Journey to the Right Place
Constructing the Honorable Health Care Relationship Through Story
Experiences of Parents During Diagnosis and Treatment of Their Child's Chronic Illness

by
Mary Alyse Capron
BSN., University of Victoria, 1995

A Thesis in Partial Fulfillment of the
Requirements for the Degree of

MASTERS OF NURSING

in the Department of Nursing

We accept this thesis as conforming to the required standard.

[redacted]
Dr. J. Isobel Dawson, Supervisor (Department of Nursing)

[redacted]
Dr. Marjorie MacDonald, Departmental Member (Depa rtment of Nursing)

[redacted]
Dr. Marie Hoskins, Outside Member (Department of Child and Youth Care)

[redacted]
Dr. David de Rosenroll, External Examiner (Department of Education)

Supervisor: Dr. J. Isobel Dawson

Abstract

Journey to the Right Place: Constructing the Honorable Health Care Relationship Through Story. Experiences of Parents During Diagnosis and Treatment of Their Child's Chronic Illness. Author: A. Capron. A hermeneutic phenomenological study of parent's stories of relationship with health care providers at the time of their child's illness.

Using honoring as a methodology, the parental experiences are recanted in a final story focusing on the construction of connection through: (a) hearing the story - the role of dialogue/listening in making the connection, (b) inviting the translator in - recognizing parental knowledge, and (c) providing comfort through validation.

The thesis concludes with a discussion of this knowledge in relation to the author's practice of nursing, suggesting that honoring and bearing witness may serve as a new means of relating in caring and serve to champion a new form of health promotion through providing a mechanism to translate patient centered theories of care into practice.

Examiners:

[redacted]

Dr. J. Isobel Dawson, Supervisor (Department of Nursing)

[redacted]

Dr. Marjorie McDonald, Departmental Member (Department of Nursing)

[redacted]

Dr. Marie Hoskins, Outside Member (Department of Child and Youth Care)

[redacted]

Dr. David de Rosenroll, External Examiner (Department of Education)

Table of Contents

List of Tables

Author's Acknowledgments

What precious words these are, toiled from the efforts of so many. Reflecting on this work, there are many I need to thank for their love, support, knowledge and guidance. Please, indulge me as I honour them.

My son Nick, the 16 year old who towers above me still asking for hugs, has provided me with the passion to explore the experiences of other families as they live with chronic illness. His courage is remarkable, his inner strength and optimism unwavering. He encouraged me to keep working and writing, spent time coaching me out of writer's block and inspired me. I am grateful for his openness to allow me to speak of our family's journey. I love you very much and I thank you for the gift you and your illness have provided me; the gift of reflection, contemplation and recognition of the important balance between work and play, worry and laughter, our world and the world of others.

To the families who shared their stories with me. I understand the courage it takes to speak out. Through sharing your stories you have touched me forever. This work is a reflection of your generous contribution to a greater understanding of the healthcare relationship.

To my committee, I thank you for your knowledge and guidance. For prompting me at just the right time, for persevering as I struggled to articulate my thoughts and for being incredible educators pushing "new writers" to find their wings.

Thanks to all of you,

Alyse.

Preunderstandings

Experiences in my own life have led me to this research. The continuous journey of living in relation to my son's congenital heart disease has inspired me to explore the development and impact of the relationship between health care professionals and families during the diagnosis and treatment of children's chronic illness. From within my chosen methodology, hermeneutics, the researcher's exploration of his or her own forestructure of understanding is acknowledged as essential to formulating and conveying the research itself. These background meanings include: (a) an understanding of the phenomenon and how it shapes our construction of the topic of study and the questions we ask, (b) an understanding of the world and the humanness we share with our participants, and (c) the theoretical and conceptual preunderstandings that guide us as researchers. The following section of this thesis lays out this preunderstanding for the reader, and also serves as a grounding point for myself, documenting what I bring to this research and from what position I have set out to explore it. This exploration of self and experience is important in guiding me to enter the research and interactions with participants in a thoughtful way. My own clarity will ensure I enter into dialogue with an enhanced awareness of what I am attempting to illuminate. Through these reflective processes I am better able to support participants in an empathic and connected way as we delve together into their experiences of relationship with health care providers.

What follows is a synopsis of my own rumination. Many hours of thinking, questioning and replaying life's events have led to the following pages. It is not easy to write this. I have struggled to articulate the depth and breadth of the life changing significance these events and relationships have held for me. I hope I have succeeded in capturing and conveying the intensity of my commitment to this research and personal belief in the importance of shedding light on the nature and potential of relationships formed between families and health care professionals at this juncture in the journey of chronic illness. Munhall (1994) writes, "Doing research can be transformative. I would dare say it should be. So what you choose to study should be close to your heart and soul and thus centered in human being" (p. 50). I dare say it is!

The Story of Nick and Me

Every illness begins with a story. Here is mine. It was late in the evening as I saw the cardiac surgeon approaching me in the hallway. I was tired and frightened, afraid of what his words would be. He stopped a foot in front of me and announced, "Why wasn't your son here before this?" I couldn't believe my ears. I had done all the right things, kept appointments, gone for testing, spoken in terms of objective signs and symptoms recognized and valued in the world of the physician. His words tore me apart. He stared, unyielding, waiting for a reply. I was small, as small as I had ever been. I simply said "I don't know"!

I remember thinking, "but I do know!" I know he should have been receiving care and medical intervention much earlier than now. In a split second, I ran over the past four months in my mind. The hours wrestling with myself, going over and over the subtle, intangible, but very real shadowy changes and feelings that something had changed, that something wasn't right. I remembered the phone calls and visits to physicians, trying to articulate my concerns, my inner sense that my child's physical condition had altered and the feeling that we were headed toward something ominous. I remember the reception that this discussion received, with the professional's response always being a search for objective evidence of my concerns. The remainder of our appointment time was spent measuring blood pressure, taking pulses, listening to heart and lung sounds followed by the reassurance that all was well. I remember leaving the office feeling relieved. It must be my lack of objectivity as a parent; I was too close to the situation! My sense of relief was short lived. Additional time with my child began to verify my feeling of concern, a return to that sense of uneasiness. Running through the items on my mental check list of the subjective, subtle, small changes combined to reinforce the sense of urgency I felt. Upon reflecting, I now believe that, due to my intimacy and understanding of Nick as an individual and the time devoted to assessing him in relation to his illness, my voice should have been heard, considered and acted upon as an insight into my child's illness.

That memory will stay with me always. It has raised many questions for me as a parent and as a nurse working within the health care system. In

carrying out my practice I have formed professional relationships with many individuals. I have always been the consummate expert, having great faith in the knowledge my profession had imparted to me, believing that this knowledge and skill would meet the needs of all for whom I cared. My beliefs in who I was as a professional and how I practiced were firmly rooted in a biomedical paradigm. I thought I was a "good" nurse. I thought I had "listened" and "acted" based on the needs and wishes of those for whom I cared. I recognize now that this wasn't true. Because I was arrogant and self-assured in my professional knowledge I had listened with a paternalistic attitude, feeling I knew what was best. I had seen this illness before. I knew the signs and symptoms and knew how to "treat" it. I recognize now that I was simply following a pattern, based on past experiences in caring for persons with similar illnesses, never recognizing the diversity of what their illnesses meant to them and how that should shape the care I gave. I never gave time to consider the possibility of individual uniqueness in the presentation of illness. I never stepped outside of my professional persona to truly understand their experience of their illness, nor to consider the importance of this understanding to their care and my decision making. I feel now as if my practice was mechanical and I am ashamed to say I feel I have never known any of the persons I "helped", nor considered what "help" looked like to them. I participated in reductionism, reducing them to "fit" my pattern of practice and science-based knowledge of illness. Although I was

very comfortable in this professional identity, those I cared for were hidden by it.

The clash between my personal experience and professional practice has lead to much reflection. This passion and pain foster a need to understand more about the dichotomy of my two experiences: that of a parent seeking care and that of a health care professional charged with the ethical responsibility of meeting the needs of those who are ill. I need to make meaning of my own personal history through telling and sharing the story of my son's chronic illness and our interactions with the health care system. I also need to understand this experience in order to enlighten my further practice as a registered nurse. However, my intention is not purely heuristic. I hope, through sharing my experience and the experiences of other parents, to contribute to a different understanding of interacting and caring through professional relationships with children and families. This research will animate the voices of parents and provide a place where the traditional patterns of relationship that we have assumed to be effective can be challenged. My interest is not in explaining why or how certain relationships form as they do. Rather, I am interested in giving parents a voice to describe their experiences in relationship. The goal of this research is to provide a place from which to visualize the relationships that surround us in our practice with a renewed interest, leaving the readers themselves to formulate their own conclusions.

In my experience, I was silenced by this cardiac surgeon. I felt pushed into an echoing stillness by the hurtful disregard for the totality of all the experiences that had brought my family and me to this moment in the hall. The subjectivity of Nick's illness and all that it entailed was ignored and we were marginalized. I felt unseen as a person, a family. Our identity seemed confined to and constructed only by the medical content of Nick's illness as defined by this practitioner's professional paradigm and scientific way of knowing. An objectification of our illness experience took place, reducing all we were as a family simply to the "sick heart in 313", leaving no room for our identity or understanding. I became curious about the very separate ways of knowing reflected within the medical and personal worlds.

As I recall this experience, the word "honour" seems somehow significant to my encounters. "Honour" keeps entering my thoughts and serves to champion my own reflection. This word seems to provide clarity to what was missing in my experience with the health care system and its practitioners. To "honour" seems to capture what was missing from my experience, but was it as important to others? My research will answer this question.

Historical Understanding of the Term - Honouring

Language that is central to the tradition of hermeneutics and the belief that people ascribe meaning to social reality through the use of text, informs

this methodology. It seems important therefore to look at the history and the etymology of the term honouring with its roots and past meanings, and to tie these to its current uses in present day language. If the term honouring becomes recognized within the healthcare experience, then a sense of the meaning it conjures outside of this context is important. Words and dialogue drive experience, including understanding honouring.

"Words serve as building blocks of communication, as tools of thought, and as outlets for emotions; but they represent more than that; they are vestiges of our past, and each bears the imprint of its passage through time" (Heller, 1986, p. xxv). Wordsworth (1809) wrote in one of his sonnets that honour is the finest sense of justice that a human mind can frame. The Oxford English Dictionary defines "honour" as: (a) respect, (b) recognition, (c) allegiance to the moral principles, and (d) to confer dignity upon. Chambers Etymological Dictionary describes "honour" as: (a) the esteem due or paid to worth, (b) respect, (c) distinction, (d) nobleness of mind, (e) any special virtue, and (f) to accept.

Historically, honour was seen as an expression of high regard or estimation. Stubbs (1875) wrote of honour being given where it is due and was recognized by the Monarchy of England for his contributions to literary knowledge. Honour has been traditionally described as a sense of or strict allegiance to do what is 'right" and or socially acceptable at any given time. To honour someone has also been spoken of as feeling or entertaining someone or something in the mind or consciousness, in recognition of a

distinct gift or contribution to human kind, to consider and contemplate what it is that they have given to us as individuals and as a society. Honour also has been used historically to highlight the contributions of certain scholars and to formally acknowledge their contributions in their specific area of work.

The notion of honour reflecting a special or significant contribution of an individual can be seen reflected in the recent works of a small number of health care researchers. Current writers and researchers use the term "honouring" to express the notion of individuality and to acknowledge the self or person and his or her right to self-determination. Examples include the notion of "honouring patient's dignity" and "honouring the personal side of chronic illness". In her book "Honouring the Woman who has Diabetes", Poirier (1997) suggests that health professionals should not find comfort in patients achieving our goals but rather we should be looking to the individuals living with illness to personally set their goals and support them to achieve success whatever that may be. Although a concrete description of honouring is not provided, what is alluded to is an appreciation of the whole person.

> Success with diabetes requires honoring and respecting one's emotional, social and physical needs. Are we in touch with the whole woman? Respect for the patient requires an appreciation not just of the diabetes, but also of the woman as an entire person (Poirier, 1997, p.165).

Poirier challenges health care professionals not to participate in the objectification of the person into their illness and cautions against the marginalization of patient's personal insight. She highlights the importance of

considering illness in relation to the individual's life not making the illness the centre of this existence and allowing it to define the person in care.

In reviewing the past and present usage of the term honouring, I have identified the following core themes associated with its meaning: respect, recognition, distinction, and acknowledgment and acceptance of contributions made that significantly influence human kind and actions.

When I think of how professional and personal lives have changed and how knowledge has grown through the contributions of human experience, I wonder what greater gift there is than that of relationship and connection to others. By honouring patients and their significant others, do health care professionals not honour themselves?

I wonder how that surgeon felt after our conversation? Did he sense the devastation I felt at that moment? When I reflect on that moment, my pain must have been shown in my face and my responses. I gained no strength from that conversation. Did that surgeon gain any knowledge about me or satisfaction in his role at that moment? If honour had been present what would that have meant to both of us?

Researcher's Conceptualization of Relationship Through the Notion of Honouring

Our family's experience with Nick's illness feels like a battle fought largely apart from health care practitioners. There is a sense of separation from the realm of the health care environment. Should it be so? At a time

when words could have allayed my fear, or at least pushed it back, instead I was met with words that trivialized and excluded. The physicians chattered among themselves with great enthusiasm about arterial blood gases, chamber sizes, ejection fractions. Yet, the direct interaction with my family consisted of awkward, perfunctory monologues, delivered with impatience and never followed by any attempt to recognize us in the process. I also vividly remember their own discomfort in discussing Nick's condition and need for open heart surgery. Nick's heart was very weak and there were concerns around doing the surgery with his muscle function being so impaired. I recall being led into a small room, in which there was a couch and several chairs. The cardiologist, accompanied by three residents and one registered nurse, entered the room after me. I sat on the couch, the professionals either stood or sat in the chairs, a safe distance away. The residents looked at the cardiologist, the wall, the floor, anywhere but at me. The registered nurse shuffled papers. I was alone. My family was traveling from Victoria, there was plenty of room on that couch. Oh, to have a hand on my shoulder! The discussion was based on test results, medical opinions and a description of the surgery. Percentages of complications were discussed and I was asked to consent. I was asked to agree to a surgery that I understood anatomically and rationally but had not put into the context of our lives. When I began to describe what was important to Nick, riding his bike, walking his dog and what were the chances of this happening after surgery, the squirming reached a frenzy. The cardiologist's response was in terms of ejection fraction

numbers, life span of the mechanical heart valve. I remember trying to get him to understand that I needed to think of this in terms of living. Could Nick enjoy living again? Yes, this surgery would likely improve the numbers but would it help Nick and our family live our lives. He couldn't understand this or see the connection I was trying to make. Without this information I felt like I couldn't make an informed decision, a decision made in relation to my family that would honour our needs. The more I tried to translate this into a personal context, the more uncomfortable the "professionals" became. The residents were silent. The registered nurse encouraged me to listen to what was being said so I could make an informed decision. I gave up. It wasn't that I couldn't hear what was being said, it was just that I needed it to be said in a different way, in a way that allowed it to make sense in relation to what we valued in our life. I had never before experienced that sense of total helplessness and vulnerability that resulted from the failure to allow Nick and our family be participants in the decision making. As the people with the most invested and as people whose personal interpretations of illness counted and whose insight was valuable, we were not included in a way that allowed a dialogue of meaning. There was no connection among us as people sharing an experience. Instead, there was the "professional persona" and the "patient". Our worlds were separated by this wall that neither could see over nor really understand in terms of how it was built in the first place, though we all accepted its existence.

How was this wall constructed? The social construction and historical development of the delivery of health care are embroiled with power differentials that contribute to the construction. The belief in the "rightness" of scientific knowledge and the "flakiness" of subjective knowledge is the mortar. The goal of curing illness versus promoting healthy ways of "living with illness" is the stone. This research is about exploring the experience of relationship between families and health care providers in the context of children with chronic illness. Although relationship contributes to the construction of the wall, some larger, socially constructed factors may be alluded to in this research, however an in-depth examination is beyond the scope of this research.

This research focuses instead on questions such as "What role should health care be allowed to play in our family's life together"? How should health care be incorporated into the lives of those who seek its benefits? Health care is a means to a full and meaningful life; it is not an end in itself. As was the case in my family's dealings with chronic illness, these professionals become integral to Nick's development of the physical capacity needed to live a complete life. It seems absurd then, that health care professionals are concerned only with the medically verifiable aspects of our life. They lose sight of the impact and potential of home life and relationships in the process of healing. The medical agenda overwhelms the human agenda. In other words, all those things that give life its value, purpose and meaning are sacrificed in order to "cure", instead of being included in the process of

becoming healthy through healing. Who would want to exist in such a barren, empty place? A patient's diagnosis does not define them, nor examinations explain the person and how to help them live. Why can the knowledge and intimacy of self not be included in the barrage of scientific strategies to diagnose and treat illness?

According to Heidegger (1975), human lives are situated within meaningful activities, relationships, commitments and involvements that provide the possibilities of human growth and potential but also constraints against living. Can you understand for me what it is like to live with the fear of illness and death? It is closer, exists at my shoulder and is more present for my family than most. I know this has had a profound impact on my family. We can rarely predict exactly when a crisis is coming, but we are always prepared through our own sense of knowing. I have kept a suitcase packed for years, for just such occasions. We appreciate the healthy, pain-free days in a way that no one can comprehend without witnessing the distress of days overwhelmed by illness. This uncertainty has been our partner for 16 years. We know it well. I have a sense of its presence and intuitively recognize its "signs and symptoms". While I lack the many years of education outlining the pathophysiology of specific disease processes and the barrage of tests available to confirm illness, I have developed a different skill; the skill of insight. In following Heidegger's beliefs, being situated in the experience of my child's illness has created a world of meanings and practices unique to this context. From this aspect of my life, unique forms of knowledge and skills

have flowed. I ask for them to be recognized and honoured. "Living is the working out of the existential possibilities that our background or situatedness provides us and accommodating those possibilities in action" (Chesla, 1995, p. 67). I have not sought out this experience. I cannot avoid it. I can only find the courage to be with it and ask others to honour me in it through finding value in the gifts I have received from it.

What works is so ridiculously simple, so simple that it's a shame to have to say it. Bravery on the part of health care professionals to step outside the usual boundaries and invite patients and families in, engagement in relationship. The sharing and incorporation of our struggle requires an investment, a real life changing investment by those who care. A lot to ask? Yes, but not without its rewards for all.

What is honouring? It seems important at this time to draw this out and lay it open by example, to understand the difference one health care professional made through interacting in what I perceived as an honorable way. I need for myself and any who read this work to clearly understand my interpretation of the positive health care relationship as constructed through the concept of honoring.

The thing that strikes me most as I think over the past 16 years is the energy that has gone into trying to figure out how to relate with the professionals who have cared for Nick and our family. Have I ever been myself? NO! I have always been trying to figure out how to access the resources, how to get them to listen to me and my knowledge, always trying

to take good care of my son. The struggle has been how to package my knowledge in a way that would give it value within the professional's paradigm.

As I described earlier, this struggle has gone on for many years. It is like a seesaw or a boat moving up and down over huge waves in a vast ocean; up and down, back and forth. Before each appointment I'd rehearse in my mind, what I wanted to say, what changes I had seen in Nick, and how I could construct my observations in a way that they would have meaning for and be significant enough to warrant attention and action. How could I articulate the sense of concern and worry that we were headed toward a dramatic change in Nick's health, especially when this sense was based on a subjective way of knowing?

I remember both physicians and nurses holding up the "offical data" of Nick's chart as if it were the definitive volume of quality information. They would ask how Nick had been. I'd begin to tell them how I sensed something was wrong. Nick didn't quite have the same energy, his face was flushed, he was snoring more, he awoke less rested. Nick was more irritable, played less with his friends. He was often nauseated in the morning. None of this was recorded in the "official record". Come to think of it, it wasn't even interesting enough to warrant consistent eye contact. The cardiologist or clinic registered nurse never once asked me what did I make of this? What did I think we should do? Instead the examination proceeded to checking height and weight. Nick was still growing! Heart and lung sounds were listened to

and blood pressure and pulse were checked. The physician looked in Nick's mouth and palpated his abdomen. No changes! I wanted to roar, "There were no objective quantifiable changes but there were changes! I live with them every day. We are going down a road, a road with signs. I can read them! Why can't you?" But I had no way to persuade them to consider this testimony. To them, what I could sense didn't exist. It couldn't be tested, validated. I had no voice there. I allowed myself to be consoled by their words that nothing had changed. I wanted so desperately to believe this was true. I wanted to forget that my son was ill. I wanted it all to go away. It did for a few hours, only to be replaced by the same sense of dread accompanied by a feeling of failure and loss of control. I'd wait until the next appointment. By then I would figure out a way to make them hear me.

This pattern continued on for years, up and down, until finally the feelings became too strong for me to continue to ignore. Nick required hospitalization in September of his 12th year. He had his medications adjusted and was sent home to be seen yet again by another specialist in 8 weeks. I remember taking him home, and was again desperate to believe I could avoid listening to my inner self yet again. But the voice was too strong. I knew Nick was very sick. The tests hadn't captured this, but I could feel it. I can't recall why. His heart rate wasn't up. He wasn't wasting away. I decided to trust my instincts and push hard! I took Nick on the ferry from Victoria to a Vancouver hospital and presented him to their emergency department. Here I told Nick's medical history and included my sense that something was very

wrong. There were more and more specialists and more and more tests. One week to the hour, I was visiting Nick in the intensive care unit after he had had emergency open heart surgery to replace a disintegrating mitral valve in his heart. Thank God I had trusted myself and someone had listened! The outcome would quite likely have been very different in 8 weeks time.

What was different about this encounter? First, it occurred in an institution that is a tertiary referral centre solely for pediatric care and works with large numbers of families and is, as a result, perhaps more open to including subjective opinion in the diagnostic process. Perhaps their openness to consider is a result of continuous exposure to, and validation of, the value of the knowledge gained through interactions with families. Having said this, there were many times where I had to struggle both inwardly and outwardly to have a voice and articulate my concerns in a way that could be heard by these professionals. Fortunately, that day in the emergency room, there was one professional, a physician who pulled up a chair next to the emergency stretcher, sat down and wanted to listen. This person acknowledged the passion and concern that had motivated me to take this frightening trip across the water. There was genuine interest in the subtle changes I had seen and acknowledgment that my observations and "parental connection" could be telling us something in terms of Nick's health. He did not dismiss them. I remember him saying "You and your family are the closest to the illness. This gives you wisdom we can't grasp in tests". He did not ask that they be articulated or translated into scientific concepts. He incorporated them into a

bigger picture of what Nick's state of health was and used them as clues to explore further actions.

I felt honoured. I had done my job as a parent. I was grateful and relieved. I wasn't crazy. I could trust myself. For twelve years I had tried to climb a fortress wall with my sack of knowledge and fight for my son's health. Someone had finally invited me into the fortress. I cried! No matter what the outcome I had done my best for my child! I had succeeded in having them hear me!

My construct of the notion of honouring reflects my need for a supportive health care relationship. It is a term I have personally used to capture the essential elements I feel are necessary to the creation of a positive interaction. To me, honour in the health care relationship is to recognize, accept and incorporate, with dignity, the unique contributions that parents, because of their situatedness, can contribute to the insight of their child's illness. Health care professionals must accept parental expertise, listen to their insights, and trust the 'gut' feelings of patients and families. The health care professionals must acknowledge the parent's place in relationship to their child, and the special gift of their unique knowledge that is created in this connection. To do so is to allow parents to fulfill their unique role and to recognize the importance of working together to build the health of the child and family. Honouring is about seeing the distinctive reality of illness through the eyes of those living intimately with it. It is recognizing that the experience of illness is shaped by the person and finding value and respect for this reality.

Honour in relationship is not to marginalize, objectify, or silence. It is to abandon the language of the science of illness and to try and develop a language of the experience of illness. It is to help us find meaning and peace in our experience of illness.

Significance of the Research Question

Competing Paradigms: Historical Context of Health Care Provision. and the Winds of Change

My experiences reflect the distinct differences in ways of knowing between the world of the health care professional and that of parents and families. I am directed through my story, to explore what parents bring to and value in this human encounter and how it can be incorporated into health care relationships through the concept of honoring.

Paradigms are normative, they instruct our thoughts and actions. "As we think so do we act, feel and move through the world." (Patricia McKenzie, classroom/personal communication, September 27, 1999). Assessment and diagnosis are paradigm dependent. Knowledge concerning these intellectual traditions sets the stage for consideration of expanded views.

> A paradigm is a world view, a general perspective, a way of breaking down the complexity of the real world. As such, paradigms are deeply embedded in the socialization of adherents and practitioners: paradigms tell them what is important, legitimate and reasonable. Paradigms are also normative, telling the practitioner what to do without the necessity of long existential or epistemological consideration. But it is this aspect of paradigms that constitutes both their strength and weakness -their strength in that it makes action possible, their weakness in that the very reason for

> the action is hidden in the unquestioned assumptions of the paradigm (Patton, 1978, p.203).

The biomedical paradigm, that has historically guided the formation of relationships and the diagnosis and provision of health care, carries some strong assumptions. Their assumptions are housed in a positivist world view. Guba and Lincoln (1994) suggest the aim of inquiry within this paradigm is explanation, ultimately enabling prediction and control of a phenomenon, whether physical or human. This infers the ability to generalize, with predictable confidence, to a population of people and settings, leaving little room for the subjective inplies of knowledge from those experiencing the phenomena.

The health care professional is cast in the role of "expert", awarding him or her "special" privilege. It is this privilege that is used effectively within the health care relationship to quiet and devalue the subjective thoughts and feelings of the person seeking care. This is the constructed reality of the individual in care. In positivist inquiry, knowledge is that which is quantifiable, verifiable and can be regarded as probable facts or laws. Knowledge that can not be supported through objective evidence is abandoned.

Health care has traditionally been delivered under this biomedical model, with recognized roots in a traditional science background. The methods and teachings of this orientation are directed toward objectivity, control, seeking generalizability and causality. My personal experiences with health care provision found that this paradigm places limited value in the

subjective stories and assessments of individuals. The appearance of listening may be granted, but more times than not, stories or individual interpretations are not considered to be of value in decisions concerning the initiation of diagnostic and interventional care options. Guba and Lincoln (1994) suggest that a paradigm represents a world view that defines, for its holder, the nature of the "world", the individual's place in it, and the range of possible relationships to that world and its parts. Given the scientific paradigm of traditional medicine it is easy to understand why subjective knowledge is not considered relevant.

Dossey (1993) describes health care as historically housed in a masculine, allopathic model, associated with power, analysis of data and technology. This model is based on linear, hierarchical relationships, allowing little room for the invisible and non material bonds among and within levels of relationships including those formed in the provision of health care services.

Dossey (1993) recounts the eras of health care provision. He discusses the current transition into "ERA III" health care, which he describes as non local or transpersonal health care. He depicts the mind and its potentials as a factor in healing relationships within and between persons. He suggests that the capacity of individuals is not describable by classical concepts of space-time or matter-energy by the biomedical model. "Any therapy in which effects of consciousness bridge between different persons is an ERA III approach" (Dossey, 1993, p.40). "Diagnosis at a distance" is included in this grouping and is described as the openness to consider evidence gathered by all

methods not exclusive of information that can be technologically verified by current scientific methodologies. This would seem to suggest an epistemology that allows not only for empirical knowledge in diagnosis but also for the advancement of esthetics, the soft humanness that includes parental knowledge in health care diagnosis.

Merleau-Ponty (1964), believes that we perceive the world through our body, thus perception is our access to human experience. Combining Ponty's and Dossey's perspectives provides a strong basis for supporting the notion of the inclusion of parental knowledge and experience in these relationships that secure care.

"It is important here to reflect that the basic moral concern of nursing is with the welfare of other humans" (Curtin, 1978, pp. 4-5.). "One of the central goals of nursing is to care with respect and dignity, supporting the client's right to self determination" (Thompson, 1990, p. 20). Nursing theorists such as Watson (1985) and Paterson and Zderad (1976), espouse this centering of care as a moral ideal in their writings, however, its reflection in practice is frequently absent. The implementation of this patient-centered practice is impeded by the larger health care system in which nursing practices and the traditional goals of care are held ransom by a larger mandate - the mandate to cure. Nursing needs to examine the integration of these concepts into the human care relationships that are established in the name of nursing. Nursing as a profession, though more enlightened in their literature base, does

not consistently transform this dominant paradigm of caring into their professional practice relationships.

Current literature reflects a growing awareness within the medical community of the dissatisfaction of recipients of care delivered under the current biomedical model. Much has been written of the failure of proponents of the conventional biomedical approach to address the interests and values of the person with the illness, to consider the patient as a partner in care. "If we are to be healers as well as technicians, we have at some point to set aside our medical maps and walk hand-in-hand with our patients through their territory of illness" (McWhinney, 1991, p. 434). Shapiro (1995) posits that medicine, like art, requires both precise technique and intuition. "Classical medical education encourages "proper" technique to the detriment of creative intuition" (Shaprio, 1995, p. 987). He suggests loosening the constrictions of the "old rules" and providing a theoretical framework for what he describes as intuitive work with patients.

Boundaries around disciplines are breaking down, reflecting a different view of health. All the parts do not necessarily fit nicely together anymore. Current shifts in thinking around health care suggests the need to break the competing paradigms into pieces and to see how they can be fit back together, reflecting an expanded view of health, health care provision and the ability to acknowledge and value the input of patient's knowledge.

Researcher's Conceptualization of the Research Interest

How do we live both paradigms? Peter Senge (1996) suggests it is by allowing the individual to become an active partner, to rid the medical system of standardized care, and to trust the patient. Shared decision making is receiving increased attention in professional circles. Lupton (1997) suggests that consumerism, fueled by an exponential increase in public access to on-line information, is shaping a change in clinical practice. Shared decision making appears to be an interesting blend of the humanistic philosophy of patient-centredness and a newly resurgent and every growing consumerism. As individuals gain more empirical knowledge, the way is paved to gain access to decisions in health care. They begin to acquire the language that allows them to converse with the 'experts' of care. Patients are changing in their expectations of health care. They are receiving information from a wide range of sources. They are discovering different knowledge bases and gaining a voice in the decision making process. They come with a knowledge of the system, its particular language and thus have a place from which to present their needs.

The time is ripe for the implementation of this new paradigm that takes into account a spectrum of reality from 'body' through 'mind' to 'spirit' and provides a basis for understanding multiple modes of inquiry and knowledge. Although espoused in the body of nursing and health promotion literature, this knowledge is often not translated into professional practice in the acute care setting, where nursing's practice is so closely tied and restricted

due to our lack of autonomy from medicine and the medical paradigm. Although the value of individual self awareness and inclusion in care is taught in principle, it has failed to be recognized and actively included in diagnosis and treatment. Following this paradigm allows the possibility to see and experience the complimentary rather than the competitive ways of knowing in diagnosis and treatment. It has been suggested in recent literature that the intuitive knowledge of health care practitioners has a place within this new paradigm. I suggest that this can be complimented by the intuitive knowledge of patients and families in knowing their own illness. Research needs to be undertaken that expands on the subjective insight of patients and how patients see this knowledge fitting into the health care relationship. Given the historic context of health care delivery and the current shift in paradigm orientation to include the intuitive aspects of health care professionals and their delivery of care, it only seems in keeping with this transition to consider the contributions of patients and families in diagnosis and treatment. This research attempts to illuminate the perspective of parents in making this connection through relationship. An understanding of the current thinking regarding this area is necessary to ground the research and researcher.

Preparatory Understandings

Descriptive studies of families' chronic illness experiences, as well as firsthand accounts of chronic illness, support the varied nature of the events preceding the diagnosis. Thorne's (1993) recent article highlighted the diverse

patterns of onset that characterize chronic illness and the role of health care providers in facilitating or impeding its diagnosis.

Recent works support the importance of examining the relationship between families and health care providers. Stubblefield and Murray (1999) studied how parents whose children have undergone lung transplantation experience and respond to their relationships with health care providers. Being treated as an individual, seeing familiar faces, and feeling that their children really mattered were themes that emerged from this work centered on the acute hospitalization period.

Knafl, Ayres, Gallo, Zoeller, and Breeitmayer (1996) utilized narrative analysis techniques to identify 5 major pathways to diagnosis. Parent's perceptions of the nature and quality of their interactions with health care providers were channeled into one of the five pathways reflecting the varied levels of support and understanding experienced. Corbin and Strauss (1988) discussed the considerable efforts persons who are ill and/or their family members often invest in obtaining an accurate diagnosis.

Regardless of the nature of the disease, recent writings all point to the complex array of intense emotions and energy exerted on the health care system to provide a definitive diagnosis and supportive treatment. Often much of this energy is spent on health care providers, attempting to construct a relationship that supports individuality and inclusion. Included in this challenge to parents is the need to attempt to create a place of influence and

recognition for the wealth of information specific to the individual that can be provided to move toward diagnosis.

It is during this highly stressful time of diagnosis that patients and families are forming their initial impressions of the illness and their access to care. As Leff and Walizer (1992) point out, "It is at this intensely painful point in the parent-professional relationship that issues of caring, and mutual respect are emblazoned in bold relief in the family's memory and consciousness" (p.69).

Recognizing the importance of this diagnostic period, the key connections potentially formed at this juncture and the invaluable gifts of intuition and insight parents possess, the purpose of this work is to weave a story that expresses the needs of parents at this pivotal time and highlights the potential inherent in their direct involvement with diagnosis.

The humanistic nursing theory of Paterson and Zderad (1976) provides the theoretical link between this work and the implications for practice. Paterson and Zderad were the first to introduce the philosophical notion of phenomenology in their book, "Humanistic Nursing". The view that nursing as a human science includes the art and science of caring is supported by other nursing leaders and theorists (Watson, 1985; Munhall and Oiler, 1986). Included in this perspective are the important aspects of life and awareness such as feeling and intuiting. Relationship is espoused as central to this knowing. However, little has been written about how to actualize these theories in practice. In experience, this theoretical centering is often absent.

Heidegger (1975) suggested, if it is one's plight to endure this freedom of person, it should also be one's promise to do so in the company of others. Paterson and Zderad (1976) included this important theme in their writings, suggesting a person's relation to others, responsibility to cultivate communities of dialogue, and the possibility of personal growth through authentic relating, form the central premise of what it is to be human.

For the chronically ill, health and the discovery of 'being', is often accomplished through making meaning of life's experiences. For the chronically ill, health is not about curing but about comfort, comfort with the illness and with their life. Comfort becomes the answer to the question 'why' health care professionals are involved with the chronically ill. This work is framed by the pretense that persons can be comforted without being cured and the promotion of a comfortable way of being in this world should be the immediate concern for the chronically ill. This can only be accomplished through relationship and, as previous research has indicated, the nature of the relationship established at diagnosis is pivotal.

This work is a call for a blending of science and relationships with an enhanced focus on the "art" of providing health "care" as shown by parent's story of interaction.

Research Process

It was during one my initial conversations with my committee discussing what had brought me to this research interest and where and how I saw it being shared, that a personal epiphany occurred.

I was ruminating over the struggle I was having over recent encounters in my professional life and discussing the focus of my research. As a nurse manager in a large health care facility, I frequently worked along side physicians and had chosen to share a brief synopsis of my research work with them. Their reactions were less than pleasant. Of the three, one said nothing, the other turned his eyes toward the ceiling, and the third became very uncomfortable, shifted in his chair and murmured "Oh!". I moved on to a different topic. Unfortunately, though not as consistent, the reaction was similar among my fellow nurses.

I went on to share this moment with one of my committee members. I spoke of my struggle with what to do with the knowledge generated by this research. How do I express it? How do I make it palatable to physicians and other professionals who do not necessarily value the gathering of knowledge related to the "art" of caring? How do I make these voices heard within an agency that traditionally does not necessarily value this type of knowledge? She smiled and suggested the parallels between this predicament and the struggles of the parents to share their perspectives and knowledge.

Parents wrestle with how to present their knowledge to health care professionals. The struggle continues in the same manner, through this

research process, as to how to present an understanding of these experiences in a way that touches those responsible for care. To many practitioners, research worthy of attention is that which applies the "perfect method" to seek out accurate, clear, statistically defensible pictures of clinical reality, rather than being open to capturing all that is occurring within the same context. If the provision of health care is both a science and an art, then the art must include the parent!

Both the interactions of parents and my plan for research are being constructed around the concerns of how to package information in order to market it in the health care professional's world. Gadamer (1998) suggests the key to understanding the esthetic components of the subjective, inner human being is not through manipulation and control, but through openness, participation and dialogue. While before I would have continued the struggle to transform and conform the knowledge and understanding I gained into a framework that fits this powerful discourse, I now recognize that this is not my role as a parent or as a researcher. Rather my responsibility lies in being open, to be present in the relationship and to put the information out there. I offer the understanding contained in this thesis as a means by which to encourage others to challenge their assumptions against this different backdrop. This research provides an opportunity for professionals to examine their own position and beliefs against a different perspective that includes the voice of parents. Although my hope is not to "convert" all who read my work,

my goal is to challenge them to think differently about their relationships in care.

In the process of conversation between two people, each is open to and accepts the other's point of view for what is (Thompson, 1990). This is all I hope for. However, I acknowledge that some are not always able or willing to participate in this way. My belief is that if no one ever communicates from a place where we are encouraged to examine our own horizon, there is no possibility of change. Is it possible to create an understanding of the notion of relationship described in this text, that would break through the differences inherent in the scientific and intuitive worlds and their languages? Can we change the reality by changing the language we use to describe and understand illness and the relationships that surround it?

Research Question

My intial purpose through this study was to search for the patterns and meanings that would illuminate the various dimensions of honouring and provide an understanding of the essence of honouring as it relates to the experience of participation of parents in the diagnosis and treatment of their child's illness. What follows is an exploration of the evolution of the research question and how honouring became the vehicle rather than the destination.

The intent of this research is to shape a place, lifted above the goings on of everyday life, where things slow down enough that people could hear the message in the stories. This research is about finding the identity or voice

within each story and letting the voice speak to others touched by similar experiences and to those caring for individuals through their journey of illness.

Relationship and connectedness are important to me and I believe they are important to healing. This research illuminates the experiences of parents in relationship with health care providers and provides insight into the voice of parents as they speak to what is important and effective within these relationships.

Philosophical Underpinnings

Qualitative data have always been used in the social sciences, particularly in anthropology, history and political science, but it is only in recent years that the qualitative paradigm has found a role in health care research. Miles and Huberman (1994) suggest qualitative research is the source of well-grounded theory, illustrated with rich (or thick) description and the explanation of processes that occur in an identifiable local context.

> Drawing on work from phenomenology, symbolic interactionism, existentialism, ethnography, and hermeneutics, this method of knowing focuses attention on experiential knowledge. Variously termed grounded knowledge, thick knowledge, deep or holistic, this type of knowledge is obtained through experience by the provider and qualitative methods by the researcher (Coulter, 1998, p. 29).

This way of knowing becomes paramount when the subject in care is the "total patient." The total patient represents all the objective and subjective elements of humanness, which includes the inner self and the intuitive voice.

Miles and Huberman (1994) suggest that when using qualitative approaches, reality and life are explored with an emic perspective, from the views of the participants in the setting under study. Everyday life is explored in an uncontrolled, naturalistic setting, with an allowance for investigation of all of the above elements.

Understanding relationships calls for grasping the essence of the whole person in the context of our experience. Communication, words and text are essential to this inquiry. Communication is shaped by the context within which it occurs. Context is defined as "that which leads up to and follows and often specifies the meaning of a particular expression" (Morris, 1982, p.316).

Interpretive inquiry lends itself particularly well to capturing the context of communication. The focus of such research encompasses the subjective experience, individual perceptions, shared language, inter relatedness, time and space considerations, and the context dependency of human experience (Munhall and Oiler, 1986, p.23).

Phenomenology as a world view, is a philosophy and a methodology that reflects the underpinnings of the experience I describe and the research question I propose. "Far from inviting us to explore our everyday meanings as they stand, it calls upon us to lay them aside for the moment and to open ourselves to the phenomena in their stark immediacy to see what emerges for us" (Crotty, 1996, p.6). What we will have caught may be a new meaning. It may be a new meaning with a twist, but it will no longer be an inherited meaning but *our* meaning, toiled authentically from experiences shared. Thus,

the researcher asks the question: "What is it like to have a certain experience?"

A phenomenological perspective attempts to illuminate the essential characteristics in the structure of the phenomenon, the essence. A phenomenological study aims to reveal the essence of the lived experience and to describe it. The term essence is derived from the Greek "ousia" which means the true being of a thing, the inner essential nature of a thing. The essence is that which makes something what it is (without which it would not be what it is). "It is that which makes a thing what it is rather than its being or becoming something else" (Van Manen, 1992, p. 126). Phenomenology is, therefore, the study of phenomena and the appearance of things. The discovery of their essence is the ultimate purpose of such research.

This research seeks to understand the essential elements of the supportive health care relationship, not by defining or categorizing, but by experiencing it directly through the lives of other parents. "Phenomenologists attempt to describe the essence of the phenomenon through common themes derived from conversations, interviews, words or pictures of the participants" (Molzahn & Sheilds, 1997, p. 15). Phenomenology is a descriptive form of research that includes neither induction nor deduction in its purest form. The phenomenon itself is described through the experiences of those who can speak to it. It is a method intended not to generate theory, but only to allow the reader an insight into the lived experience of the phenomenon.

Nursing research has developed an interpretation of phenomenology that focuses on the study of subjective experience. According to Osborne (1994), the goal of the "new nursing" phenomenology is to obtain a first person description that stays in the first person.

Phenomenology is both a philosophy and research methodology. It was initially developed by Husserl (1913), who perceived it as a way of examining the "primordial essence of phenomena" as they appear in consciousness. He launched his position from the cry of "Back to the things themselves". He wanted to study reality as it presents itself to the human consciousness, while refusing to divorce reality from consciousness.

"Consciousness, in other words is always the study of something. In presentation something is being presented, in judgment something is being affirmed or denied, in love loved, in hate hated, in desire desired, and so on" (Crotty, 1998, p. 44). From this thought flows the concept of intentionality, the idea that the human mind is reaching out and into the objects of which it is conscious. "Intentionality means referentially, relatedness, directedness" (Crotty, 1996, p.38). The object of knowledge comes to dwell within the knower. We are speaking of the relationship between subject and object. Following the thoughts of Heidegger, a student of Husserl, Crotty (1996) suggests the world and objects in the world may be in themselves meaningless; yet they are our partners in the generation of meaning and need to be taken seriously. It is therefore important to distinguish a theory that is consistent and driven from experienced reality from that which is not.

Objectivity and subjectivity need to be brought together and held together. While all knowledge is created in relation to an objective object, it is only in relation to the subjective knowing of this objective object that we can begin to articulate the meanings essential to our humanness. Belensky, Clinchy, Goldberger and Tarule (1986) wrote of the notion of constructed knowledge, where an individual experiences him or herself as a creator of knowledge. There is the view that knowledge is contextual and values both the objective and subjective. Traditional phenomenology addresses these beliefs, and differs from the "new" nursing phenomenology as described by nursing researchers such as Munhall (1994). This new phenomenology seems to have moved from the study of phenomena as the immediate objects of experience, to a study of experiencing individuals. My choice is to embrace the latter in a description of the experience that is relevant and reflective of the participants' stories and of the prevailing cultural understanding. To not do so would seem dismissive, hurtful and dishonouring of the participants' openness to share their understandings as constructed through the concept of intentionality.

> To embrace the notion of intentionality is to reject objectivism. Equally, it is to reject subjectivism. What intentionally brings to the fore is interaction between subject and object. The image evoked is that of humans engaging with their world. It is in and out of this interplay that meaning is born (Crotty, 1998, p.45).

The words of Crotty seem to reflect the possibility of the intertwining of parallel beliefs, the objectivism of science and "cure" and the subjectivism of the patient's intuitive knowing of self, into something created through the interaction of both. Phenomenology is a purely descriptive way of viewing a

phenomenon "as it is in the life world". It is not just a study of subjects, but a study of the object of their experience, their relationship.

Although Husserl (1913) argued that phenomena could be reduced to essential meanings that would universally be agreed upon, Heidegger, not believing in "a priori" knowledge, reversed Husserl's notion of "reductionism" through his belief in the "expansion of horizons". While Heidegger (1975) agreed that through careful reflection and observation, we could develop deeper core meanings, he also believed the situation of the researcher was critical to the meanings uncovered. Heidegger dispelled the belief in the existence of a priori knowledge, but rather felt that knowledge was created through interaction and influenced by personal and historical contexts. This suggests that similar methods can lead to different outcomes, a "subjectivity of truth". His ideas support the position that the meanings we assign to our experiences radiate between or are extracted from ourselves and particular situations.

"Husserl, the father of phenomenology, viewed phenomenology as essentially a descriptive exercise, in relation to the observer or subject, with no reference to analysis of its essence beyond the phenomenological reduction, which consists of the bracketing exercise" (Corbin, 1999, p. 61). Data are presented in their raw state, with the researcher's preconceptions, values and beliefs 'bracketed' so as not to influence outcome. Husserl believed there was an a priori understanding of an experience that could be captured and articulated. He saw the world as an objective entity. This results

in a separation of the researcher from the study participant, and is vaguely reminiscent of positivist paradigm objectivity.

In hermeneutic phenomenology, the researcher becomes part of the study and "bracketing" is not emphasized. Gadamer (1998), like Heidegger, disputed the concept of a priori knowledge. Gadamer includes the respondent as a co-researcher, and refers to the hermeneutic circle as including the researcher as well. Hermeneutic phenomenology finds a role for preunderstanding. Referred to as "forestructure", this tradition calls on the researcher to examine her own situatedness in relationship to the phenomenon in question. The usefulness of bracketing is questioned. All understanding is purposeful and without this historical knowledge the researcher cannot situate herself appropriately within the question. The hermeneutical phenomenologist believes that meaning and understanding are interconnected elements. The researcher needs to acknowledge his or her own pre-understanding and prejudices about the situation. "Prejudices represent the prejudgments that stem from our forestructures of understanding" (Nakkula & Ravitch, 1998, p. 26). Gadamer thought of them as biases that are shaped by the richness and limitations of our experiences, and by the language we have available for describing and understanding the phenomenon we chose to explore. This is supported by Palmer (1969) who suggested that for the interpreter to 'perform' the text, he must have some pre-understanding of the subject and situation before he can enter into the horizon of its meaning. The researcher

would then seek to clarify whether his/her understanding matched those of the research subjects, as in this case with the notion of honouring.

The purpose of research is then to explore the phenomenon from this position of awareness. Although honour captured my meaning making, did it speak so for others? We must know our history and experiences and how they place us in relation to the phenomenon, and then work towards a revised or expanded understanding that enhances our further experiences as we engage with our world. To achieve this, the researcher enters the hermeneutic circle. In this process the researcher identifies, then sets aside his/her own preunderstandings in order to accommodate those of the participants. This is achieved by a process of moving dialectically in conversation between persons. Each is open to and accepts the other's point of view for what it is. "Understanding the experience may well aid the researcher to enter the circle in the right way, to formulate questions in ways that bring out the significant aspects of the experience, and to present a truly empathic, shared account of what the informants tell the researcher" (Chesla, 1995, p.77). It would seem an appropriate methodology to explore the "art" of caring through relationship during the process of diagnosis and treatment, to gain esthetic knowledge associated with the art of healing. Current literature reflects the delivery of health care as both a science and an art. It is time to further understand this intuitive or aesthetic element of knowledge. As Heidegger (1975) suggests, to explore "prereflectively" is to know our instinctive,

intuitive, and visceral experiences of being in the world versus knowing through concrete, empirical methods.

Although each of us constitutes our world in unique ways, we do, nevertheless, have some aspects of the world in common with other members who share our language and culture. To be human is to participate in a social, cultural and historical context. So in order to understand a person's behavior or expressions, one has to study the person in context. As my research question concerns a practice discipline, in a specific context, it seeks to understand individual uniqueness within the experience of diagnosis of children's illness. This real world of practice occurs through interaction between patients, families and practitioners. The methodology chosen to research practice issues can not be detached from that which makes us human, our connection to each other in time, in situation, in context. By becoming an active participant in the research process, the researcher is able to recognize the inter-relatedness of the elements that compose the object of investigation. "The researcher is encouraged to recognize that all things and events perceived by the senses are interrelated connected aspects of the same reality, and are not dichotomous opposites that exist only in relation to one another" (Weekes 1986, p. 1311). Research is a participatory and dialectical activity.

Gadamer's hermeneutic phenomenology encourages researchers to move away from the notion of the perfect method. The idea that there is no absolute truth frees researchers to explore more comprehensively issues that they may not have considered worth pursuing. It is a freedom from the

traditional focus on gaining accurate and clear evidence of "clinical reality", to being open to all that is occurring within the health care relationship and the interpretations of individual experiences.

The methodology for this research was framed around the Heideggarian derivation of phenomenology, hermeneutic phenomenology. Heideggarian methodology reflects a shift from the Husserlian transcendental concern with consciousness as the medium through which we know objects to an emphasis on ordinary language. Language is the ground for intersubjectivity, the medium through which meaning is established. Hermeneutical theories of understanding argue that all human understanding is never "without words" and never "outside of time". Hermeneutics emphasizes the importance of language and the way language functions to "make something foreign, strange, separated in time, space of experience familiar, present or comprehensible" (Palmer, 1969, p.13).

Hermeneutical phenomenology is concerned with understanding and interpretation. Nakkula and colleagues (1998) suggest that the fundamental characteristics of any phenomenon, according to this perspective, are the essential meanings humans make of the phenomenon in question. Research is then a process of uncovering and interpreting our connection with our world as it is experienced over time. Interpretation in this tradition requires the allocation of words in order to enable expression and identification, as well as the understanding of the structures that provide the essence of the phenomena.

> "Hermeneutics utilizes particular skills, those that encourage the construction and interpretation of life stories; that promote understanding of thoughts, feelings, actions and personal meaning within broad and specific contexts; and that focus on relationship development as the primary activity of being human" (Nakkula, M., & Ravitch, S., 1998, p. 35).

In this research, I became a hermeneutic phenomenologist working with parents in the co-creation of language to enlighten others to the human experience of relationship and its place in the health care.

Research Methodology - Honouring

In keeping with the purpose of this work and my position within it, the chosen methodology needed to provide a means by which to unreservedly listen, hear, revisit and reflect on the stories told. Building on the hermeneutical tradition, what follows is a description of how the research process unfolded.

Researcher Subjectivity

Self awareness and reflection provide the cornerstones of how the researcher is situated within the phenomenological method of inquiry. As previously mentioned, forestructure or preunderstanding requires the researcher to examine his/her own background and meaning structure surrounding the phenomenon. Some phenomenological researchers suggest that the bracketing or removal from relevance of these preunderstandings is

useful in reducing error or bias. From a hermeneutic perspective, this reduction is impossible and counter-productive. These preunderstandings provide a starting point from which to begin to understand that which we have yet to describe. Further, hermeneutics suggests we can never step outside of our everyday reality to understand ourselves or others. Taylor (1985) suggests the best we can hope for is a coherent interpretation of what was originally confused or clouded.

This is not to say that the researcher must not be open to experiencing the phenomenon differently. The meaning of the phenomenon is determined through 'free variation' where the researcher, in his or her openness, examines the range of possible forms it may take. "By adding or subtracting certain features, and noting the points at which the object in question ceases to exemplify that concept, I can identify what is, and what is not, essential to the concept ... this object I can proceed to describe" (Paley, 1997, p.190). Heidegger (1975), uses the word "Gelassenheit", to describe this openness and passivity. As Munhall (1994) suggests, the emphasis is on simply opening oneself to the phenomenon, allowing it to grasp you, wash over you. While acknowledging our forestructure of understanding, we are not confined by it. Indeed, we need to release ourselves from our previously constructed concepts of viewing the phenomenon in order to "listen" to the phenomenon itself. We can't call on preconceived or prevailing social notions and beliefs to explain what we are experiencing. Although conscious of them and how they

place us in the hermeneutic circle, we are not confined by them. We are open to seeing and understanding in a different way.

The process of telling my own story began many years ago, almost from the moment the journey with illness began. As human beings we reflect and attempt to make meaning of our experiences in order to move forward in our lives. Van Manen (1992) explains that this act of reflection is the effort to grasp or understand the meaning of what we are living through. The data that are created through this reflection are those of our daily involvement in the world. It became the basis of preunderstanding for this research.

This process became more formalized as I entered into formal education and began to envision my thesis and potential areas of interest. In trying to articulate these to both myself and others, I began to know my story in an intensive way. Chronologically, I reflected on the experiences of the past years with Nick's illness. Emotionally, I relived the human journey that Nick's illness had afforded. I exposed my own prejudgments and prejudices and created my own horizon of the experience of relationship with the health care providers. By acknowledging these preconceptions and biases and holding them close through an awareness of my own story, I was able to put them to rest and consider asking others to share their stories. My hope was to support my own understanding and discover a more complete way of knowing parental experiences in health care relationships. My own preunderstanding was present, I acknowledged it, kept it close, but did not allow it to influence how I heard the stories of others. Though a challenge, it was possible. I

needed to constantly remind myself to put aside the importance of my own thoughts and conceptualizations. While some might think this constituted bracketing, I believe there was a distinct difference. I set aside the belief in the importance of my own experience but I never lost touch with these experiences. They guided me through the research process. They showed me how to enter into the dialogue, how to attend to the stories of others and grounded me in my intuitive reflection that led to this research interest. I found that I needed to call forward this original awareness in order to create a transformation of my understanding of the experience of honouring and relate this to the co-created final understanding. This forestructure provided the foundation for further learning. I remained open to this transformation and invited in the potential for understanding.

According to Gadamer (1998) there is no absolute truth to be apprehended. Together, myself and the co-researchers created a snapshot in time of the experiences of parents in relationship with health care providers. The knowledge or understanding produced must take into account the "indefiniteness" of a changing reality. Any given phenomenon can always be viewed in different ways. The issue is always that of the relevance of the research work to the given situation and vice versa. There are always alternate explanations, and all explanations can be challenged. Its relevance and usefulness needs no defending to those who composed it. I leave it to those who choose to read this work to formulate their own opinions. I believe there

is no knowledge that offers a full explanation of the world, only that which helps us see and know differently in an enlightened way.

With questions that search for understanding, there can be no separation of the knowledge of the experience from the meaning of the experience. "That is, understanding the meaning of the experience can be understood only by reflecting on the context of the situation, for the individual both constitutes and is constituted by the situation" (Benner, 1995, p.7). Marcel says (cited in Zaner, 1971, p.7) this kind of involvement in research allows no detachment. I, as a co-researcher, cannot place myself outside of the problem I formulate. For me, posing the question was not something I had to search out. It came from my life.

Recognizing this, the onus is on me as a researcher to make explicit my interpretative scheme. This has been accomplished by making visible my values, beliefs and experiences concerning the subject of study. I have shared with the participants and the reader my story and my interpretation of what it means to me. I have attempted to make clear the relationship between the inner commitments (the interest and passion) and the outer activities (data collection, analysis and linguistic transformation) in order to provide those who read this work with a grounding as to how I entered this research and the validity of its undertaking.

Time spent reflecting on my values, beliefs, and experiences in discussion with other nurses, parents, and fellow students was invaluable. The process of sharing and discussing what had drawn me to this issue of interest

and tradition of research better prepared me to articulate it in written work. This sharing revealed to me insights and perspectives that I was not initially aware of but were buried deep in me. The engagement in an in-depth examination of my own forestructure has allowed me to bring to this investigation a centered place from which to begin writing and researching. The process of personal awareness involved utilizing a personal journal that facilitated an ongoing journey of cognizance surrounding the meaning of the stories heard and the processes used to interpret their meaning, and has greatly enriched the experience of carrying out this research.

Participants

I had entered graduate work with an introductory understanding of the topic I wished to pursue. What began as only a distant sense of what it was I hoped to take in, through dialogue, over time arose to give clarity to my specific area of interest. During the many months of discussion that led to this point, I was encouraged by the interest my topic seemed to generate among other parents and health care professionals. In the process of sharing and talking about the research, it quickly became apparent that people were intrigued. The timeliness of this exploration was validated by the encouragement of parents, their belief in the importance of such research, and their willingness to participate. I was fortunate in that the introduction of the topic of this research created much discussion and resulted in many parents volunteering to participate. I did not need to seek out participants. Thus the

selection of co-researchers occurred through voluntary means (Morse & Field, 1996).

As well as being volitional in nature, the selection was also purposive. I selected only those parents who had the specified experience and demonstrated a readiness to tell their story. Munhall (1994) describes readiness as being willing and able to speak about one's experience. Participants needed to be able to set aside their own prejudices and explore with the researcher the meanings inherent in their experiences. This implies a certain distance and resolution of the experience. Some parents, though interested in participating, felt the experience was "too fresh" and for some too painful to begin to share. They felt they would not be able to reflect and articulate their stories as their experiences remained raw and hurtful. They had not yet begun the process of making meaning of this life event. Several parents questioned how they could share something that they themselves had not fully shared with themselves. "Participants need to be comfortable reflecting, focusing, intuiting and describing as the phenomenological endeavor requires" (Crotty, 1996, p. 172). For some parents, the "newness" of their experiences was prohibitive.

Thus the participants were required to have the necessary lived experience, to volunteer to participate, and to demonstrate a readiness and ability to reflect and create meaning from their stories. In order to fit the number of participants to the time and resources available, six families became the co-creators of this research. The desire to develop relationships, gain trust

and share deeply our experiences, required a greater length of time spent with a smaller group of participants.

The development of relationship and trust is essential to the methodology of this research. I recognized that how I brought myself and my knowledge into this relationship would greatly influence the depth of the stories shared and would shape the experience of the participants. How my co-researchers entered our work together and their sense of me and the research question was equally important. It was with a great sense of responsibility that I reflected on my role in this research.

Use of Self

Following the hermeneutical tradition, all knowledge is created within the context of relationship. The more comfortable and trusting a person feels with the researcher, the more open and giving that person will be in sharing personal experiences (Polkinghorne, 1983). Time spent nurturing this resource results in a greater richness of sharing of experience which in turn influences the insight that can be gained through the research undertaken.

My first step in this direction was undertaking to share myself with the participants. I wanted to develop a trusting relationship. The voluntary nature of the participation aided in a sense of purpose and direction. What needed to be enhanced was a sense of connection with each other. This was established through meeting individually in settings arranged by participants. At the initial meeting, consent was obtained and a brief outline of the process of

conducting the research was undertaken. No data were collected at these initial meetings. Our relationship began to develop through the relaying of empathy and understanding of each other's experience and a sense of a common purpose. By allowing participants to approach me regarding involvement in the study, and to set out the time and place for our interactions, a neutral relaxed environment was created. We began that reciprocal sharing that occurs between individuals as we established the relationship that would allow us to share our stories through conversation (Polkinghorne, 1983). I answered any questions the participants had, including responding to their desire to know of my experience. The bond created through this sharing forged a sense of unity that only served to enhance the outcomes of this research.

Through these initial interactions I began to discover what my role was in the creation of this knowledge. I recognized my influence in how the lived experience was approached and conveyed. I was a filter for the data. In reading and writing I would influence how the final story was told. I sifted through the conversation, attentive to the voices of others, helping participants to articulate essential elements of their experience. Often these hidden fundamentals were buried so deep that the participants couldn't hear them without someone to reflect their story back to them. Munhall (1994) suggests that attending to the speaking of language means being sensitive to the suggestive way language speaks. The end result was that the participants

understood their own experience differently and gave language to their interpretations of the essential elements of relationship.

Through back and forth, careful pondering, I was able to give these thoughts voice and language, creating a chronicle that honoured the experiences of parents. Through borrowing the descriptions of the participants' experiences and reflecting on them, a linguistic account of their experience was created.

Ethical Considerations

Of foremost importance in any research involving human subjects is the safety and well being of these participants. Traditionally, there are several mechanisms that can be employed to ensure this. Prior to beginning this research, an ethical review approval was obtained through the University of Victoria Human Research Ethics Review Committee (Appendix A).

Informed consent (Appendix B) was obtained from each participant at our initial meeting, prior to the start of our first taped conversation. Once the consent was signed, a discussion ensued as to: (a) who I was, my history and how I came to be interested in generating further knowledge regarding this topic, including the use of this research to obtain a Master's degree, (b) the nature of their voluntary participation and its continuation for the duration of the research, which afforded them the opportunity to leave the study at any time with no repercussions, (c) the time commitment of three meetings, (d) their participation in the creation of the final story, ensuring their voice were

accurately captured, and finally, (e) a discussion of the personal costs and benefits of participating, including being heard and provided with an occasion to reflect on their experiences, weighed against the vulnerability created in personally engaging in telling their stories.

This initial meeting offered an opportunity to answer any other questions I hadn't anticipated and to ensure the participants were well aware of their individual rights within the research relationship. Participants were enlightened as to how the data would be handled in terms of confidentiality and anonymity. I, as the primary researcher, would be the only person gathering and working with the data. Each participants' story was personally transcribed by me, with the tapes and resulting transcripts locked in a filing cabinet to which only I had access. In the final thesis document, no names are attached to individual stories, nor are institutions identified.

Data Collection

It was through this beginning relationship that the dynamic, collaborative process of producing meaningful understanding began. Kvale (1996) held forth the idea that conversations are a basic mode of obtaining knowledge; they provide a space where knowledge can be constructed. Van Manen (1992) states:

> In hermeneutic phenomenological human science the interview serves very specific purposes: (1) it may be used as a means for exploring and gathering experiential narrative material that may serve as a resource for developing a richer and deeper understanding of a human

> phenomenon and (2) the interview may be used as a vehicle to develop a conversational relation with a partner (interviewee) about the meaning of an experience. (p.66).

Conversations composed the primary method for the co-creation of data. Nonetheless, as this process unfolded I continued to journal, to chronicle the research experience. This enabled me to keep close to me the experience that was research, to reflect on the process of being in relationships and the evolution of myself as a co-researcher. This account aided greatly in the reflection contained in these pages.

As a novice researcher I initially approached the task of data collection in a very structured way. However, I learned that in this evolving quest for understanding, I needed to lighten up on order, certainty, the need for answers and let the knowledge come to me. This is reflective of Heidegger's (1975) notion of "being in the world" and being open to what appears.

The researcher has three tasks: (a) to gather data that reflects the participant's experience of the phenomenon in question, (b) to attempt to examine personal beliefs, values, and experiences concerning the subject under question, and (c) to capture the prereflective level of experience (Osborne, 1994, p.17). Initially I had expected these to be sequential steps. The discovery that this was a journey more than a calculated trip, created discomfort. It was difficult to accept that I needed to trust the process, be clear as to how I was centered within it and then simply begin the dialogue.

From this place, the work would flow, almost like a tide, in and out but always with a purpose and a rhythm. It did. The experience unfolded. "Tending to the phenomenological attitude is like floating on water. "Let yourself float, let the adviser float, let there be silence, peace and contemplation" (Munhall, 1994, p. 47). I found I needed to remind myself: "Don't rush up to the research or you'll scare it away. Stay calm, take time and the ah-ha's will come."

Van Manen (1992) believes that a person can only really begin to understand phenomenology by doing it. This is very true! To trust yourself and to relax freely into that which is phenomenological research requires faith, faith in the process, yourself and those you are working with. By being clear on where I was within the question, how I wanted to interact with my co-researchers and a sense of how we wanted the final story to be told, I had already completed the first "steps" to a successful piece of research. This initial work, described by Van Manen, as turning to the nature of the lived experience and living the question, reflects the first step in phenomenological research. By doing this successfully, the results of the dialogue fall into place.

Members of my committee suggested that a test interview would be helpful to assist in developing my comfort with the interview itself and to ensure a consistent, congruent approach in interviewing. I selected someone who had shared the parental experience, but also someone with whom I had established a personal relationship that was comfortable and relaxed. Consent

was obtained and we agreed that the knowledge highlighted through this dialogue could be used in the final research document.

I set out to do this "pilot interview" with what I felt were appropriate, semi-structured interview questions that would keep us on track. The initial question to start the discussion was "Can you tell me about a time when you felt honoured as a parent in relationship with a health care professional"? I had thought that this question would stimulate discussion, instead it was a roadblock. The participant for my pilot interview looked at me searching and asked, "What do you mean by honoured"? It was a revelation for me. What was so clear to me, and I had assumed would be for others, was not at all. It was at this moment I realized I was interviewing with a specific goal, we were not having a sharing dialogue. I was guiding my questions in order to attempt to create data that supported my notion that "honouring" held some importance and could somehow encapsulate all that was to lead us to a greater understanding of the human experience within the health care relationship. I realized what was truly needed was for participants to know that I was interested in hearing their story and not validating my own. While I thought my notion of honouring captured the key element of this relationship, instead this conviction was really a reflection of my own inability to set aside personal preconceptions. The writing and conversing that had gotten me to this juncture, allowed me to see my biases. The experience of the pilot interview allowed me to truly understand how to set them aside.

I now considered how I could honour their experiences and expertise? It could be accomplished by sitting quietly and putting their experience and knowledge at center stage. This was most important, not because it fit my specific methodology, but because it felt right!. Perhaps the need to begin in this way flowed from my personal experience with the health care relationship. As I have discussed, I felt I was not honoured through the actions of the health care professionals with whom I interacted. This was, in part, my way of righting this wrong for others. Respecting the value of others' experiences became part of my own healing process. Kvale (1996) highlights the importance of overcoming this personal barrier in order to generate rich data through story. For me, the authenticity and trustworthiness of the research, and my own integrity as a researcher, also hinged on this being so. Through this one event the validity of this research was secured.

Although I had thought I needed to begin interviewing with structured questions to guide the conversation, I now understood the exact opposite was true. I needed to engage in a conversation and hear their story. It was as simple as that. It was a conversation, a process of storytelling, that would lead to understanding. I needed to let go of my preconceived notion of honouring and the fear that without structure, what would result would be confusing and without substance. Through trusting the relationship, what was important to share would evolve and be determined together. Out of the dialogue flowed opportunities to hear. Polkinghorne (1983) suggests that in an attempt to understand the meaning of another, a to-and-fro dance occurs.

It is not simply a question and answer process, but a dialogue that leaves room for the conversation to find its way to the center of understanding, an understanding created together through interaction. The structure is the topic, the context is the relationship, with trust and comfort the gatekeepers to access rich and rewarding data. Our job as co-researchers was to link together the information shared and create coherent descriptions and trust that through conversation, not interviewing, the important information would surface and we would recognize it.

Munhall (1994) discusses the concept of working in the shared space. During the pilot interview our interactions felt very separate. With my epiphany and the abandonment of "following directions", the freedom for the conversation to run within flexible boundaries was created. The dialogue came to represent a co-creation of meaning versus the presentation of structured facts around one concept. The knowledge was co-created in a design that emerged from the relationship itself. The necessary structure was created through the reflection of myself and participants on both our previous experiences and the experiences gained through sharing the research process.

Although difficult initially to abandon the idea of understanding "honouring", the moment I did the open dialogue and reciprocal sharing that occurred and the relationship that developed enhanced the exploration and took us deeper to understanding the experience of parents. Munhall and Oiler (1986) suggest the phenomenon itself, if we are attuned to it, become part of it, will show us how to study it. Although I didn't know whether honouring

would become part of the final story, I was now open to all that could be offered.

After completing the pilot interview, digesting and reflecting on this experience, I felt ready to set up times for the initial conversations. Participants selected the time and location for these interviews. Written consent was obtained and the conversations were taped. After recognizing that asking about honouring confused participants, I searched for a way to begin the dialogue and not confine it. It then occurred to me that the place to start was simply to ask parents to tell me about the experience of the diagnosis of their child's illness. While being attentive to what was said I seemed to intuit when to explore a statement. It was amazing how, through just talking and sharing this common experience, the richness of the data was shared. I was thrilled. The participants were amazed at their own individual discoveries.

In discussing the research at this point with my committee, another epiphany occurred. One member suggested that "Honouring" was perhaps my methodology rather than my question. That was why it was so important to begin with hearing their story. It rang true to me. Now the struggle to hang on to honouring made sense. Honouring as a methodology provided an opening to recognize the "gift" that illness had brought to all of us as parents, that of "insight" and "knowing".This was a gift that needed to be shared. I needed to not only provide a place for this gift to be shared but I needed to honour the participants gift to me, the gift of their story. They had all been silenced at

one time or another in their attempts to share this story. I could honour them and myself through listening and using their gift to compose this thesis. Honouring is the methodology. This was the right place from which to begin.

Words that had been close to me from the beginning stages of framing this research turned out to be the methodology, instead of the question. In my research methodology, honouring is enacted through bearing witness. To bear witness is to hear the story in an open way. In this context, bearing witness is more than a cleansing act for the storyteller. I recall the definition of honouring mentioned earlier that included "that which is entertained in the mind". Through hearing and marking the experience, bearing witness provides the mechanism by which the experience is taken up and honoured in its application.

Conceptualizing bearing witness and honouring were the essential first steps that cleared the way for me to delve deeper into our shared experience. I understand that now only through the experience that is this research and the guidance of my committee.

Gadamer (1998) spoke of our inner and spoken vocabularies. Munhall (1994) wrote of the three types of dialogue: (a) the internal dialogue representing thinking and responding within one's self to all that has gone before and comes to present itself, (b) the external dialogue as the public spoken or written word and the understandings imparted, and finally (c) the eternal dialogue that never stops, that which we may not be conscious of either internally or externally, but that which surrounds us in emotions, stories

and even lyrics of song. I believe that only through hearing our own experience and reflecting on this through our external dialogue can we reveal the eternal dialogue that is the key to our human potential. Using honouring as a methodology was congruent with these beliefs. My methodology of honouring the experience, through bearing witness and giving voice, yielded rich, dense data. The story ran through me, my mind capturing the quintessential aspects for story building. The parents needed to tell their stories, to immerse themselves in it again in order to provide the excerpts essential to constructing a final narrative that spoke to their experience. Honouring and bearing witness accomplished this and provided a means of personal healing. A goal of this research that I was now aware of had always been important to me as a person, a parent, and a nurse.

My own experiences with this kind of health care relationship provided the impetus and curiosity to explore this issue. In honouring myself, I felt I needed to include my own experiences in my research. Some researchers might argue I am in danger of losing openness to what the research might find through biases constructed in bringing my story to the dialogue. I believe however, that by hearing my own story, it not only honours me, it enriches the final story and clears room for other experiences within my own world of understanding. My story further enriches the data. It is feasible, according to Van Manen (1992), for the researcher to have similar experiences and perceptions to those of the participants. He added that experiencing the same phenomenon may provide the investigator with clues to

guide the research and a personal orientation that will enhance the research. As a result, my experience as shared in the introduction of this research was captured and utilized in the creation of the final narrative. This was supplemented by continuous reflection on my experience as a researcher. I read recent writings that represented the evolution and refinement of this research interest and continued to journal as I worked toward the final draft of this work.

This data generation phase continued through the first and second interviews. Although initially structured only around hearing the experiences, through my own forestructure and personal sense of the experience, I was able to hear common descriptions and emotions within the stories. It was at this point that I employed open-ended questions to attempt to assist participants to draw out the meanings and importance housed within the story. Initial concerns over having to remain outside the conversation were quelled when I found I could be present in the relationship, hear the story, and trust that through my understanding I would be able to sense and not 'miss' the clues to the quintessential elements. With each interview my comfort with this process grew. At home listening to the tapes, transcribing, and reading, provided the opportunity to step outside of the interview and consider the information shared in relation to the research. Reflecting on each interview, I became more skilled at hearing what was explicitly said and hearing what was hidden within the dialogue. Subsequent interviews provided an opportunity to clarify specific aspects with the participants. The journal that I had initiated at

the start of this research, provided a means to chronicle this reflection and document specific areas of interest for follow up. To best describe this process of data collection is to say the research was always with me. At times my engagement with it was cerebral. During interviews my mind was awake conscious, active, aware, listening intently. At other times, while I read the transcripts or pondered in the backyard, the work was more abstract. I recall not even being conscious of it, but it surfacing when it was supposed to and being open to its discovery. It was hidden in lyrics of songs, in movies, seeming to add to the ethereal nature of the work. I found myself journalling, carrying a tape recorder in the car, ready to record the inspiration as it came.

Data Analysis

Van Manen (1992) presented an approach to phenomenological inquiry. His method includes the interplay of four essential processes: (1) turning to the phenomenon that interests us and commits us to the world, (2) investigating experiences as we live them rather than as we conceptualize them, (3) illuminating the essential themes that characterize the phenomenon and, (4) describing the phenomenon through the art of writing and rewriting. "Phenomenological writing may be descriptive or interpretive, but it is essentially written text and open to varied interpretation depending on the experience of the reader" (Morse & Field, 1996, p. 20). Although phenomenology focuses on description of phenomena, hermeneutics, a type of

phenomenology, moves to an interpretive level. Hermeneutics is a systematic approach to interpreting a text (Streubert & Carpenter, 1995).

In the hermeneutical approaches of Heiddegger (1975), Mereau-Ponty (1964), and Ricoeur (1991), the researcher is able to go beyond Husserl's notion of phenomenological reduction, beyond what is directly given. In doing so, the researcher is able to use what is given as a clue for meanings that are not given, or at least not explicitly. Ricoeur refers to the Heiddeggerian process of inquiry as the "grafting of hermeneutics into phenomenology" in that phenomenology with its emphasis on the uncovering of underlying core meanings, is joined by hermeneutics, with its emphasis on interpreting that which is uncovered.

Ours was a back and forth journey toward the final story, turning to and from the data. Polkinghorne (1983) states, understanding is derived and seldom can one discover an absolute starting point. That which was true called out loudly. The process of data analysis began during the initial interview. Looking back, I am able to recognize that decisions I made to explore various aspects of a conversation were the first decisions around analysis and influenced the data collected. Immediately following each conversation I listened to the tape and personally transcribed the conversations verbatim. Then I read the transcription. Then I went back to the tapes. It involved making sense of each story, reading, reflecting, rereading and synthesizing. Once I felt centered in the person's story I was able to see the key themes that emerged. I made notes intuitively on the transcripts,

jotting down the descriptive examples or expressions as they spoke to me. Van Manen (1992) describes a theme as "the experience of focus, the meaning or point" (p. 128). I undertook this process for each family's experience, taking it back to them at follow up interviews, ensuring it spoke of their experience.

The process of data analysis continued to evolve through the experience of sharing these discoveries with the participants. In taking back my account, asking for feedback, and refining the story, the participants were both co-creators and interpreters of the data and final story. I worked through all initial interviews and corresponding transcripts, immersing myself and securing my understanding of each individual story before moving on to the next. I then reread each initial story, again moving back and forth between them, looking for common elements of the experience. This process was invigorating but exhausting.

Clearly, there were common threads to their experiences. It was an intuitive process to begin with, but I always looked back to the tape and transcript for confirmation of my interpretation. The transformation of the transcribed conversation into the final story occurred with the same reflection and intuiting. I would work until overwhelmed, my mind so full it raced. I'd go away from it, sit in the hot tub, only to have to race out to jot down another thought. Another set of one to two hour interactions resulted in clarification for me of my interpretations of their individual stories. However, the creation of these stories was but one step in the data analysis. I often left

the transcripts for days, but during this period the work seemed to be reflected in all manners of my life. Thoughts popped into my head, sending me scurrying for my pen and back to the transcripts. Finally I felt comfortable enough to begin to create the final story, highlighting the common elements or essence represented in each story. This involved identifying the focus of the experience, the meaning, the final point to be made. According to Van Manen (1992), themes describe an aspect of the structure of the lived experience. I tried to find the phrases or statements that seemed most revealing or essential to the phenomenon being studied. From these descriptors or themes, I reflected on how they shaped the experience, what essence they created. I began to string together these themes to provide the structure to allow me to understand the essence of the experience as a whole. Appropriate to the object of study, the methodology was intuitive in nature.

Van Manen (1992) states that research grown from a desire to understand the lived experience is primarily a reflexive process in keeping with the nature of writing. The final story is a compilation of thoughts of many years, writings of many months and reflects the notion of listening to what I heard from participants and within myself. Van Manen (1992) has termed this process of writing a "poetizing activity" (p. 41).

I began to write and as I read and rewrote the phenomenological description became clear, generating the story of the experience, validated by a direct ability to see illustrating examples as to how the story was constructed from the experience. "The phenomenological writing should be

both an example containing examples, as well as a description of this human experience" (Parker, 1998, p.295). Validation was further supported through writing a dialogue that when read by others who had had the experience, awakened and clarified it for them.

Data collection and interpretation are potentially endless pursuits. The final written text captures the insights gained through this work. It is a shifting chronicle, a cumulative story of the participants, and represents a snapshot in time. Its interpretation is not static but represents a possible platform for further exploration. The goal of this research was to create a meaningful story, not the final truth, to provide readers with a powerful glimpse into the phenomenon of relationship, allowing them to personally experience it in relation to their own existence. This methodology should not be seen as a compromise or failure of presentation, but as a means of providing a snapshot of humanness, held in time.

Soundness of the Research

There is a wealth of information that discusses the rigor or soundness of qualitative research methodologies and what criteria should be employed in its evaluation. (Kvale, 1996; Guba & Lincoln, 1994; Sandelowski; 1986). Van Manen (1992) suggests that a good phenomenological description is an adequate elucidation of some aspect of the lifeworld - it resonates with our sense of lived life.

As suggested by Van Manen, the aim of a phenomenological research endeavor should be the search to become more human, seeking insight into the fullness that is life. The goal of this research was to shed light on the role of relationship in the provision of care toward healing in chronic illness. Through this research allowing patients and families to understand their experiences and head toward a fuller life, I believe the validity of the research is apparent.

The outcome of this research was evaluated by the participants and myself in terms of how it spoke to our individual experiences. First, the validity and reliability of this research project were dependent on the extent to which the final story captured the essence of the phenomenon, as determined by returning the results to the participants. The steps I employed to check authenticity and validity were:

(a) speaking with narrators several times, (b) providing the narrators with the transcripts, discussing individual stories, and sharing the final narrative in order to ensure feedback at all stages in the research, and (c) incorporating all of the participants' feedback into the appropriate narrative. This research is authentic in the fact that it is honest, bears witness to the experiences of others and is done for a greater good, motivated by a desire to share the truthfulness of these parents' experiences. There is a fit between the purpose, the passion, and the method.

The rigor of the study was further assessed by considering credibility, consistency and congruence with the values of the research methodology.

Credibility was ensured through the recognition of the researcher's preunderstandings, personal thoughts, feelings, plans and designs around the issue and their potential impact on the research. The use of a systematic, tracable method of data analysis, which allows revisiting and examination of data, further enhances the credibility of the study and ensured the transparency of my interpretive process. The reader of this work should be clear on the writer's stance and understandings.

Congruence is necessary between the phenomenological philosophy and methodology and the experience of relationships in health care. This had been laid out in the previous pages. In order to "care for the whole person", an understanding of their lived experience must be attempted. If we hold forth that health is more than the absence of disease, we must include in our dealing with each other on the health care front, the interpretive sense of the phenomenon that is each person's existence. Phenomenological approaches highlight such realities.

The use of journalling enhanced the trustworthiness of the work allowing a vehicle for reflection and self check concerning the purpose and mandate of the research itself.

The Final Story

The Story Tellers

A brief introduction to the families who have shared their stories with me:

Juanita and Joe

Juanita is a 36 year old registered nurse, who moved to Victoria eight years ago from Dawson Creek. She is a single mother to six year old Joe, a blue eyed, blond haired, rough and tumble boy. Joe suffers from pulmonary hemosiderosis, an extremely rare chronic disorder. The cause of this disease is unknown. Medical practitioners do not fully understand the pathophysiology of this illness, nor can they predict the outcome for Joe. Despite being told that Joe had a fifty percent likelihood of seeing his first birthday, Joe goes to school, plays with his friends and lives with the effects of this illness. Not only is Joe's lung capacity significantly impaired, the disease has spread to his bowel and skin. Joe's life has been touched by our health care system from the first day of his life.

Angie and Patrick

Angie, a 41 year old born and bred Victorian speaks with great passion about her life with eight year old Patrick. Patrick has Autism. Angie is employed in the traditional sense but describes her most important role as being the voice of Patrick, his advocate. She describes her dream: Children with autism have a normal life expectancy which means she will not be here when Patrick is aging, thus, she longs to know that the proper supports, resources and attitudes will exist for Patrick to live an independent and

meaningful life. The family, composed of Angie, Patrick and 10 year old Katie, work together towards health and happiness and this common goal.

Bill, Winnie, Patricia and Martin

A true nuclear family, mom, dad, daughter and son, however the Ozzie and Harriet image is shattered when you learn that Martin has Ducheyne's Muscular Dystrophy. At 9 years old, the physical manifestations of this disease are as yet, minimal. However, the emotional impacts of chronic illness are spoken of eloquently by this mother and father.

Leonore, Arthur and Rick

Autism has also touched this family. Five year old Rick is "moderately placed" on the autism spectrum. He has no language skills and currently attends programs at the Queen Alexandra Facility for Children in Victoria. Leonore and Arthur were born in the Philippines and immigrated to Canada as young children. Both in their late thirties, they speak proudly of being Canadian and are grateful that they are living with this chronic illness in a country with universal health care. They plan to have no further children. Both Leonore and Arthur work outside the home.

hyllis, Donald and Jeremy

Jeremy was born May 1996 at British Columbia's Children's Hospital. The first and only child for this family, Jeremy's birth was awaited with great anticipation. However, that day in May held mixed emotions. Within 36 hours of Jeremy's arrival, he was in the operating room having surgery to correct a severe congenital heart defect. Four years and three operations later, this family has had a wealth of experiences from within the acute care healthcare system.

David and Tristan

Widowed in 1995, David, a 44 year old civil engineer, moved to Victoria to raise his only son, Tristan. At 7, Tristan has had many encounters with the healthcare system. Tristan has severe food and environmental allergies. He has had multiple medical investigations for suspected allergy related systemic symptoms, including severe headaches, gastrointestinal dysfunction, skin rashes and mood swings.Tristan has been unable to regularly attend school and is often too tired to interact with other children.

The Quest - Journey to the Right Place

Living is a journey. Birth, adolescence, old age and death are examples of life's passages filled with both joy, anguish and uncertainty. Throughout our lives there is disorder. Illness brings disorder and destroys our agendas, our security, and undermines our carefully laid plans. But there is an order in the disorder that can permit healing, if only it can be found. We, as those touched by illness, need help to find this order.

Illness is a journey, a journey that demands the re-ordering of our lives. The period of transition to this new understanding is not an easy one, especially for the chronically ill. The changes are significant in their permanency. It is a road we will walk all our lives. The experiences we have in first understanding our illness will influence where we will be in the end with it.

The stories shared through undertaking this research reflect this passage, the personal peregrinations through diagnosis, to making meaning of illness in relation to living; the making of order from disorder. These stories speak to the importance that relationships hold in forming the foundation that allows individuals to undertake this journey. Without support and inclusion in the process of defining their illness, the individual is forever lost, the understanding of themselves in illness is always waiting just beyond their grasp. All time and energy are spent trying to find a way to make sense of the illness, seeking out the relationship that will help facilitate this understanding, as opposed to finding a place for this illness in life.

What follows are the words of six families who are on this journey. As agreed to by all who participated, the words have been gathered up in a collective sense to speak with one voice, creating themes that accurately portray relationship as encountered in the context of chronic illness. Interwoven in their words are my validated interpretations of their message along with the words of others that support the position articulated.

They have shared their stories and together we have created our vision of the "Right Place" achieved through the steps of (a) Hearing the story - Making a Connection through Dialogue, (b) Recognizing the Possibilities - Inviting the Translator In, and (c) Promoting Comfort through Validation. Also identified are detours on the way to this place of understanding

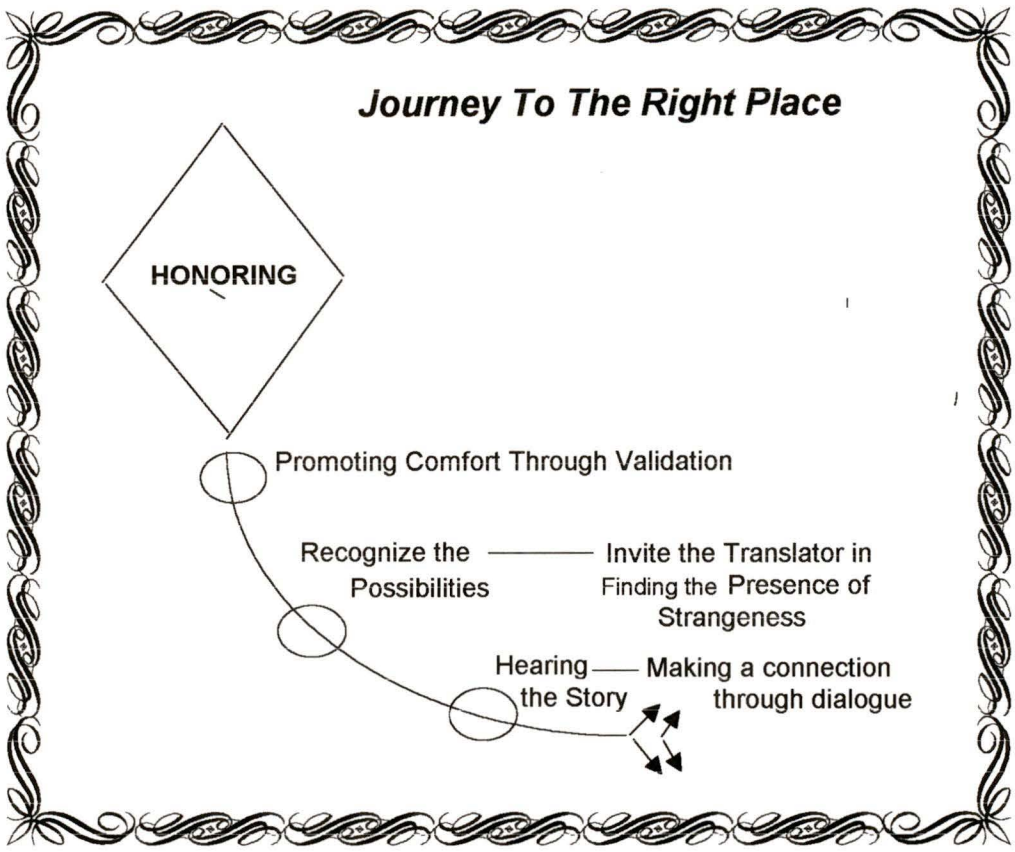

Table 1 - Journey to the Right Place

Hearing the Story - Making the Connection Through Dialogue

Where to begin? Beginning at the place we want to be, Bill speaks of a magical moment, a turning point in his family's journey with chronic illness:

"We talked about what it did to Martin, how he talked about it, felt it, understood what was happening. I remember the doctor asking if it felt real yet and if there was anything he could do to help that. It was amazing. I think we took the first step to accepting Martin's illness with that simple sentence.

He became part of the inner circle and after that I shared everything and no matter what happened I could accept the illness. Sure there were ups and downs with that but it was way better."

Bill articulates the importance of making the connection between caregiver and family. By acknowledging the emotional side of the illness state, by providing and valuing time spent exploring this aspect of illness, openness to talk, consider and share are created. The health care professional placed himself next to the family. His words acknowledged the vastness of what the illness experience is. The family felt his interest and commitment, and the connection that resulted served to allow the family to trust, share and accept the illness and the practitioner into their world. The sense of value and trust created, left the family in a place where they could let go of concerns regarding the practitioner, his medical decisions and care. As a parent this role of protector is paramount, however once the family felt they had secured the "best" care then, energy could then go into living with and making meaning of the illness.

But how is this constructed. How do we make this connection when dealing with families? What is important to them?

Juanita shared:

"I really felt that until I found someone who would take the time and show the interest to listen to me, I wasn't going to get anywhere."

When questioned as to where "anywhere" was, Juanita replied:

"Back to being normal, back to having a normal life without being obsessed with Joe's illness. It's taken over our life. I just want to get on with it. But I needed someone to help me figure out how. I needed to know we were the best we were going to get, then, I needed to stop so I could get on with life and figuring out how I was going to do that".

"I'd just ask them to at least listen and honour me as a person. Listen to me and take it seriously."

Angie's words convey the image of connectedness created through listening in an unconfined way, free from the literal-mindedness that traps practitioners. Stories can lead to different knowledge, knowledge that clarifies and enlightens everyday living with illness and can articulate the traditional presentations of illness in the words of those experiencing them. Representations of the traditional "medical model" signs and symptoms can then be used to generate diagnosis and define treatment in the traditional way of the health care practitioner s' world.

Story telling is a conversational event. Speakers and listeners engage with one another. The story is anchored in the experience, in this case of the experience of illness, its presentation and significance to this patient and family. Practitioners who listen to the story use their own experience, the experience of traditional medical education, to understand it. This way there is a discourse that represents both worlds and holds up a place for meaning making for those in care. Here, the experience in its totality was not sacrificed in the name of objective, accurate data for diagnosis. The family felt respected and recognized in the completeness of their identity and given permission to

trust, opening up the possibility to explore the illness and find a place to incorporate it into their world.

This is again reflected by Juanita:

"It worked when my decisions were respected, my opinions were reflected upon. When they took the time to sit down and hear what it was I was saying. Not just the stuff about shortness of breath, his bleeding, but about what it was like to live with that and how it was important for that to be heard so I could put it away and get on with it."

And, simply by Leonore:

"He's a really good GP because he listens to me".

Richard Darville (1989) wrote of the impact of story telling in his literacy work with students:

> The use of generative stories can work powerfully in several ways. First, it can open up experience to expression. The telling of experience changes, and enlarges, what can be told. Second, by opening experience to expression it can also open up it to reflection. Third, it can work to coalesce the meanings of experience and explore its implications for action (p.5).

In each individual story, I heard a searching, the seeking out of a place for the meaning making of illness to take place, not only in the day to day workings of life but also in the health care interactions that become part of this day to day reality. Humans live in a realm filled with meaning that we desire to interpret (Polkinghorne, 1983). Meaning is established through relationship and dialogue with others. The trek to get to this place begins in the relationship established with health care practitioners. The nature of this relationship greatly influences how individuals and families perceive the

illness, the health care system and their continued interaction with it in relationship to living their lives.

The health care encounter should be constructed around dialogue. Its core is conversation - a space where understanding or knowledge is created together. What needs to be in place for individual meaning making to take place is situational and contextual and can be constructed through dialogue. "If we regard knowing not as having an essence but as a right to believe, we may see conversation as the ultimate context within which knowledge and understanding are created" (Rorty, 1979, p.389).

Angie said: "But it was like, some kids yes, they do have one or two of these problems but when I had red flagged 6 or 7 things I was concerned about it was like they weren't looking at the total picture, they were just sort of hearing and half listening and half trying to rush you out of the office and reassure you that this child is fine. He had his hand on the doorknob, trying to escape out of the room. He never did a thing about any of the things I told him".

To the hermeneutic philosopher Gadamer, we are conversational beings for whom language is a reality.

> For conversation is not just one of our many activities in the world. On the contrary, we constitute both ourselves and our worlds in our conversational activity. For us they are foundational. They constitute the usually ignored background within which our lives are rooted (Shotter, 1993, p. 6).

Angie continued: "I had to deal with the fact that this health care professional was not listening or was insisting it was my coping or parenting skills or something else, using the brush off. They weren't even interested in considering my input. I couldn't get past that. We were stuck and there was a lot of pain in that."

If we are to incorporate the reality of illness into our lives and make sense and order of it, we can only accomplish this through dialogue and connection with those who hold the key, the health care professional.

Relationship and its powerful connection appeared to occur when the individual felt recognized, received and heard by the professional. There is a bonding together as a direct result of the sharing of the emotionally charged story of the illness experience. While the professional and parent do not necessarily feel alike in relating to the story, both parties give up themselves to taking in the understanding of the other.

Donald said: "I would just ask them to listen a little harder, be open to considering that I might see things or describe them in a different way, but they could relate and be important. Its not about doing everything I ask. Its about listening, thinking and deciding to act, but being open to the possibility. Have the interest and desire to explore what the family is saying. Let them know through what you say that they are important."

From the voice of the participants, dialogue is seen to serve another purpose that defines connection through partnerships. Through discussion the business of working together is articulated.

Juanita described how she envisioned the relationship:

"I wish someone had said I enter this relationship with you to get to the bottom of this. Your child has something that we haven't seen a lot of, its going to be difficult, but I'll try and help you figure out what is wrong with your child. A kind of understanding and compassion."

There is an inclusiveness to Juanita's words that reverberates in its absence from other participants stories.

Leonore shared:

"He was irritable, kept crying, wasn't sleeping and I mentioned this to the pediatrician and he kept telling me "that it must not be that bad because you look pretty darn good for someone who is not getting any sleep. Again I was brushed off."

David shared: "Part of the problem was they only saw him for several minutes, they weren't seeing the whole picture and I think that was the biggest frustration for me".

If the connection is not made within the first few encounters a sense of urgency grows. Advocacy spawns from not being heard or involved. When met with resistance or apathy, parents then begin championing their rights born from the intensity of their perceived parental responsibility. Advocacy creates tension within the health care relationship, a tension with far reaching implications. Parents felt they were seen as stepping beyond the traditional boundaries of the patient/professional relationship.

Phyllis said: "He thought I should just sit there and be quiet and he would tell me what to do, you just sit there and be the "subservient client" was the impression he was giving"

Juanita: "You just had to keep pushing and advocating away until you finally got someone to recognize you."

David: "He got quite annoyed when I went ahead and made the appointment myself, but in hindsight it was the best thing that ever happened."

Juanita described a "fierce patience" that she kept against what she saw as the authority of professional knowledge. As a result of this proactive stance, parents are classified as overwrought, anxious and/or in crisis, leading to further distancing due to perceived contamination of the objective evidence

by subjective emotions. Our health care system's belief in the usefulness of objectivity is evident in these remarks:

Juanita: "This doctor called me an anxious mother and accused me of fabricating or imagining the things I was telling her. I can remember feeling totally incompetent. I wondered what I was doing wrong. I doubted myself and even felt guilty. Then I got mad!"

Angie: "You're not coping well, you're in crisis! "I'm not in fucking crisis! I'm fighting for what I need. For what I need and is my right to have."

When parents feel a connection is not successfully made, they describe feelings of being dismissed, disrespected, angry, blamed and guilty. There is a pattern of reaction that moves from self-doubt and blame to finding the energy to overcome and seek out new relationships established under different ground rules. Parents describe their reactions to having their knowledge and instincts disregarded:

Juanita describes how she was feeling at the time:

"I can remember feeling totally incompetent. I felt, what was I doing? What have I done wrong? I felt like a neurotic mother but my instincts were pulling me to keep strong".

"Misrecognition shows not just a due lack of respect. It can inflict a grievous wound, saddling its victims with a crippling self-hatred and doubt" (Taylor, 1985, p. 26). The lack of recognition of parental knowledge, leading to their marginalization by health care practitioners who objectify the child's illness and family concerns, is a potential hazard. Without this recognition, parents describe feeling isolated, embarrassed and alone.

Phyllis shared: "I'm sure if you asked the people at _____ what they believe, they would say that they are doing this, but that's not the message that is getting across. I have a bigger life. I have my work and my other child and my social life and my own life and maybe even my own interests outside of this. And your left on this island thinking "you bastards! It's never going away, you can't make it go away, but if you'd have listened and made this less of a fight, I'd have been way more comfortable with it. How can I trust anything if I feel they have been holding out on me."

While the final outcome of this disconnected pathway finds the parent taking an assertive role, and obtaining the care needed, it does create a permanent roadblock to true connectedness in these and other relationships with health care providers. The participants spoke of how these previous experiences influenced the manner in which they entered into new partnerships.

David: "I had to set the ground work for that relationship, which puts parents with sick kids in a vulnerable place. It hurts you, you feel sick, you feel you want someone to say "We'll help you", "We are in this together". I didn't get any of that. I had to fight to be heard".

Juanita: "So then as a parent I had to think about the relationship. I had to decide if she was going to come into the relationship with me and my son. This took a lot of energy and personal pain to go through this. Why? If only the nurse had listened in the first place, now everything is different."

Donald shared: "When I saw Dr.____ for the first time I really tried, really tried to go in without attitude. It was hard because of what has happened before. I went in interviewing him. I went in on the defensive but I had to. If he is not the right guy to help me and my son, then he is not going to be the guy and I had to really keep to that attitude and be aggressive because I really had to push those feelings of something more being wrong than what the first doctor had said. This had to be established. I had to be open with that right from the beginning with this physician."

Phyllis: "Your interviewing him. You are going to tell him something is wrong with your child and you don't know what it is yet, but you have done this and we need a Pediatrician who will listen."

Juanita: "I think now a better experience would have been, 'I hear you, maybe something is going on, maybe there isn't something going on, but let's keep track of the progress, let's get to the bottom of it together. You know if there was that kind of attitude diagnosis could have been quicker, easier, might not have left so many scars, mistrust. It leaves anger. You are angry at having to fight so hard, and its because of them not listening. Parents are able to help. And as a parent you can't get on with living or helping your child to live cause you have all these feelings in the way now. How can you ever trust again? How can you trust that they and you are doing all they can. I just want Jeremy to have the best life he can. I just want to know and accept what's wrong and get along with being sick the best we can. Now I'll never be sure that that is happening."

What is requested by parents is a mutual vulnerability and openness to each other, achieved through hearing, listening and creating a "connected" relationship that allows parents and practitioners to take the next step.

Recognizing the Possibilities - Inviting the Translator In

> Truth, comes not only from the intellect but also from the body. When we listen to our bodies, we begin to listen to reality through our own experiences; we trust our intuition, our hearts. The truth is also in the "earth" of our bodies. So it is a question of moving from the theories we have learned to listening to the reality that is in and around us. Truth flows from the earth. This is not to deny the truth that flows from teachers, books, and from tradition. But the two must come together. We must learn to listen and then communicate (Vanier, 1998, p. 26.)

On most journeys we encounter strange, unfamiliar sights, sounds and sensations. In order to fully appreciate and understand the experience we often seek the insight of those who are immersed in the culture of the area, a translator.

Parents described themselves traveling between two distinct worlds; the scientific, objective realm that is health care culture with its unquestionable customs and language and their subjective, intuitive, personal world.

David spoke of this in describing his role in diagnosing Tristan's illness:

"I tried to be very calm and rational. I was trying to be the scientist but not the parent. This is what I am observing...."

Parents described not only needing a connection as portrayed earlier, but also a connection between these distinct ways of knowing. The words of these participants suggest that this can be accomplished through the role of parent as translator, transforming knowledge between these two distinct traditions.

David: "I was writing everything down, writing the food I was giving him, patterns of sickness, what was wrong, what he complained of, and really trying to show them that everything I had been telling them was the way it was."

Parents begin to try and create this connection by way of versing themselves in the dialect of health care professional's world. A great deal of time and energy is spent acquiring the language and mastering the culture of the health care system in order to be heard. Juanita's experience was:

"It had to be objective and logical. I had to learn the buzz words before they would listen or actually take note of what I was saying."

Angie shared: "I couldn't talk about him not sleeping, wanting to cuddle all the time. I had to talk about blood and respiratory rates".

However, abandoning their own family culture in order to assume that of the health care was not a fit for parents.

Juanita: "I'm not saying I am close to their ideas, but they have to respect, you know, they don't have a clue how much work is involved with these kids. Every single day, 365 days a year! There is a lot of work and time and energy and heartache. And I think recognizing that and recognizing how much you know. Respecting the parent. But no! In order to get anyone to listen I have to talk their language. My living with it every day and the things I sense from that don't count. They won't order a test or even listen to what I have to say unless I translate it into their language. It was a lot of work."

Parents also spoke of their responsibilities at home. Expected to be competent caregivers at home, once placed in the context of the structured health care system, they perceive their knowledge and ability as disregarded. These quotations from participants resonate this belief:

David: "I don't have the luxury of falling apart. Somebody's got to be there for him."

Juanita: "Wait a second, this is MY kid, I live with him 24 hours a day, 7 days a week, and who knows him better? Who can see the changes, sense something is wrong, and who knows better what this child needs."

Donald: "Well, you deal with these kids 24hrs a day and you know that and you know what works for your family and what works for your child".

Angie: "I spend 24hrs a day, 7 days a week towing the line here. You know I have walked the walk."

Based on parents' efforts to verse themselves in the working of the health care system, to educate themselves in the scientific processes of specific disease states, combined with their daily relationship to the illness in question, parents feel they are in an unparalleled place from which to assist

the health care professional in accessing the uniqueness of each individual's presentation of illness.

Juanita: "I want people to respect that I am the expert about my son. I can see and feel things they can't. I know because of my intimacy with Joe, things in ways they could never know. They just aren't there. I'm either an equal team member or they don't work for me because he is never off my caseload."

Parental knowledge could alert health care professionals to the signs and symptoms as they are individually presented by the child and assist the health care professional to translate these individual presentations into the scientific categories necessary for diagnosis. Parents see themselves as translators between the logical, physical, objective plane of the health care culture and the instinctual, personal, subjective reality of their experience of illness.

Angie: "I think that you can take the experiences of Patrick and not only the physiological symptoms, but use my understanding to relate those symptoms to how he is living. It gives clues. Behavior is communication".

Phyllis: "Parents are interpreting what signals they are getting from their children."

Only with the cooperation of the health care practitioner can this bridge between the objective and subjective be built.

Juanita shared: "I remember sitting in the hospital room and the nurse slapping the test paper in my face as if to say here is the proof, nothing's wrong. I remember sitting there knowing she was totally wrong, but how could a mother say. The pieces of the puzzle just didn't fit for them. I think they had given up and now they were just getting angry instead of trying to keep listening."

In order to be open to this translation, "inviting the translator in" can be accomplished through finding the "presence of strangeness". The Oxford

English Dictionary (1989), describes strange as "not known before, heard or seen, of external origin, kind or character, exciting curiosity, surprise, wonder" (p. 2256). Presence is described as "the state of being in one place and not elsewhere" (p. 1791).

Donald shared. "It's like he was hiding behind his own experiences. Like the way he had learned it or encountered it in his life was the only way it could be. I think he was afraid. Afraid he didn't have the answers either. But that would have been O.K.."

Finding the presence of strangeness involves not only identifying the way in which health care professionals think about the experience of illness but identifying the world or culture in which they formulate this awareness.

David said: "Respect and acknowledge the family's contributions. Look from your own desires and experiences and think about what you would want. Step from behind the professional persona. Its more than a job to us. Believe the interpretation."

David requested: "Ask the physician not to hide behind the "medical mask". Finding the "presence of strangeness" requires experiencing the phenomenon through the lens of the patient's values, beliefs and community and for that time you hear the story abandoning any preconceptions. It is asking the professional to put aside the definitional approach to administering care, to "unknow" the scientific illness state as they perceive it should present itself and instead to be open to the interpretation or representation of this illness through the individual's translation. Practitioners who practice from a position of strangeness are open to the presentation of the illness as described by the persons experiencing it. Health care practitioners should not rely on nor assume that the traditional ways of demonstrating and defining illness

provide the clearest understanding, and put aside their professional identity for the time needed to hear the story. Medical knowledge is relegated to the back-seat to make room for the story and all its possibilities.

Juanita's frustration is reflected in this statement: "The parent is interpreting for the child. You are interpreting your child's behavior and stuff to the physician and sometimes that upsets the physician. Instead, you hear your child should be doing this or doing that. You know? If you take every parent and believe them right off the bat as to what they are telling you, instead of being skeptical. I think when your in the health care profession you are judgmental. Get rid of the judgment. Get rid of the signs and symptoms categories and boxes. Every new person you meet, if you can go in with a nonjudgmental, not all knowing attitude then you can put together the story a bit better."

The Oxford English Dictionary describes unique as individual or unparalleled. While uniqueness belongs to the patient, and is their responsibility to convey, the presence of strangeness is generated from within the health care professional. It is an openness and freeing from cultural boundaries and experiences in order to be in a place of receptivity. Professionals utilize this place of strangeness to be able to see, hear and understand the uniqueness of the individual in care and to use this understanding to diagnose, treat and support the individual in care.

Definitions or categories of illness dictate a particular approach to administering medicine. The argument is that these definitions create conceptual boundaries to enable decision making and guide access to care. They are charged with creating a "clinical objectivity", however, a consequence of this is that there is an assumption that the health care professional already knows how to "think" about the individual's illness and

how to "be in relation with" this child and family. Categorization and clinical diagnosis can result in the fragmentation of the person into a neat package of illness symptoms designed to fit the constructed categories.

Donald: "It's almost like there is a preconceived box and when I went in the room unless my child fit that box or whatever it was supposed to be or has the right physical symptoms, then whatever fell outside of that there wasn't interest or desire to explore it or try and tie it to the box."

Donald went on to suggest. "I've had doctors and nurses too, actually lots of different professionals who already thought they knew how to think about my child. They cut off the fragments of who we were and what we were saying about how he was feeling so it would fit into a neat little picture."

The context is one of "we know" this, we already have "the story". This assumed preunderstanding negates the need to listen, removes the humanness, and leaves the family isolated and unheard. Objective knowledge is paramount, whereas subjective thoughts, feelings and intuitive knowledge are deemed unreliable and unscientific.

Angie: "They don't recognize it as very important information and they don't respect the fact that you are there in your child's best interest and there is a lot of you getting the blame rather than being part of the solution."

The words of Mary Fisher (1995) drive home this theme:

> Let me be clear: With HIV have come unimaginable fears and vicious pain. But also with HIV has come new and fuller meaning in my life. It has created an urgency and shaped a new message just for me. The virus is brutal, but my life - my experience with it - is a gift. Therefore, I have learned to say to those in power: Do not pity me, do not assume to understand my illness: listen to me. I am not a victim: I am a messenger. Be open and explore (p.23).

Finding the presence of strangeness requires abandoning the power inherent in a position of medicine or nursing.

As Juanita describes: "I am feeling totally embarrassed because the doctor has the power. Like I felt he has the power, it is his word that is final. There was no ifs, ands or buts about it, my son had asthma and all I could do was give him the medicine, wait for it to not work and then that would prove it".

You can sense this isolation in Angie's words: "He basically told me he was the pediatrician and he would tell me what was typical for this child because I remember that person saying to me "you probably don't know too much about developmental pediatrics".

Phyllis describes one encounter: "I felt like I should just sit there and be quiet and he would tell me what to do. He was the professional and he would tell me what to do, just sit there and be the subservient client was the impression he was giving."

Juanita describes this as: "The omnipotent attitude of people who are supposed to care."

Believing that this power imbalance is generated as a result of practitioners belief in their possession of "specialized scientific knowledge", the recognition of patients' and of familys' specialized intuitive wisdom should correct this imbalance. Through dialogue, sharing and recognition of both aspects of contributing information, a state of "interactional symmetry" should be established.

Winnie shared: "So I went to see Dr. John Doe and he said to me "you know what your talking about when it comes to Martin. He started asking me questions but listened to my answers and based on them he sent me to a specialist. He doesn't always do the tests I want or send me to a specialist, but he always listens and tries to explain what I'm seeing in medical terms. I don't feel nuts going in there. I can always tell him everything. Sometimes he says he can't explain, but he checks Martin out and makes a note of my concerns. He often asks me about them when I come back. It feels like he believes me"

Parents are laying claim to prior experience with their individual orientations to illness and locating themselves within this indisputable place of specialized knowledge. Potter (1996) in his work on the representation of reality describes this particular strategy as "category entitlement" by which individuals' experience entitles them to special knowledge about a topic. This knowledge needs to be incorporated and legitimized within the health care system.

Leonore shared: "I just knew instinctively, I just knew something was wrong. I don't know where the seed was planted from, but I remember the patterns were there. But it was more than patterns. It was a little voice in the back of my head. I tried to push it back but it was always there."

Winnie said: "Somewhere inside me I knew and I understood it was true, Martin was sick but no one would listen to me. They thought I was the anxious, neurotic, older mother. I tried to put it into words. It was hard."

Juanita: "I am a knowledgeable woman. I know something is not quite right with my child and I wanted to find out why, what was making him uncomfortable, no matter what he looked like, something was wrong".

Phyllis shared: "There was something inside of you that told you your child's behavior wasn't normal. I knew something was wrong and so did my husband. I can't describe how we knew. We knew before we ever went near the doctor. It was like a feeling that walked behind me but was part of me. I couldn't describe the feeling except to say it was inside and it pushed me on to find someone to figure out what was wrong. Cause something was wrong. It was instinctual.

Angie reflected: "Some people call it a gut feeling, but mine wasn't in my gut. It was like feeling sadness or fear. It felt like something I had always known. Sure there were the outside things that contributed to me being aware, the crying, the cuddling, the fussiness, the change in appetite, but it was more than that. I just knew it. I can't describe it. There are no words, it was just within me and it egged me on cause I knew I was right."

Leonore had a similar sense: "I don't know how to describe my intuition. I felt it before I saw the changes in Rick. It was just something, it was always needling away. My husband felt it too. You couldn't see anything. I couldn't

put a handle on it. He, my husband, kept saying things to me like "do you think there is something wrong?"

Angie told the story of her autistic child who became upset at the daycare one morning. The social worker was trying to persuade the child to come into the school. The child refused and stood waiting in the parking lot. Forcing the child to come in led to an emotional and physical outburst. When the social worker asked the mother her interpretation, she knew that he had been waiting for the bus. Patrick had traveled on the bus the previous day for a field trip. While the caregiver was not able to make this connection, the mother was. Despite being within and experiencing the context of the experience, the professional could not see this issue until translated by the parent. Had the parents' intervention been sought earlier, less distress would have been experienced.

Not only is this insight useful in the diagnostic process, it becomes vital to assisting families and individuals to making choices around treatment options. Accessing this resource offers a mechanism for taking what can objectively be offered in the scientific realm of medicine and seeing how it fits with the family's values. It is a way of translating those values into the medical relationship and the individual's future of living with the illness.

Juanita: "And it works the other way too. They can give me ideas, knowledge, choices but I'm the person who can put it into my son's world or translate it into his world or his life or his language or his being".

Finding the presence of strangeness makes room in the mind of the practitioner and ultimately the health care culture for the translation of

parental knowledge to its place and role in the diagnostic continuum. Through this process families are involved and supported through our belief and trust and provided with the tools to live in comfort with chronic illness.

Angie said: "But we are living a life with this and this should be the goal for all health care professionals. That supporting us in recognizing that we live this life with illness within a larger life that we need to continue on with so we need support to do that."

Leonore: "This is the reality of our lives, you live with it every day so we need to have the information, to share to make our lives what they can be".

Promoting Comfort Through Validation

To cure is goal-oriented, centered on the mind, to give comfort is centered in the heart. Spiritual masters in the scripture often told stories to reveal truths and awaken the heart. Vanier (1998) suggested when we tell stories we touch the heart. If we speak in theories, ideas, concrete medical interventions the heart remains untouched, no comfort is given. To listen, to hear the story, to trust and believe validates the parents position and knowledge within the diagnostic process thereby producing the comfort required to move patients forward in healing.

In the experience of these parents, diagnosis was initially seen as the ultimate validation of their parental insight.

Leonore spoke: "When you finally get the diagnosis, it is like a confirmation that your instincts were right. It was in many ways a relief because you do start to feel a little paranoid".

Juanita shared: "The only way I was going to get validation from everything I told them for three years was when they diagnosed him. It was almost like picking up the phone, as my GP phoned me in Vancouver after Joe was

diagnosed. One of the physicians in Vancouver came and apologized. It was a good thing. It made me respect the doctor for apologizing to me. When Joe was diagnosed there was a sense of relief and it was also a feeling of "I told you there was something wrong with my kid".

But for most this validation soon became hollow and empty, providing little comfort. The nature of the clinical relationship that had established this diagnosis, shaped the feeling of parents:

Angie remarked: "So, it was confirmed what I felt and then of course what do you feel next. Anger at the people who haven't listened in the past. It was confirmation, but you dealt with this anger about the fact that health care professionals were not listening or were insisting it was either your parenting skills or something else."

Phyllis: "Families should feel empowered through being active participants in the diagnostic process, not look to this diagnosis as some sort of mechanism to vindicate themselves in the eyes of the professionals. Its a two edged sword. You feel justified in the fight you've had to take to get to this point, but you fear the fight isn't over. What happens now? In some ways it's even more frightening. Will they listen as we try to come to terms with what this means and how we are going to live with it? Its almost too late, the damage is done."

Diagnosis could be a source of inspirational and creative power. When diagnosis is collaborative, the result is liberating and empowering. Through this process, honour is bestowed on the experience of illness and those living it. However, as indicated by these parents' experiences, the key to obtaining this outcome is the nature of the relationship in which it is discovered. Without the correct pathway to these answers, new emotional challenges are created:

Juanita: "He didn't even hear me when I told him Joe coughed up blood. He phoned me and told me Joe had pneumonia and I remember being on the phone saying "but he doesn't have a pneumonia, he hasn't even had a cold or

been sick". Yeah but the chest x-ray shows... and we'll treat him that way." End of story! It was so invalidating".

Angie: "I didn't have the feeling that the Pediatrician believed what I was saying. A couple of sentences to relieve the anxiety. I don't mind you getting involved. O.K., we can work together because you have a place to write things down and bring him in".

If the relationship is inclusive and trusting, healing can occur. Comfort, created through validation of each parents instinctual knowledge of their child, is supported from the onset and validated by diagnosis.

Angie professed: "It would have been different if we had started from "I enter into the relationship to get to the bottom of this. Your child has something that we haven't seen a lot of, its going to be difficult, but I'll try and help you figure out what is wrong with your child". A kind of understanding, compassion, writing down the little things. I never once saw anyone write down any of my observations."

Parents ask that health care professionals trust the interpretation/translation and don't negate it because of the emotional component tied to its discovery. The emotions tie us to our humanness and our humanness to our instinctual knowing.

Juanita shared: "Yes, he said it was my job to be an anxious mother. He listened, and I felt validated by him, maybe because of this experience. He trusted what I was saying."

Angie continues: "It had to be objective and if they couldn't see it, touch it, it wasn't there, and it was all in your imagination. Somehow they think we can't be objective. Well maybe we can't see these signs in our kids without feeling scared, afraid, worried but that doesn't mean they still shouldn't listen to us. Who knows, maybe the emotions tie us into what is going on, give us a more direct connection that the professionals have. Why is this degraded? It should be embraced! Not to replace science but to point it in the right direction!"

Comfort can not be obtained through cure in the case of chronic illness. Comfort is instead about seeing your reality reflected and respected in the actions of others. Charles Taylor (1985) wrote:

> Our identity is shaped by recognition of its absence, often by the misrecognition of others, and so a person or group of people can suffer real damage, real distortion, if people or society around them mirror a confining or demeaning or contemptible picture of themselves. (p. 25).

Without respect for the "truth" that is each families' experience, scarring and distrust are established. This acts as a roadblock to the acceptance of living with illness, creating questions and uncertainty both in the capacity of the professional to provide care and self doubt on the part of those wrapped up in the experience of illness. It is difficult to trust that all is being done that could be and that life is being led to the fullest, if you are unable to trust those whom you rely on. Comfort is about living in security with your own understanding of the illness and being supported in a place that values the potential of self-awareness in healing.

The Right Place

The journey to "the right place" begins as those involved enter into the health care relationship. As these parents have expressed, what initially occurs within its boundaries shapes their future experiences. To be successful a certain "vulnerability" is required in order to be open to the richness of the relationship.

Juanita shared:

"I had to set the groundwork for that relationship, which puts parents in a vulnerable place. You don't know what the reaction will be."

Angie said:

"Because you are vulnerable. You need these people's help. It's all our hopes and dreams and everything. It's everything! And leaving yourself open to someone else to decide that they are going to take that all away from you, not help you find it and then say there must be something wrong with you. You can't help... It's scary, but you have to go there cause its the only way. I love my baby and I just want the world for him and I just want you to help me. So, that's the whole thing. It's very convoluted."

To reach the "right place" for healing requires assuming this position of vulnerability, and opening one's self up to the question of whether to invite the other on a personal journey.

David described: "We were at this time, when I was talking to all these health care professionals but it felt like neither of us had committed. I was going to them. Were they coming to me? I didn't know, but somehow it seemed important."

Without the supportive companionship the journey has the potential to be much more arduous.

Juanita shared: "Hearing him say it was my job as a parent to bring these concerns to him, him saying that gave me the confidence to say, O.K. I'm in the right place."

The image is someone who walks with them, along side, in a sense "an accompanier". The word accompaniment comes from the Latin words cum pane, which mean "with bread", implying eating together, sharing together, nourishing each other. We as professionals can be accompaniers, nourishing strength through validation.

Illness breaks the patterns of our lives and requires us to reevaluate it. It appears tragic because it moves us from the secure world of order to the chaotic world of the unexpected, and into disorder. But from this disorder can come new energies, new freedoms and a new meaning of life and the world.

The right place, created through connection, is a place that honours parents, honours them through validation of their knowledge, place and importance in defining the reality that is their diagnostic journey through chronic illness.

Implications for Practice- Honouring Families By Bearing Witness and Providing Comfort Through Validation

Nurses guided by the notion of honouring families in their experiences of illness will provide validation of the truth of their illness experience through bearing witness to options, choices and individual construction of that family's life with chronic illness.

Counselling psychology has long understood the therapeutic actions of bearing witness to victimization and trauma. "The failure of others to bear witness to the client's victimization and suffering can have devastating consequences for their ability to heal" (Viederman, 1995, p. 1170).

Laub (1995), in speaking of working with Holocaust survivors, wrote,

> This loss of the capacity to be a witness to oneself
> and thus to witness from the inside is perhaps the true
> meaning of annihilation. It is the encounter and
> the coming together between survivor and listener,
> which makes possible something like a repossession

> of the act of witnessing. It is a source of reemerging truth. It leads to a reclamation of the past and the development of a coherent life story (p. 62).

Trauma survivors commonly cite the importance of the therapists validating role.

As practitioners we need to be open-minded, compassionate witnesses and adopt a position of solidarity with those who are ill. This means allowing those experiencing chronic illness the opportunity to construct their own interpretation of the illness experience, one that affirms the dignity and honour of family. The health care practitioner must hear, listen, and accept the words of the family's subjective reality and somehow integrate them into the plan of care. By bearing witness to this reality, the nurse provides the foundation of trust that allows the family to validate their experience and find comfort in the safety of care received.

Witnessing can be difficult. Although the final decision about what happens in terms of conventional testing and treatment, is often outside the scope of nursing practice, nurses are called upon to witness the outcome of these decisions and to support those in care. I believe witnessing can be as simple as choosing to stand with families, listen to what they think and feel and try to understand what is their truth and reflect this back to them. In my practice I will now strive to treasure the 'who' that these people are and to bear witness to their choices without judging. I believe that truth is subjective and I should not question the "truth" of their reality. Without understanding that truth, I can't touch the people I care for nor begin to be their companion.

Moving with the flow of people's reality requires a deep belief that people know their way, a deep belief in the subjectiveness of truth and the role of bearing witness versus directing or taking action in care. Reflecting back to Heidegger's (1975) belief in the "subjectivity of truth" would support the belief that there is no absolute truth to capture or to impose.

Why then does this seem so difficult to do within my professional role? Is there a sense of accountability that moves me to action to a certain way or direction? If curing is the ultimate goal, where does the accountability lie? I believe it is assumed by those who provide care, by me the registered nurse. If instead, caring and providing comfort become the focus, there is a potential shift in responsibility and with it freedom in practice. If we assume only those in care can define their own truth, decisions would then come to rest with the individual, a central concept to the creation of comfort. By giving back to the patient the responsibility, believing only they can account for their choices, health care professionals are free to care, care in a way that does not necessarily require action. I am now able to provide comfort through validating their choices and listening to their illness experience, perhaps nothing more! My role is not to shade patients in my own assumptions of life and care, but allow the individual to shine through the darkness of illness.

> I constitute my health in mutual process with the universe.
> The nurse's true presence with me call me to learn the meaning
> I give to situations but in me and my world is the way - I
> know it in my tacit and explicit - I know it at all realms of my
> universe, in ways I cannot say and that no others know.
> (Parse, 1998, p.34.)

In chronic illness a cure is not possible. Instead the focus is living with the disease, living in comfort, comfort generated through the belief in one's self and the health care system and the support its practitioners provide. A new way of relating in caring, a way of thinking of health promotion specific to living with chronic illness can be created.

All human beings intuitively know that when they are ill the presence of comfort and a commitment to share the journey is of crucial importance. Yet this has been relegated to the realms of "common sense" and in doing so is lost in in its' invisibility. Out of sight, out of mind, they have slipped away rather than being central to our work as nurses.

Howard Brody, a physician intrigued with stories of illness, is a well-respected authority on the use of narratives in health care. Brody (1987) speaks of stories and story telling being central to the "craft" of professional health practice and suggests that while science deals with the general, stories deal with the particular. He goes on to suggest that the meaning that arises out of these stories is every bit as important to healing as understanding the objective illness state.

A "skilled" companion recognizes the opportunity to raise the notion of companionship to a place that incorporates acting in ways that are therapeutic and bring healing. Exploring the experiences of others relates directly to validating their truth and promoting comfort so essential to recovery, life and living.

According to the Chambers Etymological Dictionary (1986), the word "validation" comes from the latin word "validus" meaning strong, able, healthy, to be strong, to be well. If our goal as health care practitioners is to assist persons to live with chronic illness then validating their reality and giving them strength through believing in the meaning they construe and how they incorporate this illness into their lives is the first step. By creating comfort in their own belief in themselves, by supporting their trust in their own knowledge, insight and choices we build their personal strength. Through an affirmation of the "emotional truth" that is their illness experience, an honouring is achieved. We bear witness to their individual truth, rather than an objective truth creating a new way of relating - the caring truth of our nursing practice, a meaningful, coherent, truthful way for those experiencing chronic illness to narrate the entirety of their life.

However, all responsibility does not lie with the health care practitioners. Invitations to participate in conversation must be seen as more than rhetorical by those seeking care. Power differentials within the health care relationship, the history of paternalism in health care, and the belief in objective criteria - based diagnosis make sharing this subjective knowledge difficult. Individuals, lacking the formal clinical teachings that provide legitimacy to knowledge within the health care relationship, find the sharing of their feelings even more uncertain. Couple this with the viewed emotionality and lack of objectivity often reserved for parents, the assessment of children's health by parents are held even further afield. However, based on research

(Benner, Tanner & Chesla, 1996) that identifies intuition as enhanced by experience, knowledge of the situation and the individual, it would seem that parents would be in an ideal situation to enhance the health care practitioner's assessment. Young (1987) spoke of intuition being dependent on the desire to 'tune-in'. Patients must unlearn that the health care professional is not the real purveyor of knowledge in an interaction of asymmetrical power and therefore choose to share their subjective knowledge with no disclaimers. A major shift in how socialized health care is envisioned, resourced and dispelled is required, and is not a small task. Perhaps research such as this will help formulate the first step in this large undertaking.

The question is then how do we build this caring truth and its inherent insight into the traditional structure of health care delivery. Literature in nursing and health promotion supports patient-centered care and health promotion but rarely mentions the value of intuitive knowledge or personal truths in this equation.

I believe we can hear the truth through a position of finding the "strangeness" of illness. I suggest that health care professionals should "approach the stranger", entering into relationship with them assuming they know nothing about that person, who they are, have never seen this illness before nor can begin to understand what their illness means for them. Uniqueness is generated by the individual seeking care, and their responsibility to convey. It encompasses the meaning and understanding they assign to the illness as they incorporate it into their life. However, "finding the strangeness"

is initiated by, and the responsibility of, the health care professional, and should guide the way in which they position themselves as they enter the relationship. In "finding the strangeness" the health care professional would not use their preconceived knowledge of the typical illness description and presentation as the basis for knowing how to enter into the relationship, what to expect and how to treat. Rather they would enter greeting the person not the illness. The illness would not serve to guide their actions once in relationship. Instead, finding the strangeness would leave the practitioner open to considering the diversity of presentation of illness in relation to how that individual decided to speak of their illness. Conformity and cure would not be the objective. Not bound by the traditional patterns of interaction, there would be room to include individual ideas and needs around treatment. Medical knowledge and previous experiences in diagnosing the illness would be held up along side personal presentation and interpretation of illness.

Cohen (1987) spoke of Husserl's (1913) notion of the life world as the world of everyday experiences. We travel through this world often not noticing the true nature of these commonplace experiences. Finding the strangeness is about slowing down and seeing experiences with a renewed awareness. It is often the health care professionals' tendency to follow a strict biomedical model and to apply an action oriented repertoire of skills to a particular case. However, this does little to support the patient and family in finding coherence in their illness experience. Perhaps it does serve, however, to allow health care providers to avoid dealing with issues that, due to the

entrenched traditions and current resourcing of health care provision, they are not given the option to consider.

While personal definitions of health and personal determination in relation to health care interventions are encouraged, the basis for allocating nursing resources is still dependent on objective, traditional ways of knowing. Does patient centered theory fail to translate into care because of how resources are allocated? I believe so and that this failure has impeded patient centred theory translation into practice. This is w here theory has not been translated into practice. The building of this relationship is compromised by time and cost. Listening to the story requires time. However, the rationing of services and cutting of staffing levels all push to make efficiency the benchmark.

Furthermore, the tradition of the "science" of medicine, and the power inherent in it need to be dismantled. Power is quickly equated with what is right. This power needs to be shared with the individual in care, making their insight an equal motivation to action. The parental struggle to be recognized within this power differential is reflected in the following quote:

> The ontology of Dasein may then be understood as a symbol of an anguished struggle for individuality and grounded authenticity in a world where one is in perpetual danger of absorption in the pressures and influences of the social milieu (Thompson, 1990, p. 153).

From the very start our world is interpreted for us by virtue of our membership in a particular culture. The culture and history of medicine are

distinctive, powerful and well recognized within our social structure. I argue it is this very culture that inhibits the "art" of health care. Vanier (1998) writes, "Philosophy, anthropology, theology and other sciences that tell us what it means to be human can be dangerous if they are considered the ideologies that dictate reality; instead, they need to be viewed as the seats on which we rest to humbly listen, marvel and discover ourselves" (p. 17).

As patients and professionals, we need to be together as persons rather than members of specific groups confined in our actions by the rules and orders of conduct inherent in each group culture. Health care professionals will have to leave the security of the health care culture and persona, abandoning the security and power of the group, in order to leave on the journey with patients.

Physician training is based on memorization, patterning, objective structures and patterns of illness. "Given the growing body of knowledge on intuition it is sad to note that researchers who adhere to the traditional belief of the linear cognitive process continue to ignore this growing volume of research evidence" (King & Appleton, 1997, p. 200). Browman (1999) in his editorial on science, language, intuition and the many meanings of life discussed the findings of a recent survey of academically based Canadian oncologists regarding quality of life (QOL) issues. More than half the respondents in the survey identified nurses, rather than the individuals experiencing the illness, as the most reliable source of information. In his review (106 citations) of drug therapy in the treatment of breast cancer,

Browman revealed that QOL information generated by interviews of those facing the illness was virtually ignored in favor of the more traditional outcome measures of tumor response and survival for informing treatment recommendations.

Despite efforts of researchers in the fields of psychology, psychiatry and nursing to utilize humanistic modes of inquiry, the context of their practice remains housed in a medical paradigm, influencing health care delivery, and leading to the valuing of hard data and the paradigm of positivism over subjective truths. Hence intuitiveness, subjectivity and openness have been concepts challenged and denigrated in a substantially technological and rationally oriented health care environment. English (1993) suggests that this disparaging rhetoric between natural and medical scientists continues. But diagnosis is a puzzle, and we require two dimensions to see it, thinking of the concrete curvatures of the puzzle edges and how they fit together, but also the abstract visualization of the creation. What is needed is the ability to sense, imagine, anticipate the final picture. Without these two different, but complementary views, we won't succeed in solving the puzzle of illness. Education, specifically for physicians needs to be re-envisioned.

While some might argue an increased cost in the provision of health care would result from following the subjective "clues" provided by patients, I argue the opposite. The cost to health care would be minimal to none at all. Incorporating intuitive ways of knowing, hearing the stories to understand presenting signs and symptoms may in fact reduce unnecessary tests, increase

the accuracy of diagnosis and reduce the cost, both human and resource, through providing care that meets the needs and fits the values of those who seek it out.

How do we maintain the old, the virtues of a positivist, scientific way of knowing and prepare for a new way of giving care that includes individual truth and knowing? It is not a question of rejecting the past but of letting the past flow with the present. Agan (1997) supports Chinn and Jacob's (1996) assertion that once all of the patterns of knowing are recognized as legitimate then methods of developing new knowledge would alter dramatically. In a time when technology is pushing the mandate of curing to new levels, is it not time to balance this scientific race, this empirical knowledge, and consider all factors and knowledge that will provide the best "life" for individuals in care? Given the increasing awareness and discussion over the shifting paradigms of health care delivery, and, given the role of intuitiveness and patient subjectivity in the provision of care, it would seem advantageous to look to the contributions individuals and families can make to this transition.

By listening to the story and experiencing it through our professional lens, we will be guided to the right place! This place values openness, wholeness, inclusiveness, and the human potential for self-awareness and healing. It is not for families to be crushed by the reality of illness, nor for health care professionals to hammer illness into what we think it is or should be but to commit ourselves to helping those chronically ill find the place that they can define, accept and live their lives. The important first step that sets

the direction for this journey is established in the health care encounter. We need to recognize its significance.

> Growth toward openness means dialogue, trusting in others, listening to them, particularly those whom we don't like to hear. The birth of a good society comes when people start to trust each other, to share with each other, and to feel concerned for each other (Vanier, 1998, p. 34.)

McWhinney (1991) identified several areas for further exploration, one of which was the need to attempt an enlightenment of the "essence" inherent to the creation of a relationship deemed positive and fulfilling by all parties involved. I agree with McWhinney, and believe there is a need to make explicit what is implicit and as yet unset in language, to attempt to articulate those personal essences and patterns of relationship that support a positive connection between parties in the health care relationship. I believe this research has created a framework from which both professionals and families can begin to understand each other's perspectives and experiences as they are influenced by the context of the traditional health care interaction. While I remain curious and want to explore further the true state of intuition, it has not been possible in this research. Although eluded to by parents, they spoke of not having the language to describe it and struggled to articulate this experience. Further research in this area would be of interest and I believe of benefit in enhancing an understanding of our patients' "truth".

Parents are in a position from which to dictate the significance of human behavior and presentation of illness in relation to their individual child, helping to translate this knowledge for health care professionals so it can be

used to build a basis for diagnosis. Health care professionals need to replace skepticism with curiosity for the intuitive, subjective knowing and trust the story of the individual will lead the journey to a collaborative diagnostic experience and finally to the right place free of the pain, scars and mistrust that can occur. This requires openness to hear the story and consider what it is saying intuitively in representation of the objective, scientific evidence that is normally required to act. The common thread of humanness can be used to bridge the gap between the science of health and the art of intuition. We all have this sense of who we are and what is happening within ourselves, both as practitioners and patients. Let this thread guide us on the quest to the right place for our patients. Knowledge and intimacy of self needs to be included and given equal weight among the scientific strategies to diagnosis and treat illness.

"To become truly free is to give more importance to truth and justice than to desire to fulfill at all costs our own compulsive needs." (Vanier, 1998, p. 111). Parents, in this research, suggest practitioners should throw aside the need to cure and correct and instead start out with assisting patients facing chronic illness in the journey to the right place. This place may not be free of illness, but it will be a place of acceptance and support. It is through relationship that this place is found.

This raises the time old question of what is the science of healing versus what is the art of healing? Which is more important? In chronic illness, the voices of these participants suggests that art is key. Although their disease

can not be cured, their disease is their life and their life their disease. The greatest gift that a practitioner can provide to the person and family who must live with the illness,is helping them to find a place where this different type of healing can occur. A place where the illness is not the enemy but welcomed in, the fear removed, and comfort given. A place of rest.

Conclusion

My belief in the notion of honoring is as strong as ever, clear but yet far more complex than I had imagined. I have struggled to bring together a picture of care for chronic illness, of which I believe honour plays a role. Initially I believed honouring existed in and of itself. I know honour is achieved through a variety of beliefs and actions, each unique and dictated by the context in which it occurs and the under the influence of those involved.

> I may "know" that I love or hate, sense, perceive, comprehend. I may believe or disbelieve, enjoy or dislike, be interested or bored by... It is only to reference to the flow of feelings in me that I can begin to conceptualize an answer... I taste a foreign dish. Do I like it? It is only by referring to the flow of my experiencing that I can sense the implicit meanings (Rogers, 1969, p. 68).

These thoughts from Carl Rogers, with the addition of Husserl's notion of intentionality, situates the argument of the importance of subjective knowledge as suggested by Rodgers, within the context of not just a "being" with an inner world to explore but rather "being-in-the-world", unable to be

defined apart from it. As human beings we are destined to address the world, make sense of it and act upon it - to shape what it is as it shapes us.

As Rogers (1965) suggests, it is to lay aside old meanings and open ourselves to new meanings, to enjoy a new freedom, a freedom born of patience and persistence. This research represents a beginning attempt at creating an enlightened understanding of parents' experiences within the health care relationship.

References

Agan, R. (1997). Intuitive knowing as a dimension of nursing. Advances in Nursing Science, 10(1), 63-70.

Belensky, M. F., Clinchy, B. M., Goldberger, N. R., & Tarule, J. M. (1986). Women's Ways of Knowing. The Development of Self, Voice and Mind. New York, NY: Basic Books.

Benner, P. (1995). Expertise in Nursing Practice: Caring Clinical Judgement and Ethics. New York, NY: Springer.

Benner, P., Tanner, C., & Chesla, C. (1996). Expertise in Nursing Practice: Caring, Clinical Judgment and Ethics. New York, NY: Springer.

Brody, H. (1987). Stories of Sickness. New Haven, CT: Yale University Press.

Browman, G. P. (1999). Science, language, intuition and the many meanings of quality of life. Journal of Clinical Oncology, 17(6), 1651- 653.

Chambers Etymological Dictionary (10th ed.). (1986). London: W.R. Chamber

Chesla, C.A. (1995). Hermeneutic phenomenology: an approach to understanding families. Journal of Family Nursing, 1 (1), 68-78.

Chinn, P. L. & Jacob, M. K. (1996). Theory and Nursing: A Systematic Approach. (2nd ed.). St.Louis, MO: Mosby.

Corbin, V. (1999). Misusing phenomenology in nursing research: identifying the issues. Nurse Researcher, 6 (3), 53 - 67.

Corbin, J., & Strauss, A. (1988). Unending Work and Care: Managing Chronic Illness at Home. San, CA: Jossey-Bass.

Coulter, I. (1998). Clinical reasoning, clinical decision analysis, and clinical intuition: The think no evil, do no evil, know no evil of clinical practice. Topics in Clinical Chiropractic, 5 (2), 27 - 33.

Coulter, I.D. (1998). The physician, the patient, and the person. Chiropractic Humanities, 1, 9-20.

Crotty, M. (1996). Phenomenology and Nursing Research. Melbourne, AUST: Churchill Livingstone.

Crotty, M. (1998). The Foundations of Social Research. Meaning and Perspective in the Research Process. Thousand Oaks, CA: Sage.

Curtin, L. (1978). Nursing ethics: Theories and pragmatics. Nursing Forum, 17 (4), 4 - 11.

Darville, R. (1989) The language of experience and the literacy of power. Adult Literacy Perspectives, 8, 1- 22.

Dossey, L. (1993). Healing Words: The Power of Prayer and the Practice of Medicine. San Francisco, CA: Harper.

English, I. (1993). Intuition as a function of the expert nurse: a critique of Benner's novice to expert model. Journal of Advanced Nursing, 18, 387 - 393.

Fisher, M. (1995). Sleep with Angels. Philadelphia, PA: F.A. Davis.

Gadamer, H.G. (1998). Truth and method (2nd rev. Ed., J. Weinsheimer & D.G. Marshall, Trans.). New York, NY: Continuum.

Guba, E.G. & Lincoln, Y.S. (1994). Competing paradigms in qualitative research. Handbook of Qualitative Research. Thousand Oaks, CA: Sage.

Heidegger, M. (1975). Basic Writings from Being to Time (1927) to The Task of Thinking (1964). In D.F. Krell (Ed.). New York, NY: Harper & Row.

Heller, A.F. (1986). Health and Home: Women as Health Guardians. Ottawa, CAN.: Canadian Advisory Council.

Husserl, E. (1913). In W.R. Boyce-Gibson (Ed.), Ideas: general introduction to pure phenomenology. New York, NY: MacMillan.

King, L. & Appleton, J.V. (1997). Intuition: a critical review of the research and rhetoric. Journal of Advanced Nursing, 26, 194 - 202.

Knafl, K.A., Ayres, L., Gallo, A., Zoeller, L., & Breeitmayer, B. (1996). Learning from Stories: Parent's accounts of the Pathway to Diagnosis. Pediatric Nursing, 21 (5), 411 - 415.

Kvale, S. (1996). Interviews: An Introduction to Qualitative Research Interviews. Thousand Oaks, CA: Sage.

Laub, D. (1995). Truth and testimony: The process and the struggle. In C.Caruth (Ed.). Trauma: Explorations in Memory (pp. 61-75). Balitmore, MD: John Hopkins University Press.

Leff, P.T., & Waliser, E.H. (1992). Building the healing partnership: Parents, professionals, and children with chronic illnesses and disabilities. Cambridge, MA: Brookline Books.

McWhinney, J.R. (1991). Primary care research in the next twenty years. In P.G. Norton, (Ed.), Nursing Research (pp. 126-145). ew York: Brunner/Mazel.

Merleau- Ponty, M. (1964). Sense and non-sense. (H.L. Dreyfus & P.A. Dreyfus, Trans.). Evanston, ILL: Northwestern University Press.

Miles, M. & Huberman, A. (1994). Qualitative Data Analysis. housand Oaks, CA: Sage.

Molzahn, A. & Sheilds, L. (1997). Qualitative research in nephrology nursing. ANNA Journal, 24 (1), 13 - 19.

Morse, J.M., & Field, P.A. (1996). Nursing Research: The Application of Qualitative Approaches (2nd ed.). London: Chapman and Hall.

Munhall, P.L. (1994). Revisioning Phenomenology: Nursing and Health Science Research. New York, NY: National League for Nursing Press.

Munhall P.L., & Oiler, C.J. (1986) Nursing Research: A Qualitative perspective. Norwalk, C.T.:Appleton-Century-Crofts.

Nakkula, M., & Ravitch, S. (1998) Matters of interpretation: Reciprocal transformation. Therapeutic Developmental Relationships with Youth. San Francisco, CA.: Jossey-Bass

Osborne, J,W. (1994) Some similarities and differences among phenomenological and other methods of psychological qualitative research. Canadian Psychology, 35 (2), 167-189.

Oxford English Dictionary (1989). (2nd ed., Vol. 7). Oxford, ENG.: Clarendon Press.

Paley, J. (1997). Husserl, phenomenology and nursing. Journal of Advanced Nursing, 21 (2), 1123- 1129.

Palmer, R. (1969). Hermeneutics. Evanston, IL: Northwest University Press.

Parker, R. (1998). The Phenomenological method. In Munhall, P.L. (Eds.), Revisioning Phenomenology: Nursing and Health Science Research. (pp. 243-269). New York: National League for Nursing Press.

Parse, R.R. (1998). The Human Becoming School of Thought: A Perspective for Nurses and Other Health Professionals. Thousand Oaks, CA: Sage.

Paterson, J. G., & Zderad, L.T. (1976). Humanistic Nursing. New York, NY: J. Wiley & Sons.

Patton, P., (1978). Qualitative Evaluation and Research Methods. Newbury Park, CA: Sage.

Polkinghorne, D.E. (1983). Narrative Knowing and the Human Sciences. Albany, NY: University of New York Press.

Poirier, L. (1997). Honoring the woman who happens to have diabetes. Diabetes Spectrum, 10 (3), 162 - 166.

Potter, J. (1996). Representing Reality. London: Sage.

Ricoeur, P. (1991). From Text to Action. (K. Blamey & J. Thompson, Trans.). London, ENG: Athlone Press.

Rogers, C. (1965). Towards a science of the person. Readings in Humanistic Psychology. New York: MacMillian.

Rorty, R. (1979). Philosophy and the Mirror of Nature. Princeton, N.J: Princeton University Press.

Sandelowski, M. (1986). The problem of rigor in qualitative research. Advances in Nursing Science, 8, (3), 27-37.

Senge, P. (1990). The Fifth Discipline: The Art and Practice of the Learning Organization. New York, NY: Doubleday.

Shapiro S. (1995). Talking with patients: a self psychological view of creative intuition and analytic discipline. Therapeutic Action and Technique, 18 (5), 986 - 988.

Streubert, H.J. & Carpenter, D.R. (1995). Qualitative Research in Nursing: Advancing the Humanistic Imperative. Philadelphia, PA: J.P. Lippincott.

Stubblefield, C., & Murray, R.L. (1999). Parents call for concerned and collaborative care. Western Journal of Nursing Research, 21 (3), 356 - 371

Taylor, C. (1985). Multiculturalism: Examining the Politics of Recognition. Princeton, NJ: Princeton University Press.

Thompson, J. (1990). Hermeneutic inquiry. In L. Moody (Ed.) Advancing Nursing Science through Research: Vol. 2.(pp. 223-285). London, ENG: Sage

Thorne, S., & Robinson, C. (1993). Health care relationships: The chronic illness perspective. Research in Nursing and Health, 11, 293 - 300.

Young, R. (1987). Intuition and the nursing process. Holistic Nursing Practice, 1 (3), 52 - 62.

Van Manen, M. (1992). Human Science. Researching Lived Experience. Ontario: Althone Press.

Vanier, J. (1998). Becoming Human. Toronto: House of Anasi Press Ltd.

Viederman, M. (1995). The reconstruction of repressed sexual molestation fifty years later. Journal of American Psychoanalytic Association, 43, 1169-1195.

Watson, J. (1985). Nursing: Human Science and Human Care: A Theory of Nursing. Norwalk, CT: Appleton-Century-Crofts.

Weekes, P. (1986). Theory free observations: fact or fantasy? In P. Chinn Ed.), Nursing Research Methodology: Issues and Implementation, (pp. 11-21). Aspen, CO: Aspen Publications.

Wordsworth, W. (1809). In W. Davies (Ed.), Selected Poems of William Wordsworth. Totowa, NJ: Rowman & Littlefield

Appendix A

Human Subjects Approval Form

University of Victoria

Human Research Ethics Committee

CERTIFICATE OF APPROVAL

Principal Investigator	Department/School	Supervisor
Mary Alyse Capron **Graduate Student**	**NURS**	**Dr. Isobel Dawson**

Co-investigator(s):
N/A

Title: Honoring in the Health Care Relationship: The Experiences of Parents During Diagnosis of their Child's Illness

Project No.	Start Date	End Date	Approval Date
191-00	**01 Jun 00**	**30 May 01**	**01 Jun 00**

Certification

This is to certify that the University of Victoria Ethics Review Committee on Research and Other Activities Involving Human Subjects has examined the research proposal and concludes that, in all respects, the proposed research meets appropriate standards of ethics as outlined by the University of Victoria Research Regulations Involving Human Subjects.

J. Howard Brunt,
Associate Vice-President, Research

This Certificate of Approval is valid for the above term provided there is no change in the procedures. Extensions/minor amendments may be granted upon receipt of "Request for Continuing Review or Amendment of an Approved Project" form.

Office of Vice President Research
Room 424, Business & Economics Building
P.O. Box 1700,
Victoria, BC V8W 2Y2

Tel: (250)472-4362
Fax: (250)721-8960
Email: lalleman@uvic.ca

Appendix B

Informed Consent Document

My name is Mary Alyse Capron and I am a Graduate Student in the department of Human and Social Development – Nursing at the University of Victoria. Thank you for your interest in my research study entitled "Honoring in the Health Care Relationship: The Experiences of Parents during Diagnosis of their Child's Illness". As discussed, this research is part of the requirements for a Master's degree in Nursing and it is being conducted under the supervision of J. Isobel Dawson, B.Sc. (N), M.Sc. (N), MA, Ph.D.

The purpose of this study is to understand the the human phenomenon of honoring as it relates to the experiences of parents in their relationships with health care professionals during the diagnosis of their child's illness. I am asking you to tell me in detail about your experiences, impressions, thoughts about the relationship you had/have with health care professionals.

Data for this study will be collected through 3 - 5 personal interviews of approximately 1 hour in duration. I am flexible in the location and timing of the interviews to ensure minimal disruption to you or your family.

My hope is that you will find the benefit of sharing and contributing to creating to the development of new knowledge outweighs the cost of the time committed. Anticipated benefits associated with your participation include co-creation of the generation of further understandings of the health care relationship and the ability to hear and reflect on your own experiences.

Participation in the study is completely voluntary. I want you to be aware that you may withdraw at any time from participating and have no need to share a reason or justify your withdrawal to me. Any information you have shared with me will be destroyed and not used in the research.

There are no anticipated risks or discomforts associated with this study. However, if at anytime you feel the need to discuss your experiences in a professional therapeutic relationship, I can provide access to these resources.

Do not hesitate to ask any questions about the study either before participating or during the time you are participating. I'd be happy to share the findings of our work together at any time during the research process. I will provide you with a copy of the finished document. However, your name will not be associated with the research findings in any way, and only myself as the sole researcher will know your identity as a participant.

During data collection and transcription numerical indicators will be assigned to each person. with the corresponding index kept in locked file cabinet only to be accessed by myself. You will only be speaking to me and I will be personally undertaking all the transcription and data analysis. All tapes, transcripts or other forms of data will be kept in a locked file cabinet with myself being the only person having access. Once the research is completed all supporting data, in any form, will be destroyed.

The sharing of your experiences and the knowledge constructed from it, while contributing to a broader good, will also be used to assist me personally. The final written narrative will be presented in a thesis document to reside at the University of Victoria, where it will be accessible to other students and faculty. In order to share the outcomes of this research with other health care professionals, I may attempt to publish excerpts the thesis document in professional journals or other health care publications.

I encourage you to ask questions and to contact me with any ideas, concerns, etc. at any time during our work together. My home number is 721-5138 and my work number is 727-4401. If you need to speak to me immediately, please use my pager at 413-9751. My research supervisor at the University of Victoria, Isobel Dawson, 721-7965, is also available if you have any questions or concerns.

In addition to being able to contact the myself or Isobel at the above phone numbers, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Associate Vice President Research at the University of Victoria (250-721-7968).

Your signature below indicates that we have discussed the information above, you have had an opportunity to have your questions answered and have agreed to participate in the study as outlined.

_____	_____	_____	_____
Participant Signature	Date	Researcher's Signature	Date

A COPY OF THIS CONSENT WILL BE LEFT WITH YOU, AND A COPY WILL BE TAKEN BY THE RESEARCHER

Vita

Surname: Capron Given Names: Mary Alyse

Place of Birth: Victoria, B.C., Canada

Educational Institutions Attended:

University of Victoria	1995 to 2000
University of Victoria	1990 to 1993
Camosun College	1985 to 1987

Degrees Awarded:

B. Sc. (N) (Honours) University of Victoria 1993

Honours and Awards

Nursing Excellence Awarded Camosun College 1987

Partial Copyright License

I hereby grant the right to lend my thesis to users of the University of Victoria Library, and to make single copies only for such users or in response to a request from the Library of another university, or similar institution, on its behalf or one of its users. I further agree that permission for extensive copying of this thesis for scholarly purposes may be granted by me or a member of the University designated by me. It is understood that copying or publication of this thesis for financial gain shall not be allowed without written permission.

Title of Thesis:

Journey to the Right Place: Constructing the Honourable Health Care Relationship Through Story. Experiences of Parents During Diagnosis and Treatment of Their Child's Chronic Illness

Author 

Mary Alyse Capron

December 18, 2000