has also shown that families and children develop their own expertise through their experience of living with the illness on a day to day basis. Recall in Chapter six Lynda and her family's knowledge about diet and feeding regime and Erin's expertise in the management of her diabetes. Children and families not only develop quite sophisticated medical knowledge about the condition and management but are also able to integrate and adjust this into the lifestyle of the family. Unfortunately, as has been shown in other studies, children and families do not believe that their expertise is recognised, respected or given value equal to that of health professionals (Balling & McCubbin, 2001; Morath, 2003). As described in Chapter two, health professional expertise, especially medical expertise continues to be afforded greater value than that of the child or family. The relationship and role of family/patient expertise receives little attention in contemporary health professional literature (Hardy et al., 2002; Higgs & Titchen, 2001). Despite the professional rhetoric regarding partnership and family centred care we have yet to see in practice family/practitioner interactions that reflect a relationship between experts. Morath (2003) suggests that the wisdom, resiliency and capacities of families along with the knowledge and skill of the health care workforce are a "source of abundance within the health care system" (p.19) yet the findings of this study suggest that this "source of abundance" is not being fully utilised. I believe that honouring and using the expertise of all participants in family/practitioner

relationships would offer the child more cohesive and effective care and expand and enrich the practice of both family and practitioner.

Making the web visible

The intricacies of a spider web often remains invisible until light shines upon it. The findings of this study have shown that the web of relationships which surrounds a child with a chronic illness similarly remains hidden, particularly to health professionals, unless opportunities are made to make it visible. While it is likely the patterns and intricacies will be unseen on a daily basis, it is important that all participants in the family/practitioner relationship regularly review and come to appreciate the complexities of the web. Difficulties in seeing the web often relate to fragmented health services, poor communication between health professionals, and difficulties in accessing information. Chapter seven and eight describe the frustration for families and practitioners when information is not shared and they find themselves 'between' or 'going around' to resolve the contradictions because the work of each participant is not visible. It is important for families to have access to the clinical record. The families recognised that it not only contains information about their child's illness and treatment but also includes a picture of the web. This study has shown that this record is usually held by the individual health services and thus is not readily available to those who are often in the best position to see the web: the family. I believe that the findings of this study call for a less fragmented and more supportive health care service, with more opportunities for communication and information sharing across disciplines and between family and practitioner. This is not to suggest that health care services to children should become less specialised but that the links between services allow for more seamless movement. It is the child and families interest that there is the opportunity for participants within the web to have equal access to information and each other. Berry, Seidders and Wilder (2003) suggest that a patient centred access model utilising information technology and alignment of care with need and preference may provide the way forward in the 21st century. They believe that such a model provides better access for patients and practitioners and also strengthens the patient-provider relationship. Other authors

have also suggested that the use of information technology, such as web portals, e-mail and telemedicine, can provide more co-ordinated care for patients and families, and allows the health professionals to appreciate and learn from the expertise of those involved in the care of the patient (Lobe, 2004; Marcin et al., 2004; Meadows & Chaiken, 2003). While this literature comes from the North American managed care environment I think that within the New Zealand, where geographical distance and limited specialist services are a reality, this technology would provide a excellent medium for making the web visible. The Ministry of Health's Child Health Information Strategy (CHIS) (2003) suggests that information systems at a national level may along with improving services and outcomes for all children could "simplify multidisciplinary management of complex health conditions" (p.5). The recent introduction of Telepaediatrics in New Zealand already offers a vehicle for better access and communication between services and health professionals (New Zealand TelePaediatric Service, 2004). However current strategies remain focused on communication between health professionals and are controlled and administered by health professionals and health services. I believe such services and strategies could be extended and expanded to include children and families. While I acknowledge that on a everyday basis the web may recede into invisibility, this could be the means by which light is brought to the web more regularly.

Being a 'companion' on the journey

When considering the findings of this study and how the relationship between family/practitioner might operate I am drawn again to Buber's metaphor of the "narrow ridge" (Buber, 2002, p.218). As already described families walk a narrow and often uncertain path when they have a child with a chronic illness. It is a place where they often have to balance the contradictions of practitioner advice and make decisions as to how to proceed. I see the practitioner relationship with the family as one of companion. A companion is someone who from time to time supports the family and their journey. This is an intermittent relationship because as described in this study there are often times when the child is well or the illness is under control that families can and do walk unaccompanied. I use the word 'companion' because I

wish to create the image of walking alongside, journeying together, sharing expertise, sharing the uncertainty and planning the way forward together. I see the 'companion' changing as the health needs of the child and family change. Sometimes it may be the doctor, sometimes the nurse. At other points of the journey there may be several companions who support and help the family maintain their balance on the narrow ridge. Titchen (2001) proposes a "skilled companionship" (p.69) model for nurse/patient relationship and while her work has resonancy with the companion relationship I am proposing, her model places more emphasis on the nursing role. Although the contribution of the patient is included within Titchen's conceptual model the relationship is still predominantly practitioner led and does not allow for changes in leadership and the times when the family will want to walk unaccompanied. The 'companion relationship' I am proposing also has some similarities to the notion of partnership promoted within paediatric practice (Casey, 1988; Coyne, 1996; Farrell, 1992), especially in relation to negotiation and power sharing. However I am promoting a notion of companionship that provides more opportunities for movement and flux in regard to who leads or holds the power at any given time. At various points along the journey the family or practitioners have greater knowledge and power in relation to the child's illness. Wilson's (2001) study supported my findings in describing that in New Zealand there is an "ebb and flow of power" (p.299) in the relationship between families and child health nurses. A 'companion relationship' accommodates not only the uncertainty of the journey but also this shifting power dynamic. It is always open to and expecting change.

The companion relationship will however come with many of the same challenges as existing relationships. There will be, as now, the risk that the family's choice of companions may pose a risk to the child and therefore this type of relationship will require the same protective state systems and legislation currently offered to children. There may be times when the family find themselves with too many or too few companions. I therefore believe that the family will require an 'agent': someone who can guide or show the family around the various health services available. The agent will be a practitioner who can explore with the family what service various health

professionals' offer, in what circumstances they might be useful and how they might access the service when they need it. Further they will seek out and renegotiate health care relationships with the family when situations change. In a similar way to the agent in the marketing world (Mitchell, 2001), the agent turns the relationship "right side up" (p.21) helping the family seek out and extract value from health professionals. I do not believe that the 'agent' role should be attributed to one professional discipline although some may be better positioned to take up this role than others. The 'agent' does not necessarily have to be a specialist in the child's condition but is a practitioner who knows what services are available or how to find the services that may be required.

What I am arguing is that it is time to turn the relationship "right side up". It is time to put the child and family in control of how the journey through chronic illness will proceed and who will accompany them. As has been suggested by a number of author's, healthcare services in the 21st century need be focused on building relationships that meet health care consumer expectations and are consumer driven (Morath, 2003; C. M. Scott, 2003; Studer, 2003). Becoming a 'companion' and/or 'agent' with families and children who have a chronic illness provides a way of forward in regard to a child and family centred relationship.

Implications for education

In addition to practice considerations, the findings of this study have implications for the education of health professionals. How can health professionals be taught how to be in relationship with a family? Certainly the findings of this study would concur with other authors (Candib, 1995; Epstein et al., 1993) that the teaching of communication strategies alone does not prepare health professionals for their relationship with families. I argue that the relationship between family and practitioner is all about 'being human'. This requires being open to the humanity of each other, of recognising the uniqueness of each situation and the impact this has on

all the participants in the relationship. Teaching communication strategies or collaborative frameworks addresses only a part of the relationship and does not reflect the dynamic and unique nature of each relationship.

Teaching strategies are needed that provide practitioners with understanding of the web, its tensions and the complex yet simple nature of health care relationships. Opportunities to explore, link and value both the phronesis and techne of practice need to be provided. Narrative pedagogy is one way of achieving this. Narrative pedagogy attends to the sharing and interpreting of practice experiences. It seeks to uncover that which may be hidden or unspoken and its significance for the participants (Andrews et al., 2001; Diekelmann, 2001; Ironside, 2003; Swenson & Sims, 2003). Practitioners need to hear the experiential stories of families and children. They need to be given opportunities, across disciplines, to reflect on the tensions inherent within these complex and often intense relationships. To reflect and learn from the practice of others will bring to play the Aristotelian notion of 'moral reflection' as described by Gadamer (1982). Because this is not always possible within the busy world of practice, opportunities to share practice experiences must be created within undergraduate programs, professional development programmes and conferences. At a recent scientific meeting of the Paediatric Society of New Zealand a colleague and I had an opportunity to present using practice narratives. For many of the medical staff attending this was an unfamiliar way of considering practice issues. Yet it provoked discussion across disciplines regarding the challenges of practice within paediatrics. On numerous occasions during this study, practitioners thanked me for allowing them the opportunity to tell their story and reflect on their practice. They also expressed interest in hearing and comparing experiences with other colleagues. Reflecting on stories from practice will, I believe, assist development of relationship skills across the health care disciplines. It "brings the complexity complete with conundrums and uncertainty to the classroom" (Ironside, 2003, p.514). It also allows for "converging conversations" (Diekelmann, 2001, p.65) between conventional education strategies. It moves the conversation beyond the narrow confines of patient management, as currently contained within case

review, to a reflection on what it is to practice, combining both the techne and phronesis of practice. Currently mainly used within nursing education, I believe that narrative pedagogy, with its emphasis on engendering community, provides an exciting way forward for cross discipline understanding and learning.

While narrative pedagogies provide one way of facilitating new understandings of what it is to be in relationship, the question remains can we teach the 'being' of relationship to practitioners? For me this question remains open. While I believe the use of narrative can help practitioners learn and understand the complex and intricate nature of relationships within practice it cannot teach humanity. To be in relationship is to be human. If a practitioner is unable to grasp or be open to the humanity of the other I believe no matter how good our teaching strategies are, they will not be able to establish effective relationships with families. Perhaps in our selection process for entry into the health care professions we must pay greater attention to ensuring that potential practitioners have not only the academic skills required but also the interpersonal skills necessary to conduct health care relationships.

Having discussed the educational implications for practitioners, the question arises do we need to prepare families for a 'companion relationship'? I believe the current health care environment has, in many respects, already prepared them for this type of relationships. As I have shown in Chapter two the consumer view of health care services and the growing realisation of patient rights has led families to believe that they can and will have a say in how they conduct their relationships with health professionals. The problem is that this has not become a reality for many families when they encounter health professionals. It appears from this study that satisfactory relationships develop when families meet the humanity of practitioners and are able to negotiate their relationships with practitioners. Recall how many families wanted the opportunity to "work alongside" (Turner & Shanks, 1996, p.60), to have the practitioner provide a "safety net" (Family K:17:57) or "professional backup" (Family C:6:35) or to have someone who is "working with you" (Family D:7:101). I

believe that families are ready and waiting to engage in a 'companion relationship'. What is necessary is that practitioners are also prepared for and willing to engage in mutually satisfactory ways.

How can we prepare children to engage in the relationship? This study has shown that children like their families, are ready to engage but they are rarely provided with a hearing. This is a significant issue not only for practitioners, but also for adult family members. Adults need to consider how can they acknowledge and value the contributions of children within the relationship? Adults need to respond to children in a way that allows them to contribute their thoughts, feelings and opinions. Rather than 'leaping in' we need to stop and listen and value their contribution. Imagine how the practices of the dieticians, nurses and doctors could have been transformed if they had carefully listened to the thoughts and feelings of Lynda and Erin (see Chapter 6). Lynda and Erin's stories have challenged my own practice and response to children. Since undertaking this study I have found myself listening more closely to the stories of children. I have stopped more often to consider whether my words, my actions, my failure to await the response of children may have closed relationships down. In doing this I have not only been surprised and impressed by the understanding of children about their illness but have learnt new ways to respond to their health care needs. Children with chronic illness have much to offer their families and practitioners in relation to understanding and making ones way through the complex world of chronic illness. As adults what we need to open ourselves to the possibilities they afford.

Recommendations for practice

In summary, the key recommendations from this study are:

1. Harness and expand the expertise of each participant. This means practitioners and families need to be given time during each encounter to discuss their

observations, understandings and recommendations in regard to managing the child's illness.

2. Pay particular attention to the understanding of the child about their illness. This means allowing children time to tell their story their way. It calls for child friendly language and strategies such as play or art which assist children in communicating their understanding of the illness experience.

3. Develop care management plans that include input from each person involved, are integrated to avoid contradiction and to create synergy, and that are owned by the family.

4. Reveal the web and be mindful of the need for change. This can be incorporated into the everyday practice of the practitioner by asking the family at each encounter questions such as; Who do you see in relation to your child's illness? Who have you seen since we last meet? Is there anyone else you would like to see or believe you no longer need to see?

5. Explore opportunities afforded by communication technology to make any clinical records or relevant information accessible to the family and other practitioners.

6. Develop strategies to involve the child and family more in establishing, monitoring and updating the clinical record, and to personalise it in a way that brings human faces to the experience. For example, include photographs, stories, children's artwork and celebrations of milestones.

7. Encourage District Health Boards to review processes and systems to ensure that services have the characteristics of availability, appropriateness, preference and timeliness suggested by Berry et al (2003). Ensuring that systems support interdisciplinary communication and the child and families access to information, services and the health professionals they require.

8. Develop an understanding of the relationship between practitioners and families as being that of 'companion'.

9. Establish the role of 'agent' to assist families in negotiating their way around health care services and relationships.

10. Explore the use of narrative pedagogy within professional education forums and conferences as a way of developing practitioner's relationship skills.

11. Engage in conversations across disciplines to allow the common experience and understanding of the human face of practice to be revealed. These conversations may be incorporated into current interdisciplinary meetings e.g. case conferences, team meetings, or conferences.

12. Review and develop the entry criteria into the health professions to ensure that consideration is given to interpersonal and academic skills.

Study limitation and the need for future research

Coming to the end of this study there is a sense that although much has been done there is much more to do. While I come to this point with a sense of completion, there is also a tension that not all voices have been heard, not all meanings revealed. I recognise that the spiral of understanding is still open, that if I were to circle again more would be revealed. But with all studies there comes an end point dictated by my very being in the world. Yet it is also a beginning point for new understandings and new areas of research. This section will discuss some of the limitations of this research study and the possible areas of future research.

The meanings uncovered in this study relate to a specific group of participants and do not represent all the voices that exist within the world of chronic childhood illness. The inclusion criteria required the participants to speak fluent English and therefore the voices of families who come from other cultures are not well represented. This group of participants is not reflective of the diverse ethnicity's now living in New Zealand. The meanings uncovered reflect a predominantly Pakeha understanding of the experience. Children were also not well represented. While I had anticipated that

the voices of children would be heard within the family group interview, this only occurred to a limited extent. The recruitment process required to meet the ethical guidelines required the use of an intermediary to approach potential participants. Because practitioners who understood the nature of the study approached many of the family participants it is possible that they may have been selective in whom they approached. One family in fact raised this issue when they returned their transcript:

> The diabetes nurse asked if I'd like to participate. I don't know if she would have asked everyone, but wonder if she asked me because she and I have a good relationship, so naturally my experience will be a positive one on the whole. I wonder if you interviewed anyone who has negative impressions?
>
> Clark Family

The family's concerns is valid. This study was reliant on the help of colleagues and I do not know how the practitioners decided which families to approach. All participants were able to provide stories of experiences both negative and positive but this study does not reflect the experiences of all families of a child with a chronic illness. It excludes in particular those who have discontinued their relationships with health professionals or are operating outside of the traditional health system. Furthermore, although the practitioner participant group represents the predominant disciplines involved in the care of chronically ill children, it is by no means inclusive of all. The perspectives of social workers, play therapists, and general medical practitioners are not included within this study. Thus there are other voices that need to be heard to extend our understanding of the relationship between family and practitioner.

However, within these limitations lies the potential for future study. Of particular importance is the child's perspective on the experience of chronic illness. I believe this should include not only the affected child but also the siblings and friends who live and play with the affected child. Despite the challenges of research with children I think it is particularly important that future research include a children's perspective. There are also opportunities to extend and expand knowledge about health professionals' experience. During the research process a number of issues

were raised concerning how relationships are initiated and terminated, what happens when relationships go wrong and the experience of working across disciplines. These are all issues that could be the focus of future research. Researching the impact of technology on the relationship and the perspective of other ethnic groups in particular Maori and Pacific Island peoples is another area for potential exploration. This study is therefore both and endpoint and a beginning for new and challenging understandings which can inform the world of paediatric practice.

Conclusion

This phenomenological study has shown the rich tapestry of the relationship between practitioner and family within the context of chronic childhood illness. In weaving the web of relationships that will support and sustain the child through their illness experience both practitioner and family come to discover the paradoxical tensions of the simple and complex, and the essential yet not essential nature of the relationship between family and practitioner. Practitioners and families come to the relationship with both possibilities and uncertainties which tend to become lost within the busyness of 'being for the sake of' the child. I have challenged the mindset that this relationship can be viewed from one perspective be it that of family, practitioner or child. Being limited to one view risks failing to capture the reciprocal and unique interplay which occurs as families and practitioners work together. It misses the intricate and unique patterns inherent in the web. Considering the relationship in dynamic and multiperspectival way makes possible practices that transform the outcomes of the practitioners and families who must journey together. When the light shines on the web, its intricacy is revealed. The whole is understood, and new possibilities emerge. A beginning and most important step is to let the light in.

Appendices
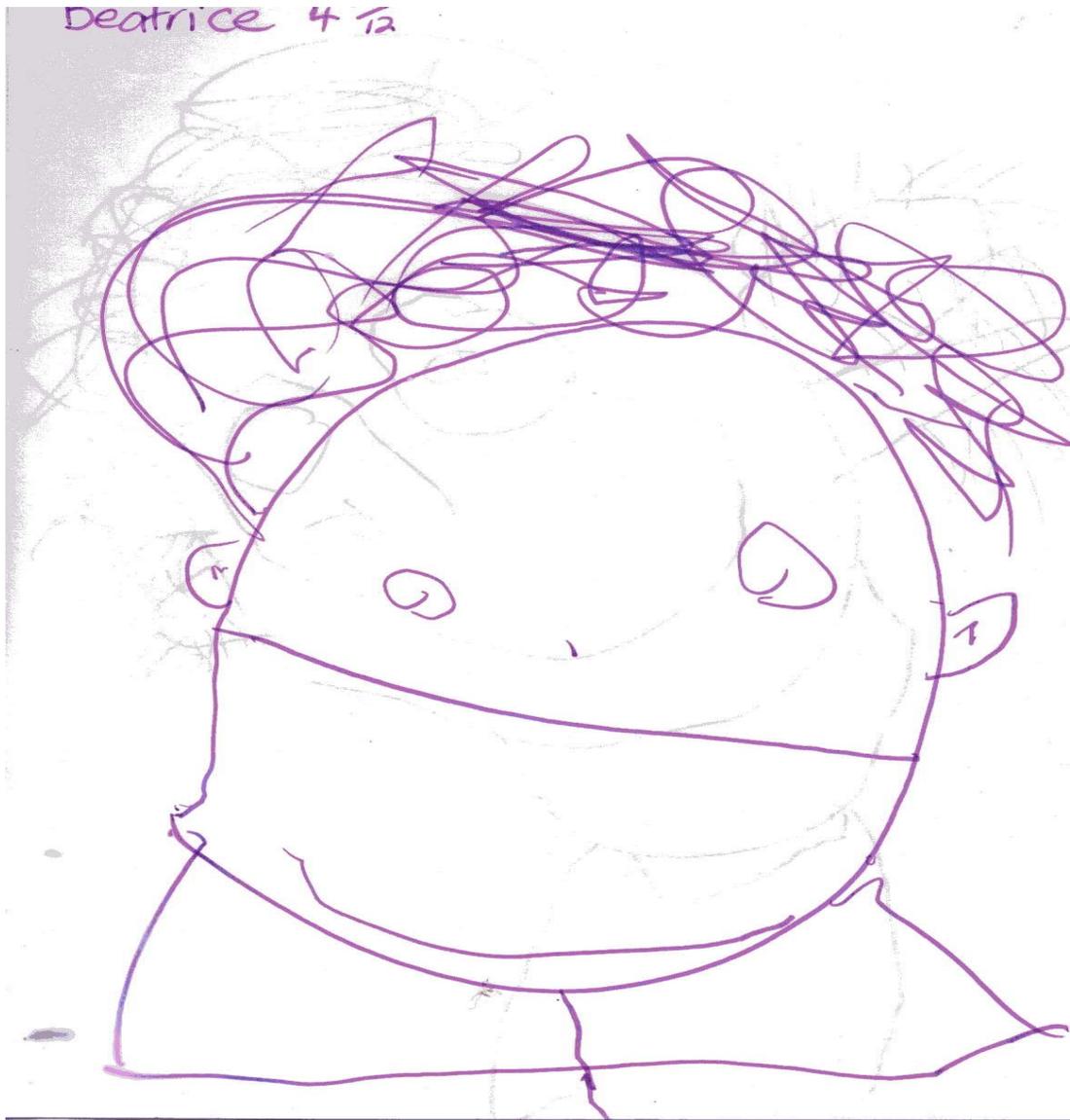
Illustration by: Beatrice Age 4years

Appendix 1

INFORMATION SHEET FOR POTENTIAL PRACTITIONER PARTICIPANTS

Title of the study: The working relationship between health professionals and families of children with chronic illness.

You are invited to take part in a study looking at the experience of nurses, doctors and physiotherapists in "working together" with families of children with a chronic illness.

Who am I?

My name is Annette Dickinson. I am a Registered Nurse currently undertaking full time doctoral study at Auckland University of Technology. I have been practicing in the area of child health nursing for 20 years and have a particular interest in the care and management of children with chronic illness.

What is the aim of the study?

The study will aim to describe and explore the experience of families and health practitioners working together in the care of children with chronic illness.

Who can participate in the study?

There will be 2 groups of participants involved in this study.

1. *Families of children with a diagnosed chronic illness* e.g. Asthma, Diabetes, Cystic Fibrosis. The family can decide who and how many people they would like to include as their family in the study.
2. *Health professionals*: Registered nurses, medical practitioners and physiotherapists currently involved in the care of children with chronic illnesses.

If I decide to participate what will it involve?

You will be involved in 1-2 interviews lasting approximately one-hour. The interviews will be conducted at a place that is private, convenient and agreed upon by us both. You will be asked to tell me stories about your experiences. Questions will be asked about how you, as a health practitioner, experience the reationship with families of chronically ill children. How do you involve families in the care of chronically ill children? Do you feel listened to? Do you feel you work together? How do you share information?

These interviews will be audio taped and later transcribed. These tapes and transcripts remain confidential to my typist, my research supervisors and me. A pseudonym or false name will be used on all tapes, transcripts and reports to protect your identity. Following the interviews you will be given a copy of the transcripts and invited to add further comments and delete any parts of the interviews you do not want included in the study. At the end of the study your audiotape and transcripts will be offered back to you or destroyed, which ever you prefer.

What would be the risk and benefits of me participating in this study?

I do not anticipate any risks to you from the study, however occasionally such interviews can raise issues that are distressing or stressful. You do not have to answer all the questions, and may stop the interview at any time.

As a practitioner there will be no direct benefits to you from participating, however, some people who have participated in this type of research have found it helpful to have an opportunity to tell their story. I also hope that this study will improve our knowledge about the working relationship between families and health practitioners, improving the health care delivered to chronically ill children and their families.

What will happen to the results of the study?

The final research report will be published as a doctoral thesis report, which will be available in Auckland University of Technology library. Short articles relating to the study will be published in relevant professional journals and presented at conferences and seminars. Your identity will not be revealed in any of these contexts. At the end of the study you will be offered a summary report of the research results.

Your participation is entirely voluntary (your choice). You do not have to take part in the study, and if you choose not to take part this will not affect your future practice or employment in any way.

If you do agree to take part you are free to withdraw from the study, including withdrawal of any information provided, until data analysis is complete. After that time it may be impossible to separate data from individuals. I you choose to withdraw you do not have to give a reason and this will in no way affect your future practice or employment.

If you have any queries or concerns about your rights as participant in this study you may wish to contact Health and Disability Advocates Trust telephone number 0800 205 555 Northland to Franklin.

This study has received ethical approval from the Auckland Ethics committee and the Auckland University of Technology Ethics committee. Any concerns regarding the nature of this project should be notified in the first instance to Dr Liz Smythe, Project Supervisor. Concerns regarding the conduct of the research should be notified to the Executive Secretary, AUTEC, Madeline Banda, madeline.banda@aut.ac.nz, 9179999 Extn. 8044.

Thank you for taking the time to read this information. If you have any further questions about the study or would like to participate please feel free to contact me via my Supervisor Liz Smythe.. Contact details are listed below.

Principal Investigator: **Research Supervisor**
Annette Dickinson   Dr. Liz Smythe
Doctoral Candidate   Principal Lecturer
Auckland University of Technology (AUT)   AUT
      .   Akoranga Campus
                                               Contact: (09)9179999 xtn 7196

October 2000

Appendix 2

INFORMATION SHEET FOR POTENTIAL FAMILY PARTICIPANTS

Title of the study: The working relationship between health professionals and families of children with chronic illness.

You are invited to take part in a study looking at the experience of families working together with nurses, doctors and physiotherapists in the care of a child with a chronic illness.

Who am I?

My name is Annette Dickinson. I am a Registered Nurse currently undertaking full time doctoral study at Auckland University of Technology. I have been practicing in the area of child health nursing for 20 years and have a particular interest in the care and management of children with chronic illness.

What is the aim of the study?

The study will aim to describe and explore the experience of families and health practitioners working together in the care of children with chronic illness.

Who can participate in the study?

There will be 2 groups of participants involved in this study.

3. *Families of children with a diagnosed chronic illness* e.g. Asthma, Diabetes, Cystic Fibrosis. The family can decide who they would like to include as their family in the study.
4. *Health professionals*: nurses, doctors and physiotherapists currently involved in the care of children with chronic illnesses.

If I decide to participate what will it involve?

Your family will be involved in 1-2 interviews lasting approximately one-hour. The interviews will be conducted at a place that is private, convenient and agreed upon by us both. You will be asked to tell me stories about your experiences. Questions will be asked about how you, as a family, experience the relationship with nurses, doctors and physiotherapists. Do you feel involved in the care? Are you able to tell them what you know? Do you feel listened to? Do you feel you work together?

These interviews will be audio taped and later transcribed. These tapes and transcripts remain confidential to my typist, my research supervisors and me. A pseudonym or false name will be used on all tapes, transcripts and reports to protect your identity. Following the interviews you will be given a copy of the transcripts and be invited to add further comments and delete any parts of the interviews you do not want included in the study. At the end of the study your audiotape and transcripts will be offered back to you or destroyed, which ever you prefer.

What would be the risk and benefits of me participating in this study?

I do not anticipate any risks to your family from the study, however, occasionally such interviews can raise issues that are distressing or stressful. You do not have to answer all the questions, and may stop the interview at any time.

As a family there will be no direct benefits to you or your child from participating, however, some people who have participated in this type of research have found it helpful to have an opportunity to tell their story. I also hope that this study will improve our knowledge about the working relationship between families and health practitioners, improving the health care delivered to chronically ill children and their families.

What will happen to the results of the study?

The final research report will be published as a doctoral thesis report, which will be available in Auckland University of Technology library. Short articles relating to the study will be published in relevant professional journals and presented at conferences and seminars. Your identity will not be revealed in any of these contexts. At the end of study you will be offered a summary report of the research results.

Your participation is entirely voluntary (your choice). You do not have to take part in the study, and if you choose not to take part this will not affect you or your child's care in any way.

If you do agree to take part you are free to withdraw from the study, including withdrawal of any information provided, until data analysis is complete. After that time it may be impossible to separate data from individuals. If you choose to withdraw you do not have to give a reason and this will in no way affect you or your child's future health care.

If you have any queries or concerns about your rights as participant in this study you may wish to contact Health and Disability Advocates Trust telephone number 0800 205 555 Northland to Franklin.

This study has received ethical approval from the Auckland Ethics committee and the Auckland University of Technology Ethics committee. Any concerns regarding the nature of this project should be notified in the first instance to Dr Liz Smythe, Project Supervisor. Concerns regarding the conduct of the research should be notified to the Executive Secretary, AUTEC, Madeline Banda, madeline.banda@aut.ac.nz, 9179999 Extn. 8044.

Thank you for taking the time to read this information. If you have any further questions or would like to participate feel free to contact me via my Supervisor Liz Smythe. Contact details are listed below.

Principal Investigator:	**Research Supervisor**
Annette Dickinson	Dr. Liz Smythe
Doctoral Candidate	Principal Lecturer
Auckland University of Technology (AUT)	AUT
.	Akoranga Campus
	Contact: (09)9179999 xtn 7196

Appendix 3

CONSENT FORM FOR FAMILY PARTICIPANTS

The working relationship between health professionals and families of children with chronic illness
(This form to be completed by each family member present)

I have read and I understand the information sheet dated October 2000 for volunteers taking part in the study designed to explore the experience of working together with health professionals in the care of chronically ill children. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

I understand that taking part in this study is voluntary (my choice) and I may withdraw from the study, including withdrawal of any information provided, until data analysis is complete. After that time it may be impossible to separate data from individuals. This will in no way affect my child's future health care.

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 have had time to consider whether to take part. I know whom to contact if I have any questions about the study.

I ……………………………………………………………….. hereby consent to take part in this study.

Date: ……………………………….

Signature: …………………………..   Signature of witness:………………….

Project explained by: ………………………   Project role:…………………………….

Signature: …………………………………   Date:…………………………………..

Researcher contact details: Annette Dickinson: (09) 6307 021 or 025 951 585

Appendix 4
CONSENT FORM FOR PRACTITIONERS

The working relationship between health professionals and families of children with chronic illness.

I have read and I understand the information sheet dated October 2000 for volunteers taking part in the study designed to explore the experience of working together with families of chronically ill children. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

I understand that taking part in this study is voluntary (my choice) and I may withdraw from the study, including withdrawal of any information provided, until data analysis is complete. After that time it may be impossible to separate data from individuals. This will in no way affect my current employment.

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 have had time to consider whether to take part. I know whom to contact if I have any questions about the study.

I ……………………………………………………………….. hereby consent to take part in this study.

Date: ………………………………….

Signature: …………………………..   Signature of witness:………………….

Project explained by: ……………………   Project role:…………………………….

Signature: …………………………………   Date:…………………………………….

Researcher contact details: Annette Dickinson: (09) 6307 021 or 025 951 585

Appendix 5

MEETING WITH THE SCHOOL

The Transcript:
(Transcript ref: 35-49)

O.K can you tell me about a time when you worked with health professionals and you thought it went really well?

Probably. What is a good example. I would both times at the beginning when the diagnosis was first made and then the following year at the beginning of school the nurses come out and talk to the teachers. When A was first diagnosed she sort of orchestrated a meeting of his teacher the secretary and another women whose the receptionist, the principal and got everyone involved and then the following year when they needed a new teacher to be trained up a little and a few other people. She got involved. And I thought that went really well. Just for there backup to impress upon the people just how important it is to know.

So she co-ordinated that all for you?

Yes. And I do think the support when you are out and about in the community, it is good in that way. They seem to realize it can be difficult for us to explain other people what it's like and they need to be fairly vigilant. It is always good to have a professional backing it up.

The story:

When A was first diagnosed the nurse was really helpful. At the beginning of the school year the nurse orchestrated a meeting with his teacher, the secretary, the principal and another women who is the receptionist. She got everyone involved and was able to impress upon everyone how important it is to manage A's diabetes. She seemed to realize how difficult it can be for us to explain to others what it is like and that you need to be fairly vigilant. It was good that she co-ordinates it all for you and you knew that you had that professional back up. When we needed a new teacher trained up or a few other people she was always there to do it for us.

Appendix 6

Annette Dickinson

48 Disraeli St
Mt Eden
Auckland 3
Phone: 025 951 585
e-mail: annette.dickinson@aut.ac.nz

Participant Letter

Dear :

Thank you for participating in my research project. I appreciate the time you set aside for the interview and sharing your stories with me. I know they will be of great value to the study.

As discussed at the interview I would now like you to have the opportunity to review the transcript from the interview and in particular the stories I would like to use in my research. You also have the opportunity now to delete anything you do not want included in the research and alter or add things in if you think I have missed something.

Attached are the parts of the interview I would like to use. I have not included the full transcript, but just the pieces I plan to use, but if you would like a full copy of the transcript just let me know and I will send it through to you.

Just to explain what you will read. You will notice that there is no longer anything which identifies you in anyway. I have removed names and identifying locations and either used a generic name e.g "the nurse" "the family" or where this is not possible grammatically used a letter not associated with the word you described. Again if you would like this changed further to preserve you anonymity please feel free to make the appropriate changes. The story in the shaded area is my rewriting of the story so that it flows and reads well. Sometimes I have had to add a little to give it meaning but again feel free to change this if you feel I have changed your meaning in anyway. The next piece of writing not shaded is the actual transcript as my typist has typed it direct from the tape. You may occasionally see ?? this means that my typist and I were unable to pick up what was actually said from the tape. Please feel free to read and make any changes directly on to the document I have sent you. I have included a stamped address envelope for you to send any changes back to me.

If when you read it you are happy with it as it is, just send it back with your signature on it and I will know that you are happy to leave things as they are. If I do not receive anything back from you after 8 weeks I will assume that you are happy for me to go ahead and use it as sent. If you have any concerns or would like to discuss things further do not hesitate to give me a call.

Once again thank you for your time and openness to share your story. As discussed you will receive a summary of the final report when it is complete.

Sincerely,

Annette Dickinson
Researcher
Doctoral Student

Auckland University of Technology

Appendix 7

(Transcript Ref: Int 18: 221-231; 609-620)

When Lynda was first diagnosed we didn't really get much information from the health professionals. Because I work as a Medical Laboratory Technician I read everything I could lay my hands on at work. I raided our pathologist's books and probably got more information than I needed to know. I used the Medical school library and the Internet, everything possible to get a handle on this disease. I don't remember being told I just figured it out when it happened. You know that you need to ask questions to get information but it is hard when you don't know the questions to ask. I didn't realize that the outpatients department had a library service where you can go and request articles until my girlfriend told me about it. There is so much you don't know and there doesn't seem to be one person to give you that information. You just flounder around and find it from all different places. Even your specialist doesn't give you that information if you don't ask, but it you don't know what you don't know, how can you ask the right questions? No one tells you that you can request to read the hospital notes either. It would take you about 3 years to read Lynda's notes but I now make sure that whenever she is admitted to hospital that I read the notes. I always find things in there that I haven't been told. I think that it is basically because I am a nosey person.

What is this story saying about how families get information from health professionals?

In this story the mother recalls how she had to get information about her child's illness. She cannot recall information being volunteered you had to seek it out either by your own research or by asking questions. It was important for this family to get a "handle" on things so that they could understand what they were dealing with and make plans for how they were going to deal with it. The mother notes that her medical background made it possible to know how and be able to access information. It is interesting that she describes that she probably got more information than she actually need suggesting that families actually have in their mind a level of

knowledge that they require and that some knowing may in fact add to the burden of dealing with the illness. Perhaps leaving some things unknown is seen as a more comfortable way of coping, but because this family had to seek out the information directly from medical sources they found themselves unable to control the level of information they received. The mother discovered she needed to use multiple sources of knowledge and there was no assistance from health professionals in how to go about this. Even finding out that she had access to her daughters notes was information not freely given, but this had now become a valuable source of her knowing and gave her some control over the management of her daughter. However this whole process of seeking out information made her feel like she was "floundering". Drowning, fighting her way through the deluge of information she was uncovering. There was no health professional available to guide and assist her. The mother quickly discovered that even from the health professional that she trusted most she could not rely on information to be offered you had to ask the questions. But that posed a difficulty when you didn't know the questions to ask. You didn't know what you did not know.

What is the story saying about the relationship between family and practitioner?
This is another story that illustrates how the relationship does not involved the free and open flow of information about the disease. Families have to seek information and this is process they have to do largely unaided by health professionals. Health professionals give only what is asked for, information at times seems to be withheld. Their almost seems a tension in the relationship for both practitioners and family as to what level of knowing is safe and comfortable, and it seems that this is was restricts or prevents the open and free flow of information.

Appendix 8

GOING AROUND MIND MAP
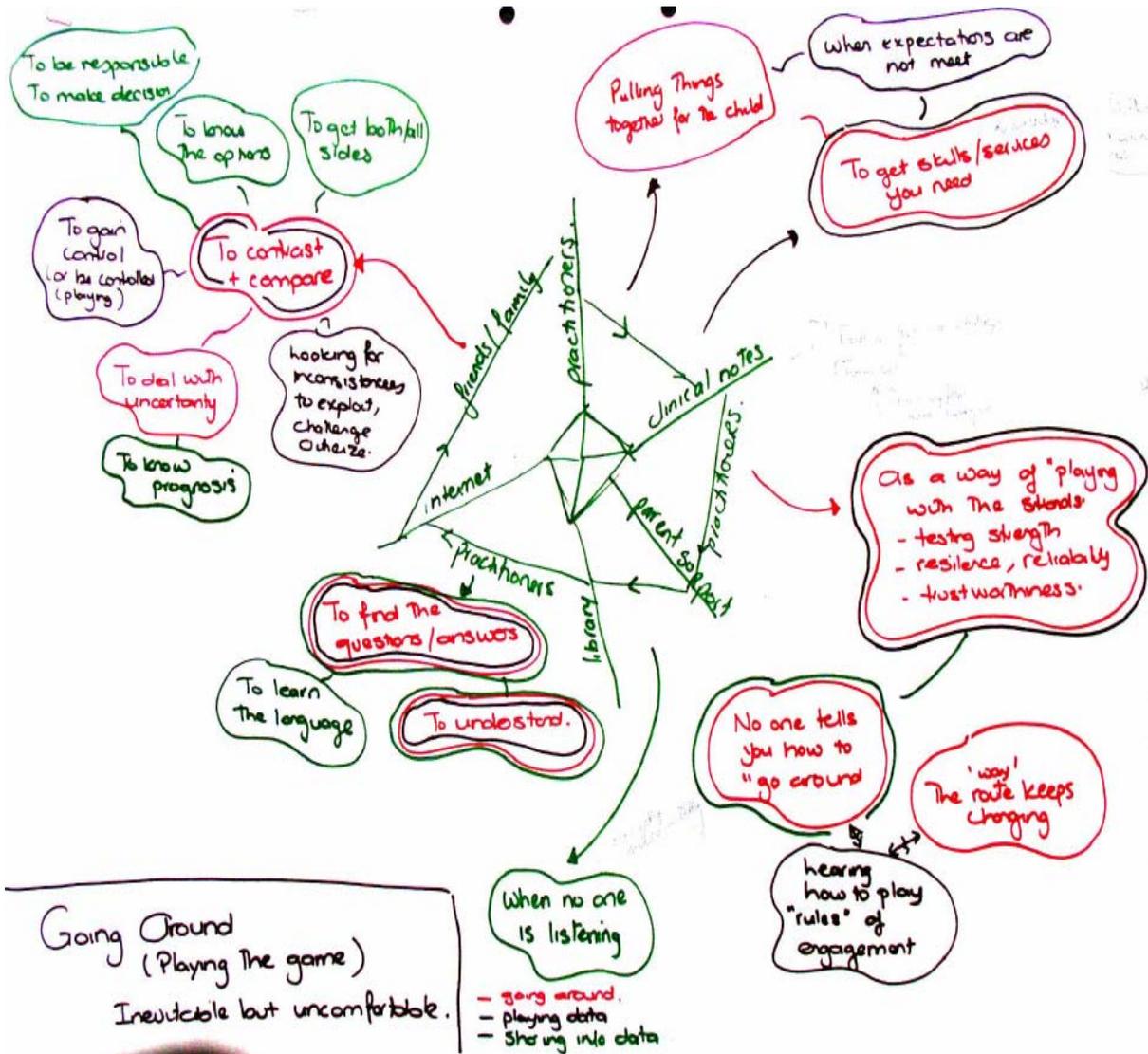
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