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Participatory Care:

The Experiences of Parents of Hospitalized Children

A dissertation submitted to
The Faculty of Graduate Studies and Research
In partial fulfilment
of the
Requirements for the
Doctor of Philosophy Degree

Submitted by
Elaine McKiel ©

Department of Elementary Education
University of Alberta
Spring, 1996

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FACULTY OF GRADUATE STUDIES AND RESEARCH

The undersigned certify that they have read and recommend to the Faculty of Graduate Studies and Research for acceptance, a dissertation entitled PARTICIPATORY CARE: THE EXPERIENCES OF PARENTS OF HOSPITALIZED CHILDREN submitted by ELAINE MCKIEL in partial fulfillment of the requirements for the degree of DOCTOR OF PHILOSOPHY.

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To my mother,

Janie Chizmazia,

whose parenting story was the genesis of this research.

Abstract

The positive welfare of children who are hospitalized is known to be dependent on maintaining continuing relationships with significant caregivers. It has been shown that a vital means of doing this is to include parents as active members of the health care team. This is reflected in parents being participants in their children's care. However, even though the need has been recognized for decades by professionals in a variety of disciplines and reported in child care literature for at least fifty years, parent participation within a hospital landscape has been slow to evolve beyond the provision of basic care.

In attempting to understand why advances in care by parents have been so slow, I explored the question: What are the experiences of parents as participants in the care of their hospitalized children. Using narrative inquiry framed within a landscape metaphor, I interviewed five parents whose children had acute, non life-threatening health problems requiring hospitalization ranging from forty-eight hours to three weeks. This group was chosen because the majority of children requiring hospitalization have short-term, acute illnesses, but are studied least in relation to parent participation in care even though they are known to be vulnerable to the adverse effects of separation from their significant caregivers. Interviews were done in hospital and in the parents' homes following their children's discharge. Telephone conversations to clarify and confirm my descriptions and interpretations of the parents' experiences as participants in their children's care during hospitalization supplemented the interviews.

Interpretations of the narrative accounts revealed that, in contrast to reports in the literature about parents of children with long-term health problems, the parents in this study storied themselves as primary caregivers to their children. Their stories also revealed that they experienced transition. In various ways, they storied uncertainty and changes in identity, relationships, routines, and abilities. From their stories, patterns of interaction and patterns of care emerged. Dominant attributes of patterns of interaction were strain and membership on the health care team without voting privileges. Patterns of care were characterized by parallel care, cooperative care, and learning new care in the absence of teaching relationships.

The knowledge inherent in the parents' stories has implications for nursing in terms of undergraduate education and staff development, for practice in connection with education, and for further research in relation to parents as primary caregivers to their hospitalized children, experience of transition for parents of children with short-term, acute illnesses, and the integration of personal knowledge with professional knowledge.

Acknowledgement

The evolution of a dissertation is comparable to an evolving landscape. The landscape may have one gardener, but it is shaped by many forces. So, too, is a dissertation. Although one author will be identified on the spine of the dissertation, it will have been shaped by many voices. It is those voices that I pay tribute to here.

For tilling and then seeding of the proposal, and for the ongoing grooming throughout its growth as a dissertation, thanks, Jean. You cultivated a learning landscape which, for me, surpassed all others in my many journeys as a student. I recall your skilful facilitation that enabled ideas, thoughts, and challenges to be generated and exchanged among those of us who came to the Centre for Research in Teacher Education and Development. I miss those times with Nophanet Dhamborvorn, Betty Ferguson, Margaret Olson, Ji-Sook Yeom, Haya Lachman, Brian Stelck, Ian Sewall, Sherilyn Grywul and the many others far more than I had anticipated.

Away from the Centre, there were others who added to the landscape in various significant ways. Thanks to Jeanne Besner for being a thoughtful listener; to Jocelyn Lehman for being a conscientious reader; to my sisters, Betty and Carole, for being there.

My learning landscape was also nurtured by committee members who introduced me to different views. To Dr. Linda Ogilvie, whose responses were so timely and supportive, many thanks. You helped me to explore the meaning of the narrative accounts in ways that had not occurred to me previously. Another special thank-you is extended to Dr. Myer Horowitz who, through his interest in facilitating the learning of students, read and responded to my proposal prior to my candidacy examination. Your feedback to my dissertation prior to the oral defence helped me to consider other perspectives. It was a privilege for me to have you join the examining committee. To Dr. Julia Ellis, Dr. Olive Yonge, and Dr. Sue Johnston, thank-you for your participation on my examining committee. With your differing backgrounds, you brought a variety of views for my consideration.

Notwithstanding the importance of those people who seeded and cultivated my learning landscape, the knowledge that I have gained could not have happened without the landscape of parent participation. Central to that landscape were the parents: Monica, Janie, Lynn, Paula, and Terry. Thank-you for extending yourselves during those stressful times of Brent's, Penny's, Gary's, and Stuart's health problems, as well as during the aftermath when I visited you in your homes and spoke with you on the telephone. In addition to these key people, I also want to extend my appreciation to the nurses, Paulina and Maureen, who were instrumental in the selection of the parents for this study, and whose interest in their experiences fostered changes in nursing practice.

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CHAPTER

CHAPTER I

Framing Research Within a Landscape

I am a Calgarian who chose to do doctoral studies in the Department of Elementary Education at The University of Alberta. During the two years of my required residency, I travelled between Calgary and Edmonton many times. During my travels, I was often enthralled by the scenery. I witnessed the changes in the rolling landscape as I passed it on the highway; the stark whiteness in winter, the rich, black soil in early spring, the lush green crop in late spring, the brilliant, yellow canola in summer, and the golden wheat in fall. These were changes that occurred from season to season. But even within a season, the landscape was never the same on two successive trips. It varied depending on whether I was going south or north, whether the sun was shining or it was raining or snowing, whether the wind was blowing or it was still, whether it was daytime, evening, or night. The activity in the fields differed. Sometimes, there was no movement visible. But then a hawk would swoop down to capture prey from the land which, until then, had seemed to be empty of living creatures. On occasion, there was a farmer working in a field. His presence not only added a person to the scene; it changed the sense of the landscape by adding a personal dimension.

Just as I knew that each time I passed any particular spot, the landscape would have changed in some way, I also knew from times when I had visited friends who farmed near the highway that my perspective would change if I stopped the car and walked into the field. By entering it, I would become part of the landscape. I would change it just as my perspective of it would change. I thought about Parse's theory of human becoming in which she posits that "...people, beliefs, events, and other elements of the environment, which we connect with and separate from, change us and are changed by us in an ongoing rhythm" (Bunting, 1993, p. 12).

I was aware that the landscape which I was viewing, whether I was passing by it or whether I had entered it, was embedded in a larger landscape. The boundaries which seemed to be apparent on the horizon were an illusion. It was not a finite space, but rather an endless expanse without a definite beginning or end. I sensed that because of its continuity, that which comprised the landscape which I could not see affected that which I could see. I also sensed that the landscape that I was part of influenced that which stretched beyond my vision. Even if I did not enter that unseen landscape, my presence and that of all that was contained in the landscape of my existence had the potential to influence that to which it was connected. I was reminded of Gleick's writing about chaos theory and its focus on the global nature of systems, of wholeness (Gleick, 1987). I also recalled the emphasis on wholism (or holism) in nursing theory and nursing practice (Rogers, 1970; Sarter, 1988).

On one of the trips to Calgary as I was once again fascinated by all that was laid out around me, it occurred to me that my understanding of a landscape resonated with my research on participation by parents in the care of their hospitalized children. Just as there was a sense of temporality, continuity, sequence, place, and causality for me in the changing landscape along the highway, so there was in the various stages of my research. I wondered about the beginning. What had prompted my interest in parent participation? I thought about the story I had written which became part of my research proposal. It was about myself as a child in a hospital. As I thought about it again, I saw an image of myself in a big bed, part of the landscape of that hospital room. I was overwhelmingly homesick as I waited for my mother. But also in that image was a conveyance of activity, of purpose, of caring. That, too, was part of the landscape. It was complex just as the landscape of the countryside was complex.

Was that the beginning? Or was the beginning sometime in my tenure as a staff nurse on a pediatric unit? As I thought about that period in my life, a variety of images came to my mind. In some of the pictures, I was standing outside a hospital room looking in. In the early pictures, no parent was present. It looked lonely. Later, a parent was always present; sometimes sitting beside the crib in which a child was lying, sometimes feeding a child, sometimes changing a baby, sometimes playing with a toddler. Some of the images were still; others had movement as the parent interacted with the child. Occasionally, other people were in the room. No two images were the same. It was like viewing a landscape, only this time, it was from a hospital corridor rather than from a highway. And as I stood outside, I was aware that there were forces in the extended landscape which affected what went on in that room.

There were also images where I was in the hospital room. Then, I was part of the landscape with the parent, the child, and all the accoutrements of a hospital environment. I had a different sense of self in those pictures. My presence altered the landscape both in terms of the physical characteristics and the interactions. Once again, I was struck by the complexity of all that comprised a hospital setting. Thinking of it as a landscape allowed all of that complexity to be contained while it was being played out; to be viewed while it was being studied.

I began to be excited by the image of parent participation being situated in a landscape. I wondered if there was a connection between a landscape and the literature review which I had done. I thought about the literature which described the need for children to have their parents continue to care for them in hospital, the acknowledgement by health care personnel that parents had an essential role in reducing the traumatic effects of hospitalization on children, and the slow progress in enabling parents to engage fully in their children's care in a hospital setting. A succession of pictures came to my mind which depicted a landscape that was changing gradually. It occurred to me that the portrayal represented the professional landscape, i.e., it presented a view of the landscape as reported by professionals over time. I wondered about the place of parents in this professional landscape. Were they an integral part of it or was theirs a different landscape?

I went on to reflect on my encounters with the parents in my study. By now, it was natural to envision each of them within a landscape, initially in the hospital and subsequently at home. Again, I was struck by the dynamic complexity being played out in the images. They were more than pictures frozen in time. The architecture and the people were visible but, in addition, there was purposeful activity, a sense of sound, and, on occasion, movement which suggested that the parent was responding to something outside of her immediate space, perhaps something in the extended landscape. The images moved from the landscape of the hospital to the landscape of a home. Here were the same participants but with a different sense of dynamics. Some of the landscape had remained the same; some of it had changed.

Thus, it is meaningful for me to frame my research report in a landscape. Doing so enables me to situate myself as a child in the unfamiliar landscape of a hospital waiting for my mother to come and care for me. It allows me to not merely read the literature about parent participation in the care of their hospitalized children, but to re-view the professional landscape over time. It keeps me connected to the dynamic complexity of the experiences of the parents as I envision them in a landscape that can appear to be the same on the surface, but on exploration, reveals something more. It invites me to enter and to explore.

CHAPTER II

Constructing the Landscape for Inquiry

If You Call My Mummy, She Will Come

The little girl's eyes slowly opened. She looked around the darkened room. She counted one...two...three... four other beds in the room. There were people in the beds. They were asleep. Then she saw another bed but it didn't have anybody in it.

She lay in the bed. It wasn't her bed. It was like those other beds. It was high and hard and the blankets were tight. There was a light past her shoulder. Her stomach hurt when she moved. But if she stretched her head, she could see through the door that was partly opened.

There was a nurse outside the door. She was sitting at a desk just like her teacher's desk. But this desk had a lamp on it. Her teacher's desk didn't have a lamp on it.

The nurse was sitting at her desk writing on her papers. She didn't move all night. She just sat there writing on her papers. The little girl knew because she didn't go to sleep all night. She just lay there in that high bed and watched the other people sleep and the nurse write.

It's light outside. She didn't see it get light even though she didn't go to sleep all night. There was a different nurse now. This nurse didn't wear a white dress. Hers was pink and white. It was very pretty. The nurse was pretty *too. And she was very nice.*

The nurse said that Santa Claus had come last night. He had heard that the little girl had an operation and so he came to visit but the little girl was asleep.

The little girl knew that Santa Claus hadn't come to visit because she didn't go to sleep all night, so she would have seen Santa Claus if he had come. But she didn't tell that to the nurse.

The nurse wanted to give the little girl a bath in the bed. But the little girl said, "No. My Mummy will bath me when she comes. If you phone my Mummy, she'll come."

The other ladies in the room were all very old. They were as old as the little girl's Grammie. She knew because their hair was the same colour as her Grammie's and they came to talk to her and their voices were as old as her Grammie's.

One of the ladies was only as old as the little girl's mother though. The lady's hair was darker than the little girl's mother's. But she was a nice lady. She wanted to braid the little girl's hair. The little girl said, "No. My Mummy will do it when she comes. If you phone my Mummy, she will come." The lady said again that she would like to braid the little girl's hair for her. The lady said that it would make the little girl feel better. So she braided the little girl's hair. But she did it wrong. She only made two braids and the little girl *always had four braids.*

The little girl was sick. The nurse wanted to empty the basin that the little girl was sick into. But the little girl said, "No. My Mummy will do it when she comes."

The little girl's Mummy came. She emptied the basin. She gave the little girl a bath. And she made four braids. And she read a story. But then she went home again. And the little girl lay in the high bed in the dark and watched the nurse through the open door. The nurse in the white dress was sitting at her desk writing on her papers. The little girl wished the nurse would come. She would ask her to phone her Mummy, because the little girl knew that if the nurse phoned her Mummy, her Mummy would come even when it's dark.

Epilogue:

I am that little girl and it is now many years later. For one of the courses in my doctoral program, we were asked to interview a classmate about the experience of being an educator. Most of the questions in the interview did focus on education. But I am an educator who is a nurse and one of the questions directed to me was, "When did you decide to be a nurse?" As I reflected on the question, the preceding story came to mind. And in the written account by one of the observers of the interview was the comment "bad experience getting appendix out -- does that relate to your desire to make hospitals better places for children?"

I wonder.

Hospitalization: A Potentially Difficult Time for Children

Listen to the child who you were, who formulated what you became, who still lives within, who is now a part of what you are.

Hospitals are mystifying landscapes for most children. They create enormous uncertainty. They are filled with unknown people who use strange equipment to do painful procedures. To be a patient in them causes distress for children of all ages (Manion, 1990; Prugh, Staub, Sands, Kirschbaum, Lenihan, 1953). For example, babies as young as five to seven months of age are susceptible to stranger anxiety so that approaches by unfamiliar people can be frightening. Infants between the ages of seven to nine months of age are prone to separation anxiety. For them, the absence of their primary caregivers can be devastating (Jackson & Saunders, 1993). As children grow older, their distress does not disappear. Instead, it is labelled differently. It is called "being homesick". The extent of the anxiety which all children experience depends upon their level of development, their previous experience with separation, and the amount of social contact they have had outside of their families (Jackson & Saunders, 1993; Schuster & Ashburn, 1986). It is influenced by each personal landscape.

As children progress in their levels of growth and development, more adverse effects of hospitalization can be experienced. Children between the ages of three and five years are described as imaginative. They are very proud of their bodies, sometimes to the point of being said to be vain. They lack a concept of time; they do not understand pain; they experience a number of tensions. For these children, hospitalization can threaten their sense of autonomy and initiative. They may be uncertain about limits and about others' expectations of them in relation to their behaviour. They may fear injury to their bodies; those bodies of which they are so proud. They fear the unknown (Jackson & Saunders, 1993; Schuster & Ashburn, 1986). Theirs, too, is a special landscape.

Elementary school-aged children live in yet another landscape. They have a concept of time, have developed some reasoning skills, have past experiences to draw on, go to school, and play with others. However, even though they have better coping skills than does the older infant, toddler and preschooler, hospitalization is still a stressful event (Bossert, 1994; Lloyd, 1955; Wong, 1995). The independence and new relationships that they have established are threatened by separation from their family, friends, and the environment to which they have been accustomed. They are able to understand simple explanations about illness and expect that over time, an illness will get better. However, it is common for them to have misconceptions which can be a source of worry (Robinson, 1987). Loss of control is also a major concern for them (Jackson & Saunders, 1993; Schuster & Ashburn, 1986).

Consequently, children who are hospitalized need the institutional landscapes to be demystified. They need their landscape of origin to be coherent with the new landscape in which they have been placed. A meaningful way of meeting their needs is to provide continuity of care and caregivers by having their parents present in the landscape (Leff, Chan & Walizer, 1991). If their parents can also participate in caring for them, connections with familiar routines can be maintained, thereby reducing the strangeness and the resultant anxiety (Hardgrove & Dawson, 1972; Schuster & Ashburn, 1986).

I Am Her Mother

It is getting close to 3:00 PM. I arrive on the nursing unit to find bedlam reigning. I will be in charge this evening...doesn't look like a good beginning.

We nurses closet ourselves in the office and hear the change-of-shift report about the patients. We now know some of the reasons for the noise and sense of confusion out there. Back out to the unit...nothing has changed...bedlam still reigns. A mother arrives with her baby. Our unit has room for fifty children. This is the fifty-first. Where will I put her? It has to be someplace where an extra crib will fit.

The single room down the north hallway...a crib will fit in there. Oh, but the boy in that room has pneumonia. Can't put the baby in there. Ah, but he isn't on isolation anymore. And besides, he's rarely in his room. He *runs all over the place. His behaviour is a bigger problem than his pneumonia...if he even still has it. The baby will have to go into his room for the time being. When a cubicle becomes available in one of the infant rooms, she can be moved.*

The nurse assigned to that room takes the baby from her mother. The mother is the mother, but the baby is a patient and patients are ours. We give them the care that they need. The nurse carries the baby to her room and puts her into the crib which has been moved there. The mother is directed to wait in the waiting room so that she is available when the intern is ready to take a history.

It's supper time. We scurry around to get all the children fed. Babies cry as they wait their turn. The parents that are there don't feed their children. That's our job. We don't suggest; they don't offer. We don't offer; they don't suggest. We all know whose job is whose in this environment.

The mother sees the intern and leaves. A nurse appears around the corner with the baby. The baby is covered with scratches many of which are bleeding. What in heaven's name happened? The boy, whose room we put the baby into, says that he did it. "Why?" we ask. "She wouldn't stop crying," he replies.

Why was she crying? Separation from her mother? Maybe, but she's pretty young. Strange environment? Maybe, but do babies this age know a *familiar environment? Wanting attention? Possibly. Hungry? Probably. According to the history from her mother, it was past her usual feeding time.*

Her mother is notified. "She was hungry," said her mother. "I could have fed her. I am her mother."

A Child is Hospitalized: What is the Parents' Role?

Listen to the parents. Seek their words. Who is this child that they are entrusting to our care? Who are they?

The need for parental involvement in the care of children cannot be disputed. This is true in all facets of a child's life be it education, social pursuits, times of wellness, times of illness. The significance of parental involvement during times of illness has been well documented since the early studies by Spitz in the mid-1940's and Bowlby and Robertson in the early 1950's, all of whom examined the effects of parental deprivation on children (Bowlby, 1952, 1965; Johnson, 1990; Robertson, 1958). Drawing on their work, many researchers concerned about child development have been instrumental in changing the landscape of child care practices. One area where this has been evident is in policies pertaining to the hospitalization of children. In Canada, for example, a survey conducted in 1986 by the Canadian Institute of Child Health revealed that parents were allowed to stay with their children full-time in 89% of the hospitals included in the study, and siblings were permitted to visit in 76% of the health care institutions ("Sick Children," 1988). Consequently, families were more visible on the landscape. This represented a major change from the restrictive visiting practices of earlier years. However, an aspect identified as a continuing problem in spite of the changed visiting policies was the lack of parental participation in care. This concern was shared by the Association for the Care of Children's Health which reported an ongoing need for a system of nursing care to support the roles of families when children were hospitalized (Johnson, 1990). Knafl, Cavallari and Dixon (1988) reinforced this by saying that child care practices needed to be expanded to envelop family-centred care. The slowness whereby this goal has been achieved is evident in such statements as:

- the traditional advocacy role assumed by nurses encourages passivity in parents which is not conducive to optimal health care outcomes (Phillips & Brostoff, 1989);
- parents have difficulty exercising their parental role in an acute care setting (Alcock, 1990);
- families are still struggling with professionals for control over their children's care (Phillips & Brostoff, 1989);
- "(parents) want recognition for their contributions to their child's health and they want their expertise recognized" (Phillips & Brostoff, 1989, p.182);
- parents must be recognized as partners with health professionals in guiding children's development (Widrick, Whaley, DiVenere, Vecchione, Swartz & Stiffler, 1991);
- "...opportunities to develop a child's potential and to foster family participation in a child's activities are limited in an acute care setting"

(Alcock, 1990, p. 21);

- "...family-centered care units underplay the role of siblings" (Alcock, 1990), p. 21);
- family-centred nursing must be more than flexible visiting hours for parents (Curley, 1988);
- pediatric health care requires an understanding of the whole child, not a limited focus on the illness (Widrick et al., 1991).

These statements alert me to the challenges facing pediatric nurses. One challenge is to involve the families as partners in care. The gate to this possibility was opened by the changes in visiting policies which subsequently resulted in parents spending long periods of time with their children in hospital (Brown & Ritchie, 1990). While there, they gradually took on some aspects of their children's care such as social activities, nonmedical comfort measures, feeding, and bathing (Knafl, Cavallari & Dixon, 1988). However, when the children were ill at home prior to being hospitalized, it is possible that parents independently comforted them in special ways, administered antibiotics as ordered for infections, determined the need for and gave medications for discomfort, intervened to reduce fevers, etc. I suggest that in the hospital setting, these same parents could and would continue to provide this wide range of care if nurses would be willing to cultivate a broader participatory landscape. This would involve relinquishing control, capitalizing on parents' motivation, collaborating with parents in understanding their children's needs, in identifying what they are able to do, in identifying what they would like to learn, and then helping them gain the new knowledge. It would require that nurses and parents view the parenting role as being central to the care of children in hospitals. Parents would be instrumental in planning and providing care. It would be a change from the current practice of parents assisting in limited aspects of care. The proposed new approach would have collaborative care involving the parents, child (patient), and health professionals as its base. Over time, as the shared system of care became well established, the landscape could be extended to include all of the family as part of a collaborative health care team. Support for this approach has been provided by Shelton, Jeppson & Johnson (1987) who called for the implementation of family-centred care. They outlined the elements of this concept as:

- recognizing the family as the constant in the child's life while the service systems and the personnel within those systems fluctuate;
- facilitating parent/professional collaboration at all levels of health care;
- sharing unbiased, ongoing, comprehensive information about the child's care with parents in an appropriate, supportive manner;
- recognizing family strengths;
- incorporating the developmental needs of children and their families into health care programs;
- recognizing individuality among families and respecting different methods of coping;
- implementing appropriate, comprehensive policies and programs which

provide emotional and financial support to meet the needs of families;

- encouraging and facilitating parent-to-parent support;
- assuring flexible, accessible health care delivery systems which respond to family needs.

Benefits of a collaborative, family-centred care landscape could include such aspects as increased knowledge and skill for all of the children's caregivers, greater satisfaction for parents as a result of greater involvement in their children's care, decreased anxiety for parents, increased mental and physical comfort for children, shorter hospital stays because parents would feel more confident about caring for children at home, and decreased subsequent admissions to hospitals (Sainsbury, Gray, Cleary, Davies & Rowlandson, 1986). In addition, because the landscape is embedded in a larger landscape, the benefits would extend beyond the apparent boundaries of the hospital. In particular, positive outcomes could be realized on the provincial landscape with resultant cost savings for the government.

The Fit Between Collaborative Care and Participatory Care

A collaborative approach to health care has been cited for many years as being instrumental to achieving the goal of quality health care (Bowlby, 1952; Koerner, Cohen & Armstrong, 1986; MacDonald, 1969; "Sick Children," 1988; Spence, 1947). Collaboration is a process in which ideas are shared and efforts are combined to achieve mutually agreed upon goals. It involves accumulating a broad spectrum of information which is used to develop a comprehensive care plan with a client[1] or a client's advocate. The plan is implemented through joint participation (Kim, 1983; Trueman, 1991). Basic to the collaborative process is the sharing of knowledge, power, control, and influence. This requires a landscape in which equality, interaction, communication, negotiation, autonomy, respect, and trust are honoured (Bennis, Benne & Chin, 1969; Hartrich, 1956; Iwasiw & Olson, 1984). In a health care setting, it is based on the following principles:

- a reciprocal relationship between clients and professionals results in distribution of power and knowledge;
- clients possess resources that can be used to recover and maintain health;
- clients' active participation in health care is conducive to optimal health care outcomes;
- consumer participation in decision-making influences the use and distribution of health services (Kim, 1983).

Thus, we can talk about collaboratively based participatory care. Although its implementation would be new, it is not a new concept. Why is it taking so long to be operationalized? What facilitates or impedes parental involvement in the care of their hospitalized children? A wide range of studies have been done in response to this issue. Organizational factors which influence collaborative care have been examined (Ferraro-McDuffie & Booker, 1993; Hall & Stacey,

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[1] In the context of this study, client is actually a client unit. It is comprised of the child who is the patient plus a parent or parents. Other family members may be included.

1979; Manthey, 1992; Parker, 1990; Reed, 1988). Parents have been interviewed to gain an understanding of their experiences. As a result, Thorne and Robinson (1988) and Wuest and Stern (1991) have developed parenting models for parents of children with chronic illness. Park (1991) has described a parenting model applicable to parents whose children have been hospitalized with acute and chronic illnesses. These models describe stages that parents go through in dealing with their situations. However, Park (1991) has asserted that, "Nowhere is there an explanation of the parenting experience in total" (p. 138). It seems that from our professional positions in the landscape, we see only a part of it. Perhaps its vastness, its complexity are obscuring our vision. Perhaps we need to study more of the parts before we can gain a view of the whole picture. The purpose of this study is to seek understanding about another part, another segment of the parenting experience, i.e., how do parents story their perspective as participants in the care of hospitalized children? What do their stories reveal about parent participation in the landscape of a pediatric unit?

CHAPTER III

Uncovering the Professional Landscape

Parent Participation in Review

Just as hospitalization is difficult for children, so it is for their parents (Knafl, Cavalleri & Dixon, 1988; Schepp, 1991; Thurman, 1991). The strife for the parents can be experienced in terms of stress and economics. In relation to stress, reactions range from overt anxiety to denial or withdrawal (Astin, 1977; Etzler, 1984). Some parents express fear, others guilt (Etzler, 1984; Hayes & Knox, 1983), others helplessness (Rothstein, 1980). Sources of stress for parents include alteration in their parenting role (Brazelton, 1976; Curley, 1988; Hayes & Knox, 1984; Miles, Spichert & Hassanein, 1984; Mishel, 1983), uncertainty regarding nurses' expectations of them (Hayes & Knox, 1983), lack of information about their child's health problem, condition, treatment, and future health (Astin, 1977; Freiberg, 1972; Mishel, 1983; Ogilvie, 1990; Rushton, 1990), disruptions in home routines (Ogilvie, 1990; Popper, 1990), and concern about the transition from hospital care to home care (Johnson, 1987). Economic problems can be incurred if parents lose salary because of a need to take time off work. Additional expenses can occur due to travel, parking, meals, and baby-sitters for other children (Alexander, White & Powell, 1986; Flynn & McCollum, 1993). To help reduce their stress, parents of hospitalized children require a landscape which enables them to continue parenting their child (Melnyk, 1994; Park, 1991); a landscape which allows them to understand what is happening and to participate in decision-making; decisions which will benefit the child in the hospital and the family as a whole (Rushton, 1990). In short, the landscape needs to be one in which parents can be active members of the health care team (Shelton, Jeppson & Johnson, 1987). The extent to which this has happened is presented in the following chronicle about parental participation, collaborative decision-making, and parental membership in the health care team.

The year was 1851. Charles West, a physician, was crusading for widescale changes in children's hospitals in Britain. At that time, children under the age of two years were not allowed to be admitted to a hospital because of the high danger of death from cross-infection. For children over the age of two, hospitals were regarded more as refugee homes for slum children than as health care institutions. West decreed the need for children's hospitals to become "places for the scientific study of the diseases which might best be treated there and of the methods by which they might best be nursed" (Spence, 1947, p. 125).

The year was 1922. Pickerill and Pickerill (1945, 1954) were concerned about the high incidence of poor surgical outcomes caused by post-operative infections. They believed that better results could be achieved if mothers participated in the children's care. To operationalize their beliefs, they established their own hospital with assistance from the government of New Zealand. In their setting, the mothers provided all of the children's care. The role of the nurse was not mentioned by Pickerill and Pickerill apart from writing that the "nurses' duties and the mother's duties are sharply and strictly divided"

(p. 428) and that "This system of mother-nursing cannot replace trained nursing but it is a very valuable adjunct to it" (p. 427). Outcomes of the mother-nursing system were positive in terms of no cross-infections, decreased need for nursing staff, more contented infants, shorter hospital stays, and improved surgical outcomes.

The year was 1947. The crusade initiated by West almost a century earlier had been successful to the point that British children of all ages were admitted to hospitals for treatment. Diseases were investigated scientifically. However, the treatment of children in hospital had given rise to a new problem. Spence (1947), a physician, was concerned about fluctuating standards of care that children received. Like Pickerill and Pickerill, he felt that better care could be attained by having mothers live in and care for their hospitalized children. His call for parent participation was predicated on the premise that many mothers had experience in looking after sick children by virtue of caring for their children during times of illness in their homes. Second, based on work by Robertson (published later in 1958), he believed that hospitals, no matter how well meaning and how well equipped with toys, etc., could never be completely successful in meeting the needs of the developing child in terms of personal attachment, relationship with significant others, and companionship. In addition to his concerns for the children, he also worried about the mothers who he described as being "at home suspended in anxiety" (p. 129). He suggested that the mother could feed, tend, and comfort the child in hospital. The nurse or sister would do the technical treatments. He projected that a system of shared care would enable a mother to maintain her relationship with her child, achieve confidence in her ability to care for her child, and contribute to the child's recovery. Because he did not suggest that the mother would be taught to do any of the treatments, it is not clear how he anticipated that she would assist the child's recovery or what would contribute to an increased confidence in her ability to give care. Perhaps his premise lay in the belief that emotional comfort enhanced physical recovery. Possibly, he believed that the mother would learn about the treatments by watching the nurse perform them even though she did not do them herself.

The nurse, according to Spence, would learn mothering skills by observing the mother. These skills could then be replicated in caring for other children. Certainly, such a learning opportunity could increase the nurse's repertoire of skills. In addition, when implemented with that mother's child, it would provide continuity of care to some extent. Spence also purported that having mothers care for their children (to the extent that they were allowed to) permitted the nurses to spend more time with children whose parents were absent. He also believed that, in having the mothers present, the nurses could learn about the anxieties that mothers experienced because of the child's illness. He did not suggest how the nurses would use this information or what interventions might be warranted. Fathers and siblings were not addressed by Spence.

The year was 1952. In a report published through the auspices of the World Health Organization, Bowlby emphasized the need for the infant and young child to "experience a warm, intimate, and continuous relationship with his mother (or permanent mother-substitute) in which both find satisfaction and enjoyment" (p. 11). He believed that children who were deprived of a maternal relationship suffered adverse consequences. Those who had an opportunity to know and trust a consistent caregiver when their mothers were unable to be present experienced partial deprivation. The children for whom Bowlby was most concerned were those who suffered "almost complete deprivation which is still not uncommon in institutions, residential nurseries, and hospitals, where the child often has no one person who cares for him in a personal way and with whom he may feel secure" (p.12).

The year was 1953. A number of studies about the adverse effects of hospitalization on children had been completed. The findings were being circulated in speeches and in literature (Prugh, Staub, Sands, Kirschbaum, Lenihan, 1953). In response to the information, some European hospitals which had the facilities to do so, were encouraging mothers to stay with their young children and provide the major part of their care throughout the period of hospitalization. Hospitals in the United States generally lagged far behind although visiting hours had been expanded from once a week to once a day. Other isolated pockets of change were also occurring. For example, a pediatric unit with a twenty-four hour visiting policy was opened at the Hunterdon Medical Center in Flemington, New Jersey where parents were viewed as members of the health team, and their participation in care was promoted (Hunt, 1956-57) .

In Britain, Prugh, Staub, Sands, Kirschbaum and Lenihan (1953) studied children's reactions to hospitalization. They implemented seven new interventions with an experimental group of subjects. One of the interventions involved more flexible visiting hours for parents with encouragement for them to participate in their children's care. Participation included feeding the children, playing with them and putting them to bed. The actual visiting policy was not described. One of the statements by the authors which gave me cause to pause and wonder was, "Such parents (those who had a satisfying relationship with their children) tended to show the most positively expressed response to the more flexible conditions of the experimental program, and appeared to handle the enhanced visiting opportunities with greatest equanimity and benefit to their child" (p. 82). There was no information in the article regarding the preparation of parents for their role in the hospital setting. There was, however, a statement pertaining to parents who were described as overprotective, clinging to their children, and "actually producing interference with his adjustment to the ward" (p. 99). For these parents, "...supportive work was necessary in order to help (them) limit their visiting.. " (p. 99). The researchers concluded that, "If opportunity is available, certain parents can make vital contributions to the hospital program through their participation in the ward care of their own children" (pp. 103-104). They also spoke of the medical team concerned with the total care of the ill child. Presumably that did not include parents. Thus, there was ambiguity, and perhaps an air of paternalism regarding the inclusion of parents in care.

In their report, Prugh, Staub, Sands, Kirschbaum & Lenihan (1953) noted that the focus of the studies being done was on the emotional reactions of the children experiencing hospitalization. They suggested there was an additional need to investigate the reactions of the children's parents or families. In explaining why such work had not been undertaken, they pointed out the difficulty in correlating observations in the hospital with those in the home. They said, "Even under relatively well-controlled circumstances, the thorny problems of methodology and the multiple character of possible interpretations of observed data have superimposed formidable limitations upon the quality and veracity of final conclusions" (p. 72). This concern may be understood in the light of the time for it was the era of the supremacy of scientific rationalism or logical positivism.

The year was 1955. Morgan, a mother, and Lloyd, a nurse, put forth the belief that the admission of a child to hospital was not limited to the child. Instead they believed that the admission involved a parent-child unit. They advocated that parents help with such aspects of care as weighing their children, taking temperatures, collecting specimens, bathing, and giving oral medications. Lloyd commented that prior to her experience at the Hunterdon Medical Center, she felt that children in hospital were better off without their parents being present. She also noted that the practice of asking parents to leave the room when painful procedures were done continued to occur frequently. However, if parents asked to stay, they were permitted to do so.

The year was 1959. The Platt Report on the welfare of children in British hospitals recommended unrestricted visiting by parents along with accommodation for them to stay with their children. However, the National Health Service was slow to implement the recommendations (Devlin, 1989; Evans & Robinson, 1983; Sainsbury, Gray, Cleary, Davies & Rowlandson, 1986).

In Canada, at that time, the scene was similar. The roles of parents and nurses on a pediatric hospital unit were clearly defined (Brown & Ritchie, 1990). In my own experience, parents were allowed to visit for brief, designated periods of time, e.g., 2:00 P.M. to 3:00 P.M. and 6:00 P.M. to 7:00 P.M. In some hospitals, they were not permitted to go into the rooms of children on isolation because of the concern for cross-infection. They were restricted to looking at their children through a window. Siblings were not allowed to visit. Nurses were responsible for all of the care.

The year was 1962. MacCarthy, Lindsay and Morris reflected on the movements by Pickerill and Pickerill (1945, 1954) and Spence (1947) to have mothers involved with the care of their children in hospital. The authors noted that, although it had been many years since Pickerill and Pickerill had shown the benefits of including mothers in the care of their children, there was continuing doubt regarding the place of parents in a hospital pediatric unit. They also reported that the "battle for daily visiting...was not yet completely won" (p. 603) even though there were centres which had expanded beyond daily visiting to unrestricted visiting.

On the unit where MacCarthy, Lindsay and Morris worked, parents had been participating in their children's care since 1953. Although the purposes of parent inclusion were to help the mother, to teach the mother, and to learn from the mother, there is an implication in the report that a number of limitations were placed on parental participation. The authors acknowledge the work of Joyce Robertson in writing:

> A mother who is informed about what an operation involves, and is given moral support from nursing and medical staff if she needs it, can be a full participant in the recovery of a child. But with the staff available we cannot possibly do this properly for three cases in (an operating room) list. (p. 606)

Therefore, only one mother and child could be admitted at a time. They had to be in a separate room because, "If all cases are in one room, a mother may be exposed to the sight of postoperative complications in another child" (p. 606). The scope of participation by the mothers was both broad and narrow. They learned to collect urine specimens, change colostomy dressings, and care for tracheotomies, but it was the responsibility of the nurse to read the thermometer after the mother took the child's temperature. Mothers also gave medications "...either under supervision or alone if proved competent (which they often are)" (p. 603).

The staff expressed concern about mothers staying with their children because they perceived a possibility that parents might be disruptive although, the authors reported, experience had shown this to be rare. There was also concern about "potential embarrassment to the doctor to have the mother there while he was doing something which is distressing or difficult and might fail" (p. 604).

In their conclusion, MacCarthy, Lindsay and Morris identified the need for any new children's unit to include accommodation for mothers in the design. To enable more mothers to be present, they advocated the inclusion of sibling visiting with nursery staff to supervise them. Even though they proposed expansion, they did not address their previous concerns about staffing or suggest the need for clarification of roles.

The year was 1963. A Family Participation Unit was opened at the Boston Floating Hospital (Hardgrove & Dawson, 1972). This unit was separate from the "regular" inpatient pediatric units. It was designed to provide a place where mothers could be with their children, help with nursing care, and be an integral part of the child care team (Katz, 1964). In addition to basic care, the parents gradually expanded their scope of care through teaching and supervised practice. When their skills were judged to be satisfactory, they gave care independently. Reactions to the unit by parents differed from those of the nurses (Katz, 1964). Parents responded positively; nurses expressed concern that parents interfered with them getting their job done. Nurses were also concerned that children and mothers would be disruptive although this seldom occurred.

The year was 1966. The first North American care-by-parent unit was opened at The University of Kentucky Medical Center (Hardgrove & Dawson, 1972). In this unit, the role of the parent was deemed to be "the critical element which makes (care by parents) a successful venture in child care..." (James & Wheeler, 1969, p. 490). Responsibility for care at all times rested with the parents. Parents gave basic care and, in addition, took temperatures, did charting, collected 24-hour urine specimens, gave medications, took blood pressures, and sometimes performed more complicated procedures such as tracheotomy care, and monitoring blood transfusions. The role of the staff was to instruct and supervise the physical care by the parents as well as observe and support family interactions (James & Wheeler, 1969; Hardgrove & Dawson, 1972). Paradoxically, although responsibility for care rested with the parents under the guidance of the staff, authority was vested in the physician who was deemed to be ultimately accountable for the patient.

Gradually over time, more care-by-parent units were opened leading to studies in which the outcomes of such facilities were examined (Evans & Robinson, 1983; Fore & Holms, 1983; Sainsbury, Gray, Cleary, Davies & Rowlandson, 1986). Researchers found that teaching and supervision by nurses enabled parents to gain competence and confidence in their abilities to respond to their children's health needs. The continuous presence of the parents promoted more interaction with physicians which led to greater accountability for decision-making by doctors. This was reflected in fewer diagnostic tests being done. Children were able to be discharged earlier because parents had demonstrated their ability to provide post-discharge care. In addition to the benefits to parents and children, Evans and Robinson (1983) were able to demonstrate the cost-effectiveness of care-by-parent units.

In another study, Lerner, Haley, Hall & McVarish (1972) evaluated the care-by-parent unit at The University of Kentucky Medical Center. Although they corroborated the positive findings, they also identified negative outcomes which seemed to be related to inadequate communication. For example, a number of parents were uncertain about their child's prognosis, and the majority lacked understanding about aspects of home care such as regular daily activities, physical activities, treatments and special precautions in spite of the teaching that was done.

The year was 1968. In a study of children admitted to hospital for removal of their tonsils and adenoids, Brain and MacLay found that the children in an experimental group who were admitted with their mothers had a significantly lower incidence of negative reactions to hospitalization, post-operative complications, and emotional disturbances following discharge than did those in the control group whose mothers did not stay with them. In spite of the findings, and in spite of agreeing that the presence of the mother was comforting to the young child, the nurses were unanimous in their opinion that mothers should not stay with their children. Reasons which they gave were that it was easier to carry out nursing procedures when the child was alone; they had more personal contact with the child whose mother was absent; and some mothers were difficult creating upset among the children and other mothers on the unit.

The year was 1969. The results of a study done by MacDonald in a Canadian children's hospital were published. She found that the majority of parents wanted to be involved in their children's care. She reported that, on the whole, parents were willing to do more than most nurses were willing to let them do. Over 90% wanted to provide care related to the activities of daily living, e.g., feeding, bathing, etc. Some indicated that they would like to suction, do chest physiotherapy, change dressings, take vital signs including blood pressure, give oral medications, and restrain the child during painful procedures. On the other hand, although nurses wanted parents to participate, they felt that participation should be limited to bathing, feeding, comforting, playing, transporting children to x-ray, and giving oral medications.

In spite of the differences between the mothers and the nurses, MacDonald noted that positive outcomes resulted from her study. Nurses described children whose parents participated in their care as being more secure. The nurses indicated that they learned more about family influences on pediatric patients and gained a better understanding about children's reactions to hospitalization. The increased presence of parents provided greater opportunities to teach about child health. In all, the nurses were able to broaden their scope of nursing practice to the benefit of children, parents, and themselves.

Also in 1969, Scofield described the parental "living-in" experiences at The Henrietta Egleston Hospital for Children in Atlanta, Georgia. In this facility, where the philosophy enveloped family-centred care, 75% of the children had a parent who chose to "live-in" and provide some aspects of care. However, in spite of the hospital's philosophy, Scofield reported that, "Almost without exception our professional nurses are young and enthusiastic and, of course, they want to work with children. They are not always convinced they want to work with parents" (p. 61).

The year was 1972. Hardgrove and Dawson wrote "...while many children in American hospitals receive high-quality technical care, their social and emotional development may be permanently damaged because little attention is paid to their reactions to separation from the family" (p. v). They described the need for parents to be prepared, educated, and supported in helping their children. They called for parents to be partners in care. However, other authors (Algren, 1985; Brown & Ritchie, 1990) have suggested since then that an inhibiting factor has been that professional health care workers do not ask parents how they want to participate. Perhaps a clue to this problem lies in the statements by a physician who said:

> It's difficult to ask parents whether they like this or that and what should be changed, since they believe, of course, that they have brought their child to a place where he will get the best possible care. So they really can't question visiting hours. If you told them they could only come for one hour a week, they could only assume that you know what is best. (Hardgrove & Dawson, 1972, pp. 78-79)

The year was 1973. In a study with parents whose children had heart problems, Beck found that the majority of parents wanted to participate in their children's care. They were most comfortable about assisting their children with care that they were accustomed to doing at home, e.g., activities of daily living and emotional support. They were uncertain about participating in care such as explaining procedures, taking pulses, blood pressures, and temperatures, and coping with a dying child. However, they did not indicate that they were unwilling to do these activities. Rather, they questioned their abilities to do them without making mistakes. They also expressed anxiety about upsetting hospital routines or being in the way. Based on the findings, Beck concluded that nursing had a responsibility to design hospital parent participation programs which would encourage parents to participate in their children's care and teach them "to function completely and comfortably with their hospitalized child" (p. 338). Advantages, according to Beck, would be improved care for the child and reduced costs for the hospital.

The year was 1975. A survey done in the Boston area revealed a dichotomy in hospital policies (Hardgrove & Kermoian, 1978). In 71% of pediatric units, parents were permitted to room-in with their children. They could stay all the time. However, in 66% of the institutions (including those which had rooming-in privileges), parents who chose not to stay twenty-four hours a day were restricted to the standard visiting hours of the particular hospitals, i.e., they either stayed all the time or they visited during times designated by the hospital.

They did not have the choice to come and go throughout the twenty-four hour period.

The year was 1976. In Britain, the Court Report (Report of the Committee on Child Health Services "Fit For The Future") was published (Jolly, 1988). In it, the family dimension in child health was deemed to be of paramount importance. There was a call for a service to ensure that parents be well informed about their children's development and health.

In 1976, in U.S.A., Hardgrove and Kermoian (1978) purported that the presence of parents when children were hospitalized was not sufficient to achieve optimal recovery. They insisted that parent education was also necessary. They based their conjectures on work by Skipper and Leonard (1968) and Wolfer and Visintainer (1975). In their study of parent-inclusive units, they concluded that most "living-in" programs did not optimize parental presence through provision of facilities, e.g., bathrooms, kitchens, meeting rooms, or parent surrogates which would enable parents to have breaks. Nor was care extended to include visits from siblings and friends. Their results also showed that expectations regarding the parental role were often not conveyed. In response to the shortcomings, the researchers identified the need for in-service education for staff in working with parents.

The year was 1977. The Canadian Institute of Child Health sought to identify the major issues in child health by consulting with parents and health care professionals. Restrictive visiting policies, little or no overnight facilities for parents and inadequate information from medical and nursing staff were identified as areas of concern ("Sick Children," 1988).

The year was 1979. Goodell studied two groups of nurses, one of whom worked in a unit where parents participated in planning and giving care to their children who had cancer, and a second group who also worked with children with cancer but on units which were not designated as parent participation units. All nurses believed that parents should stay with their children to reduce the incidence of separation anxiety and to facilitate adjustment to hospital. Most nurses agreed that parent participation programs were feasible. Although nurses with experience in care-by-parent programs were more supportive of parental involvement than those without that experience, many nurses did not consider parents of very ill children to be dependable in giving safe care. Many nurses also indicated a reluctance to have parents "perform simple duties viewed as within the nurses' scope of practice" (p. 43). Examples of these duties were not given. Nurses perceived that physicians were reluctant to have parents participate in care. From this study, a need was identified for educational programs to include opportunities for health care professionals to acquire a knowledge base and skills in working with children and their families in parent participation units.

The year was 1981. A survey of pediatric hospitals and general hospitals with pediatric units in U.S.A. revealed great variability in services. "Only a few hospitals appeared committed to child- and family-centered care" (Maieron & Roberts, 1993, p. 144). In facilities where there was commitment to family-centred care, there was inconsistency in its implementation.

The year was 1983. Mittler and Mittler reported a trend toward collaborative, reciprocal relationships or "partnerships" being developed between parents and teachers of children with special needs. As a result, there was increased participation by parents of children with disabilities in formal activities organized by professionals. It is possible then that the parents of these children admitted subsequently to hospital would have come to the health care centre with skills in interdisciplinary collaboration acquired in their school experiences.

Also in 1983, the results of a study by Knox and Hayes were published. In this research, forty-one parents were interviewed regarding the stress associated with the hospitalization of their chronically-ill children. The parents reported that many of their usual parenting tasks were taken over by others, deleted, or replaced by new tasks. For example, they had to relinquish responsibility for their children's care to others; they were not allowed to share it. They were not made to feel that their parenting skills would be helpful in planning care. They reported that expectations of them were not consistent among health professionals, nor were the expectations clear. They described parenting a child in hospital as "having a job without a job description" (p. 223).

From this study, time and trust were identified as factors which influenced parental coping. As parents spent more time in the hospital, the environment became less strange and more predictable. Trust was engendered when parents perceived that the staff gave safe care, acknowledged their needs and those of their children, and conveyed consistent, honest information. Without the latter, parents could not make decisions about their children's care or prepare their children for forthcoming events and procedures. Based on their findings, Knox and Hayes identified the need for nurse-parent negotiation of mutually acceptable roles. They advocated a program for preparing parents for the hospitalization of children just as there are programs for children to prepare them for being hospitalized.

The significance of the work by Knox and Hayes was confirmed later in a study by Lynn (1986) when she found that interactions between parents and children were influenced by the parents' ability to cope. Coping, at least in part, was dependent on the extent to which parents were able to adapt to the hospital environment and experience, and by the amount and relevance of the information they received. Mishel (1983) also examined sources of stress in parents of hospitalized children. She identified uncertainty characterized by ambiguity (regarding treatment, technology, schedules), lack of clarity (incomplete or unclear explanations), lack of information (information not known or not shared), and unpredictability (related to parental roles and outcomes).

The year was 1985. Motivated by recognition that, "In the United Kingdom, the child is under the care of a medical team and parents assist if they can and are allowed to" (p. 176), Webb, Hull and Madeley (1985) studied participation by parents in an acute, medical, pediatric unit. Parents and staff were given a list of thirty-one tasks and asked to identify the ones they thought parents would be capable of doing. The results of the study revealed that the staff thought the parents could do more than they were doing. Parents agreed with them but wanted to do even more than the staff felt they should. Support for greater participation as a result of this study was ambiguous as seen in the conclusion when the authors stated, "For some families, and in some conditions for which children are admitted to hospital, it may be more satisfactory and effective if parents remain responsible for their child" (p. 177). The authors predicted that the parents' role would continue to be mainly supportive just as it was at the time of the study.

Also in 1985, the report of a study by Algren on the role perception of mothers who had hospitalized children was published. In her research, all of the mothers reported that they wanted to participate in their children's care and they wanted to do more than they were doing. However, they were uncertain regarding their role. Seventy percent reported that the nursing staff had not explained the role which they "could or should assume" (p.8). Algren interpreted the findings as suggesting "...that the nursing staff may neither ask what the parents would like to do nor instruct them about what they can do" (p. 9). She concluded that parents are involved only superficially in the care of their children. They do basic care but would prefer to be responsible for more.

Continuing with 1985, Robinson (1985a, 1985b) completed a study with parents of children with a chronic illness requiring repeated hospitalizations wherein the parents described their expectations and frustrations regarding their experiences. These parents were expected to be, and expected themselves to be, competent primary health care providers in the home setting. When hospitalization was required, they expected their role would change from one of primary caregiver to one in which they would share responsibility for managing their children's illnesses. They expected their knowledge of their children to be sought and valued in negotiating mutually satisfying plans of care. However, parents reported a sense of being undervalued which led to dissatisfaction with the health care received and an adversarial relationship with professional health care workers. They perceived the message that the health professionals knew best. Their frustrations were further exacerbated by having difficulty in getting information that was timely, understandable, and complete. Their role in the hospital setting was unclear. According to Robinson, "Pediatric nurses must recognize that parents of chronically ill children are different, and that their needs are different from those of parents of children with acute, episodic illnesses" (p. 65).

The year was 1986. A national survey of hospitals with pediatric units having more than 20 beds was conducted by the Canadian Institute of Child Health. The findings from this survey were compared with one done in 1977 with improvement noted in two areas. Regulations had changed so that 89% of the units had twenty-four hour visiting and 76% allowed sibling visiting. Explanations regarding care had improved. An area identified as a continuing problem was the lack of parent participation in the children's care ("Sick Children," 1988).

The year was 1987. In a study by Gillis and Sony, parents reported negative behaviours in their infants and in themselves following short-term hospitalization of the babies. The children demonstrated alterations in sleeping, feeding, and play. The parents experienced fatigue, sleep disturbances, and frustration in being unable to alleviate the behavioral changes they observed in their infants. These adverse reactions occurred among children regardless of the frequency of visiting by parents. Although other aspects of the hospital experience were not examined, the findings do remind us that family-centred care must be more than flexible visiting privileges for parents. A major concern expressed by parents following the children's discharge was the lack of information they received about the condition of their babies and the follow-up care required.

Provision of information was a major category of care identified by Elfert and Anderson (1987) in a study with thirty-one families who had children with long-term health problems. Giving information or teaching included providing information about resources, giving general advice and counselling about child care and development, interpreting medical information, and teaching related to specific needs such as caring for a child with diabetes mellitus. Teaching was viewed by parents as being a nursing function although some believed that it should be done under the direction of a physician. Teaching was usually initiated by a nurse. It was not usual for parents to be involved in deciding what, when or how information should be given. A second category pertained to direct nursing care. Care was shared by parents and nurses. The reasons underlying the shared care were not clear to the researchers although they reported that there was a perception by parents that the nurses were very busy. Presumably, as a consequence, "The parents saw the need to care for their child in hospital, to feed, change, clean, but they did it because the nurses couldn't or wouldn't" (p. 17). A third category was the provision of emotional support. Many parents described receiving emotional support and appreciating it. However, they understood it to be exceptional, i.e., not a regular part of nursing care.

The year was 1988. A survey by Maieron and Roberts (1993) of 268 pediatric and general hospitals with pediatric units revealed that twenty-four hour visiting by parents was permitted in 100% of Canadian hospitals and 97% of American hospitals. Visits by siblings were restricted in 31% of Canadian and 41% of American health care institutions. Accommodation for parents was provided in 95.5% of Canadian and 96% of American hospitals. However, the accommodation was not necessarily in the child's room. Parent surrogate programs were available in 56.5% of Canadian and 39% of American units. Parents could be actively involved in the care of their children. A disconcerting note was the statistic that in 7% of pediatric units in Canadian general hospitals, parents were not allowed to participate in basic care, i.e., feeding, bathing, dressing, and play. Specific to nursing care, parents were participants in 85.5% of Canadian hospitals and 84.5% of American hospitals. The elements of nursing care given by parents were not identified in the report. Thirteen percent of the hospitals had a formal "care-by-parent" program wherein parents were the primary caregivers. In their discussion of the results from the questionnaire, the authors cautioned that the findings identified the practices that were being implemented in 1988 from the perspective of the respondents who represented various levels of hospital personnel, some of whom were not associated directly with the patient care setting. The quality of the services provided within the hospitals was not assessed.

The year was 1990. Using the Delphi method, Tucker and Roberts identified ten significant issues pertinent to the psychosocial aspects of future health care for children. The focus was on children with special health needs. However, two issues which crossed both acute and chronic care were the need for family-centred care and training of health care professionals to work in child health nursing. Popper (1990) echoed these two issues when she called for more collaboration between parents and professionals in relation to decision-making, sibling visiting, and communication of information.

Parent-nurse relationships were the focus of another study reported in 1990 by Brown and Ritchie. They identified many contradictions in the nurses' sense of their own roles and those of parents. From information acquired through questionnaires and interviews, these researchers determined that nurses' attitudes, expectations, values, and beliefs seemed to have a profound impact on parental roles. However, the nurses did not acknowledge that their behaviour or attitudes influenced their interaction with parents. Instead, they perceived that it was parents' personalities, emotional states, levels of comfort in providing care, and familiarity with hospitals that influenced parental role performance. In addition, they cited rules and regulations, and time constraints as having an impact on parent-nurse relationships.

Lack of collaboration and lack of connections with the parents were evident throughout the report by Brown and Ritchie. The authors noted that, although all nurses believed that parents should participate in the children's care, the expectations regarding what the parents should do differed among the nurses. Some nurses determined the appropriate role of the parent from their own perspective rather than that of the parent, e.g., the nurse felt that the parent would be uncomfortable being present while the child had a painful procedure done so that parents were not permitted to be there. Parents were not asked what they wanted to do. Although nurses did not say so explicitly, the researchers perceived that nurses did not trust parents to accurately perform tasks such as monitoring an intravenous infusion or taking vital signs. They were also concerned about who was responsible if parents made mistakes.

The nurses recognized the value and importance of providing parents with information and teaching them. However, many nurses felt that it was up to the parents to ask questions and voice their concerns rather than expecting the nurse to take the initiative. The hospital where the study was done had a rooming-in policy with specified guidelines. However, the nurses did not indicate that they explained or reviewed the guidelines with the parents.

Control was another issue. The nurses had control over identifying children's health problems, identifying interventions, and evaluating outcomes. The children and parents were expected to be dependent and comply with the nurses' plans for care. When parents exerted control that was not congruent with nurses' expectations, conflicts arose.

Brown and Ritchie identified the need for a nursing model with a focus on parents' strengths and promotion of growth and family functioning so that parents would be empowered to care for their children. They also identified the need for nursing education programs to include communication skills, conflict management, family-centred care, and family empowerment. They called for research to examine strategies that are used by nurses who provide effective care for children, and teaching methods which would enable nurses to learn the strategies.

In another study published in 1990, Beisecker and Beisecker examined information-seeking behaviors of adult patients when communicating with their doctors. They found that the patients desired information from doctors regarding their medical situation. However, they did not engage frequently in information-seeking behaviours. The researchers found that situational variables explained information-seeking behaviours better than did patient attitudes and sociodemographic characteristics such as age and education. The situational variables included the diagnosis, reason for the visit to the physician, and time. Also, contrary to the notion that patients should be involved in decision-making, the majority of the patients felt that medical decision-making should rest with the doctor. Few of them indicated a desire for joint decision-making. None of them wanted to make medical decisions autonomously. It is interesting to note that based on the literature, this does not seem to be true when the health care decisions pertain to children. Parents want to be involved (Cardoso, 1991; Ogilvie, 1990; Popper, 1990; Rushton, 1990).

The year was 1991. Several studies were published in which various aspects of parental participation were examined. Based on work by Epstein, Taylor, Halberg, Gardner, Walker, and Crocker (1989) who had identified standards and indicators of quality care, Bruder and Cole (1991) explored family participation as an indicator of quality care for infants in neonatal intensive care units. The four critical elements of care cited were parent to parent supports, discharge summaries, comprehensive care plans, and training on the transition from hospital to home.

Orem (1991) wrote that the nurse's role in the care of children was to respond to the therapeutic self-care needs that parents were incapable of meeting. She went on to say that nurses should provide the care until parents overcame "their limitations for giving the needed care..."(p. 244). The means by which the limitations were to be overcome were teaching and periodic guidance and supervision for parents by nurses. As a consequence, both child and parents would benefit.

Pamela Cardoso (1991), the mother of a child with multiple handicaps wrote that "...family care has progressed in the last several years (but) much remains to be done" (p. 260). She said that in order for family-centred care to be achieved fully, medical professionals must be willing and able to work in partnership with the family. However, this was being impeded by a number of factors. One was the perception by parents that they had little or no control over the situation as the physician conveyed covertly that he/she was the "boss". Another barrier was failure by health professionals to recognize the knowledge and competency of parents in relation to what they knew through experience was best for their children. Lack of interdisciplinary collaboration limited the achievement of family-centred care because it fragmented care. The focus was on the part, not the whole. Cardoso offered two recommendations. She said that the parent should be designated the "Expert in Charge", the one who disseminated and digested the information given and made the important decisions. Second, she called for professionals to have communication skills which enabled the provision of adequate, understandable information and moral support.

Cardoso's assertions were supported by Leff, Chan and Walizer (1991) who, from their work with educating health professionals, wrote about encouraging partnerships with parents. They emphasized the importance of parents in the world of children and the need for health care workers to support parental roles. They suggested that the way to do this was to collaborate with parents, to integrate them as partners in total care of the children. Specifically, they identified the need to recognize that parents know their children best, to seek and utilize the information that parents can convey to other health team members, to rely on parental observations and perceptions about their children's condition which may not be readily apparent to health professionals who do not know the child as well, to value parental suggestions for new approaches to care, and to let parents know that they want to understand what all of the family is experiencing.

Park (1991) concluded from her study of parents of hospitalized children that, "Parents cannot just be involved because they so wish or because the institutional structure includes a program in which they are to be involved" (p. 147). She said that parents require relevant information which they understand. They also need a trusting relationship with a health professional before they can become involved. She purported that the traditional health care system does not facilitate the understanding or the relationships required to support parental involvement. She noted that nurses seldom encourage parents to assume responsibility for their own children within an institutional setting. She described the prevailing view that expertise in medical/nursing care rested with professional staff; parents were not viewed as purveyors of knowledge about nursing care. She also related that parents who developed skills on their own and subsequently assumed most of their children's care, felt that they were left alone without adequate support.

The year was 1993. Chalmers outlined the tenets of the Charter for

Children in Hospitals which was adopted in 1988 by a number of European countries. It specified that children had the right to have parents or parent-substitutes with them at all times; accommodation would be provided for parents; children and parents would be informed about the care in terms which they understood; children and parents would be able to participate in decision-making based on information given; parents would share in the care of their children; continuity of care would be provided; children would be cared for by staff who were educated to respond to their physical, emotional, and developmental needs and those of their families. In 1991, the Charter was affirmed by The European Associations for Children in Hospitals. However, reflecting on the lack of progress in child health care, Chalmers asserted that controls within health care systems continued to have a strong negative influence on parental involvement. To facilitate the implementation of the principles in the Charter, she identified the need to change existing, inadequate hospital systems, educate health care workers to effectively address psycho-social issues in health care, and educate parents about the needs of children, their families and themselves when children require hospitalization.

In a study to appraise the economy, efficiency, and effectiveness of hospital services in England and Wales, the findings of the 1959 Platt Report recommending unrestricted visiting by parents and accommodation for them to stay with their children, were reviewed by several researchers (Dodd, 1993). They noted that the recommendations in that report had been "sluggishly implemented"

(p. 173).

Flynn and McCollum (1993) reported the results of their study in which they examined the support services for six mothers whose babies were born with special needs. A major finding was that within the same hospital, policies and rules differed from one patient care unit to another. Some units had open visiting hours; others were restricted. The role of the parents varied. Even in units where parents were allowed to provide care for their children, the nurses seemed to have the authority to determine care options, i.e., "...caregiving tasks were available on a very individual basis, with specific tasks made available to certain mothers" (p. 28). All of the children in this study had developmental concerns requiring early intervention programs following discharge. However, none of the mothers were referred to such programs by hospital staff. Another deficit was that no mother identified a nurse as a source of emotional support. In spite of these apparent limitations, with few exceptions, the mothers described the nurses positively. They appreciated having the same nurse repeatedly. Mothers looked to the nurses as their primary source of information perhaps because they had limited contact with physicians.

Price (1993) sought to understand the meaning of quality nursing care to four parents of children who were hospitalized. By listening to and then analyzing their stories, she described a four-stage process. In the first stage, parents maneuvered to gain the nurses' time thereby opening up opportunities for the child, parent and nurse to know each other as individuals. The second stage addressed the process of knowing. The aim of knowing each other personally was to enable the building of a positive relationship between the nurse, the parent, and the child. Without this relationship (the third stage), the fourth stage of quality nursing care could not be achieved. To these parents, quality care was that care which focused on meeting the non-technical needs of the child and parent, i.e., responding to the need for information, diversion, socialization, sleep, and decreasing stress. They did not disregard the technical tasks of establishing and maintaining intravenous lines, taking temperatures, etc. However, efficiency in performing tasks was viewed "as a given from which quality could then be developed and delivered" (p. 40). Unfortunately, the parents described the care given as being technically focused rather than relationship focused. The focus by the nurses was the actions with the tasks rather than the interactions with the parents and children. In response to these findings, Price identified the need for nursing programs to include learning activities which would enable students to gain skills integral to establishing positive relationships with clients while they master the technical aspects of care.

Northrup (1993) reviewed the development of the self-care ideology in nursing practice. She cautioned that its sociohistoric limitations diminished its attractiveness. She noted the position taken by Illich (1976) that people's perceptions of their own competence to manage their health concerns were undermined by medical institutions. This was supported in the medical, sociological, and nursing literature with the conveyance of self-care as "giving care to oneself that ideally should be given by health care professionals" (p. 61). Inherent in these views of self-care were relationships of power. Promotion and support of self-care which included patient/parent participation were orchestrated by the health care system in terms of what served it. For self-care to be shaped from the perspective of patients, Northrup advocated a need for alternative power structures with different power relationships within the structures.

Darbyshire (1993) reviewed the literature tracing the historical development of parental involvement in pediatrics. He concluded that there has been "little or no attempt made to understand what living-in is like for either parents or for the nurses who work with them." He called for hermeneutic and dialogic research to study this problem.

The year was 1994. Molter called for health care systems to have an increased focus on the needs of patients and families. To facilitate this, she advocated viewing family members as participants rather than visitors, and patients and their families as units. Participation by family members included having them present during rounds so that they could provide information about the patient's response to treatments, receive information about the patient's prognosis, progress, and issues related to care, and assist with care. Molter stressed the need for nurses to educate families about the importance of their role. Included in their education would be maintenance of their own health. She did not, however, suggest that the family participate in planning care for the patient.

In another study, Jones (1994) noted from the literature that:

> ...even in the most progressive institutions, where family-centered nursing care is advocated, nursing and other health professionals do not always encourage parents' participation in their child's health care. When a child is admitted to an inpatient facility, nurses often neglect to emphasize the value of parents having a central role in caring for their own children, thereby communicating to many parents that their responsibilities to nurture their children have ended. (p. 81)

Believing in the benefits of family-centred care, Jones investigated the relationships among parents' involvement in care, the children's reactions to procedures and the children's level of activity while hospitalized. Her findings supported the assumption that the consistent provision of routine care, emotional nurturance, and therapeutic procedures by parents would facilitate greater cooperation and less distress for children during painful procedures. She encouraged nurses to assume the responsibility for providing parents with the information, guidance and encouragement needed to be caregivers within the hospital environment. She also recommended that nurses work toward a framework for family-centred care which included parents as members of the health care team.

Conclusion

Tracing the history of participation by parents in the care of their hospitalized children resonates with taking a journey through a landscape over time. The soil that gave rise to the landscape that would control parental care was seeded by West in 1851 (Spence, 1947) when his advocacy led to hospitals where pediatric illnesses could be treated scientifically. It was disheartening to read that his goal specified the treatment of illness, not children. Possibly that explains, in part, the tortuous path which had to be travelled by those who fostered parent participation, i.e., they had to struggle against a focus on disease rather than people. Be that as it may, the fruits of West's labour flourished and his goal was realized. However, the trees that bore the fruit functioned like a windbreak. They created a landscape in which the child was separated from the family. That landscape, empty of parents, remained essentially undisturbed for decades in spite of recognition in the early 1920's of the value of parent involvement as a contributing factor to illness recovery. What could have been the growth of a movement from illness-centred to child-centred to family-centred care did not take root. The seeding of a new landscape was delayed until the 1940's. Even then, attempts by Spitz, Bowlby, and Robertson to generate new growth were stifled by lack of fertile soil. Institutions were resistant to sampling new ways. Parents were viewed as interlopers to the hospital landscape until the late 1950's and early 1960's. Surprisingly, that is a view which continues to be nurtured. As recently as 1993, an occasional hospital was cited in the literature as having restricted visiting privileges. In 1995, I am familiar with a pediatric intensive care unit where parents are directed to leave while physicians conduct medical rounds. Barren patches can still be seen.

Even when open visiting hours became common, the landscape was not cultivated to support parents as participants. Part of the problem was that health professionals were not educated to work with parents as members of the health care team. They retained authority for children's care and they used it to direct the lay of the land. Consequently, when the seeds that gave rise to parent participation were planted, they were allowed to grow only in selected areas such as care-by-parent units or patient rooms designated as "living-in" rooms.

However, because landscapes are continuous, seeds get transported by various means to new topography. This happened with parent participation. Gradually, seeds took root in distant soil and parents were seen to be caring for their children in regular, in-patient units. At least, that was the surface view. On closer look, fences continued to mark the landscape. From my own nursing experience and from publications, I perceived that the foliage that was parent participation continued to struggle for sustenance against the weeds of control, lack of trust, and inadequate facilities. In response, studies were done in search of better methods. Reports of the work indicate that primarily two fields were surveyed, planted, and harvested. One contained parents whose children had chronic illnesses or were patients in intensive care units. The second featured parent participation from the perspective of health professionals, e.g., attitudes of nurses toward involvement by parents. Both of these fields are important and I do not downplay them. However, another view of the landscape reveals that the majority of hospitalized children are admitted to standard, in-patient units for treatment of acute illnesses expected to be of short duration. Surprisingly, few studies have been done with these families particularly from the viewpoints of the parents who should be the "key players" in child caregiving. Consequently, our knowledge of their positions on the landscape from their points of view is limited. If parents are ever to be integrated into the health care landscape, it seems reasonable that research needs to be done from their perspectives. This entails entering their landscape and viewing it from their positions. It involves understanding their experiences. To do that, we must hear their stories. In the next chapter, I describe the research method of narrative inquiry which enables us to centre on stories as a source of knowledge about the experiences of parents as participants in the care of their hospitalized children.

CHAPTER IV

Methodological Landscape For Inquiry

The Need for Narrative Inquiry in Nursing

"...I have not found the findings of academic research of much help in my work as a clinician" (Polkinghorne, 1988, p. xi). This is an alarming statement for professional practitioners who look to research as a means of informing their practice. In answer to this dilemma, Polkinghorne (1988) suggests that what is needed is research which has practice as its focus. One methodology for doing this kind of research is narrative inquiry. Studies done within the configuration of a narrative representation of human existence focus attention on existence as it is lived, experienced, and interpreted by people in a particular landscape (Polkinghorne, 1988). Such work has a high likelihood of being relevant to practice-based professions such as nursing. As nurses, we require a way of doing research which enables us to study the lives of people in relation to health (Sandelowski, 1991).

The research which I undertook, and which is reported in the following chapters, had practice as its focus; practice by parents in the hospital landscape. Specifically, I studied participation by parents in the care of their hospitalized children. Reports in the literature I reviewed regarding parental care in hospital settings "spoke" to Polkinghorne's concern about the applicability of research findings. For example, studies by Spitz, Bowlby, and Robertson in the 1940's and 1950's heralded the need in all institutional settings for care to be given by parents or consistent parental surrogates. In follow-up to that research, parents of hospitalized children were surveyed to identify what care they would like to give. The impact of the research has been disappointing because participation by parents has been slow to move beyond the delivery of basic care even though parents have been reported as saying they would like to do more. In searching for reasons for the delay, nurses' attitudes and organizational influences on parental participation have been examined. However, again, the research has not led to achieving the desired outcomes.

Recognizing the need for expanded parental involvement based on knowledge of child development, the desire by parents, and the demands of the health care system, I believed that information from the parents' perspectives could contribute to greater understanding about parent participation and, hopefully, subsequent changes in practice. An appropriate way to gain the information was by listening to, and interpreting parents' stories using the method of narrative inquiry. In this chapter, I describe the process of narrative inquiry used in this research.

Connecting Events to Create a Narrative

People live storied lives (Clandinin & Connelly, 1994). This is the premise for narrative inquiry founded on the belief that human experience is basically storied experience (Connelly & Clandinin, 1994). As a research method, investigators listen to the stories or narratives being told by those who experienced them. The researchers then write their interpretation of what they heard. Thus, the research narratives are restoried accounts of what was experienced (Clandinin & Connelly, 1994). The process whereby a narrative becomes a research narrative will be described but, first, it is important to understand what constitutes a narrative.

Structure of Narrative

A narrative is a gathering together of events into a meaningful story. Meaning is central to narrative.

> Narrative meaning is created by noting that something is the cause of something else. Narrative meaning is focused on those rudimentary aspects of experience that concern human actions or events that affect human beings...The meaning of each event is produced by the part it plays in the whole episode. The episode needs to include both some end point as well as the contributions that the events and actions made in bringing about or delaying the achievement of that end point. (Polkinghorne, 1988, p. 6)

Thus, a narrative is a story consisting of a series of events connected by temporality, continuity of subject-matter, causality, sequence, place, and plot. It is my intention to describe each of these characteristics. However, just as events are interrelated to form a story, so are these characteristics. Therefore, the descriptions will not contain clear boundaries. There will be overlap.

Temporality

In our everyday lives, our activities are regulated by the "ticking" clock. In this respect, we experience time as unidirectional; it is always moving forward. We attempt to make it precise by the assignment of numbers, e.g., minute, hour, date. However, time in the narrative sense is more than a numerical element. It is not located in a measured moment. Augustine (Crites, 1971; Polkinghorne, 1988) described time as a three fold notion that includes a present as past (we remember), a present as present (we attend) and a present as future (we anticipate). This representation of time as being multilayered depicts the temporal structure of human existence as a present which has evolved out of, while remaining connected to the past, and is tied to the future through sequence, continuity, and causality. In addition to the temporal connections whereby past, present, and future form a unity, we experience time as rhythmic regularities with highs and lows which, when examined retrospectively, can be seen to have a pattern. Time is also experienced as cyclical, e.g., we organize our lives around the seasons. Therefore, unity, rhythms, and cycles are depicted in narratives as components of temporality (Clandinin & Connelly, 1986a). The attribute of unity will be seen to be particularly notable in the parents' stories in my study.

Continuity of Subject Matter

> The principle of continuity of experience means that every experience both takes up something from those which have gone before and modifies in some way the quality of those

which come after. (Dewey, 1938, p. 35)

Temporal connections whereby events are located in relation to other events that have preceded it or will come after it are important features of narrative coherence. Also important is the continuity of subject matter. Human actions and the events that affect human beings comprise the subject matter of narratives (Polkinghorne, 1988). We can all recall an experience which seemed insignificant until a later experience occurred which was tied to the earlier experience and led us to remark, "I see now what led to this" or "At the time, it (the earlier experience) didn't seem to matter." As another example, Lynn, who was one of the parents in my study, commented in relation to her son's illness, "...in hindsight, it's been happening for three and a half months." Such reflections give meaning and significance to the continuity of subject matter.

Causality

The remarks cited in the previous section not only demonstrate continuity, they imply that one event had implications for a later event. In them, a subsequent event transformed a previous event into a cause. In narratives, cause means whatever produces an effect, result, or consequence. It can include events, people's actions, or other conditions (Carr, 1986). It can relate to the antecedents of a particular event that may never happen again so that predictability and generalizability are not expectations. In this sense, cause differs from the way it is used in the natural sciences where generalizability is sought, where a cause is a constant antecedent in support of universal laws and truth, that is, if A then B, where A is always necessary for B to occur (Beckstrand, 1978; Polkinghorne, 1988; Ryan, 1982). The lack of generalizability of cause in narratives is also apparent in the expressive use of causality. Polkinghorne (1988) gave the example of alphabetical letters on a page "causing" the reader to understand meaning in them. Causality here is contextual and individual. Another reader may or may not derive the same meaning. It depends on each person's experience and interpretation of that experience.

Sequence

The remark, "I see now what led to this" also refers to a sequence of experiences, in this case, situation-transformation-situation (Boykin & Schoenhofer, 1991; Carter, 1992). Sequence can also be depicted as beginning-middle-end. It is the characteristic which gives the narrative its special syntactic shape (Carter, 1992).

Place

Narratives develop in particular settings, refer back to other settings, and point to new settings (D. J. Clandinin, personal communication, July 15, 1995). The setting or the place in which events occur takes meaning from and gives meaning to context. As place changes in terms of structure, location, and/or ambience, so does the context and subsequently, the meaning of a narrative (Sandelowski, 1991).

Plot

Temporality, continuity of subject matter, causality, sequence, and place can be identified as the organizing operations for the events which comprise a narrative. Still required is the element which configures the events into a meaningful whole by connecting them thematically. That element is the plot. It is the patterning of events around a theme. It functions to transform a chronicle of events into a schematic whole by highlighting the contributions that each event makes to the development and outcomes of a story. The contributions are based on the significance and role of each event in relation to the other events and to the outcome. It takes both historical and social contexts into account (Polkinghorne, 1988).

It is possible for a narrative to have multiple plots as in the stories which are told in Chapter VII of this dissertation. In them, a plot gives meaning to the narratives by linking the various experiences together. The particular meaning of the set of experiences is dependent on the way in which they are linked together. It is possible for them to be connected differently, in which case, the plot would be different. The narrative, however, would still maintain coherence. The possibility of multiple plots necessitates a tolerance for ambiguity because, with multiple plots, come multiple meanings.

Conducting the Narrative Inquiry

"Nursing and nursing practice both construct and are in turn constructed by the context in which they operate" (Cheek & Rudge, 1994, p. 15). All nursing operates within nursing situations (Boykin & Schoenhofer, 1991). The situations are subjected to a multiplicity of influences often with the result that they are complex and unpredictable. A means of capturing the complexity, specificity, and interconnectedness of the situations is with stories (Carter, 1992). A method by which the stories can be reconstructed so that the knowledge inherent in them can become known is narrative inquiry.

Purposes of Narrative Inquiry

Narrative inquiry is one kind of qualitative research. It seeks to achieve greater understanding and meaning by describing and explaining phenomena experienced by people within particular contexts. Thus, research done in this paradigm can be descriptive or explanatory. My study contained elements of both types. In differentiating between the types, Polkinghorne (1988) described descriptive narrative research as an account of events or actions which are connected to form a unified story. The account is interpreted so as to understand the meaning of the events, their significance, and their value. Explanatory narrative research, on the other hand, proposes to explain through narrative why something happened. Here, too, events are linked to form a unified story. However, the purpose of this narrative account is to highlight the significance of particular decisions and events and the way in which they "caused" the outcome being investigated (Polkinghorne, 1988). The knowledge gained from narrative inquiry enables participants to anticipate (not predict or control) the possible consequences of actions which might be taken in the future.

As a process, narrative inquiry does not proceed from a formal theoretical framework. Boundaries are not defined in advance. As Clandinin and Connelly

(1986) explained, "...the unfolding of a telling narrative leads where it will and researchers must follow" (p. 381). This does not mean, however, that the research commences without a purpose. Indeed, it must have one because it is the researcher's intentionality that defines the starting and stopping points in the study of experience. However, as the researcher and participants work together to acquire meaning about a phenomenon, it is possible for the original purpose to be surpassed or even redefined as new, unexpected, but still relevant events and stories with different plot lines become apparent (Clandinin & Connelly, 1986; Gadamer, 1976; Mitchell, 1994). As Mitchell (1994) wrote, "Both parties are concerned about the subject matter and both experience a buoyancy in the transmission of meaning that leads them to places beyond their original horizons" (p. 227).

Framework for Narrative Inquiry

The process of narrative inquiry can be framed within a landscape of field, field texts, and research text (Connelly & Clandinin, 1994). The field is the situation, the events, the actions which comprise the story. An important aspect here concerns the relationship between the researcher and the field. The activity of the researcher can range from that of a nonparticipant listener to a participant observer (Clandinin & Connelly, 1994; Kirby & McKenna, 1989). Regardless of participation, the presence and role of the researcher in the landscape affects the way in which field texts are collected and hence, the way in which the story unfolds (Bogdan & Biklen, 1992).

Traditionally, in the field, the researcher collects data. This is true for narrative inquiry except with this methodology, the term field text is used to convey a narrative representation of the experiences as heard or observed by the researcher (Connelly & Clandinin, 1994). Central to the creation of field texts is the relationship between the researcher and the participant because all fields texts are selectively given to the researcher who, in turn, selectively chooses what is relevant from the information received. Therefore, field texts are not merely "raw data" from which to construct interpretations. They are also the products of a fundamentally interpretative process that is shaped by all who are involved in the inquiry (Carter, 1992; Gadamer, 1989; Mitchell, 1994).

Constructing Field Texts

There are a variety of ways in which field texts can be constructed. The researcher who assumes the role of a participant observer collects information and begins to interpret it in the setting (Woods & Catanzaro, 1988). Schön (1983) calls this reflection-in-action which is akin to thinking during practice (Connelly and Clandinin, 1986b). After leaving the setting, the researcher will continue to make interpretations. This is termed reflection-on-action (Schön, 1983) or deliberation (Schwab, 1978). It involves follow-up interviews with participants to probe more fully into specific acts which the researcher had previously observed the participants to be doing.

The process of deliberation can also be done by investigators who were not active participants in the setting. The researcher could have been a nonparticipant observer, or it is possible that the researcher was not an observer at all, in which case, the field texts are gathered in a variety of other ways. These can include oral histories, annals and chronicles, family stories, artifacts such as photographs and memory boxes, journals, autobiographies, letters, and conversations (Clandinin & Connelly, 1994). However, even though the researcher may not be present physically and making observations, she/he will be creating mental images (mental observations) as the stories are disclosed orally or through other means. The creation of the mental images are an interpretative process that will further influence the researcher's understanding and interpretations.

My role as a researcher could be described best as a modified participant observer. I did not participate in any nursing or parenting activities. However, because I was either in the child's room or within hearing distance of the room, I was able to anticipate that the parent needed to interrupt our interview and see to her (his) child. At such times, while the parent tended to the child, I was able to reflect on our conversation. Reflection-on-action also occurred in the research process during follow-up interviews in the parents' homes and by telephone.

Also included as part of field texts are field notes. These can be constructed in various ways. For example, they may take the form of descriptive memos, theoretical memos and journals (Bogdan & Biklen, 1992). Both memos and a journal entry related to my research are presented in Chapters VI, VII, and VIII.

Regardless of their form, all field texts are imbued with subjective interpretation. Because of this, Peshkin (1988) advises researchers, notwithstanding their reputation for personal integrity, to systematically identify and record their subjectivity throughout the course of the research. He says that in doing this, the aim is not to exorcise one's subjectivity, but to manage it by monitoring it, to be able to see where self and subject intertwine, to "consciously attend to the orientations that shape what I see and what I make of what I see" (p. 19). Acknowledgement of this subjectivity is not restricted to the field texts. It should also be recorded in the research texts so that the reader, too, will be aware of it. Examples of my subjectivity are acknowledged in the research texts.

Narrative Analysis

Field texts are reconstructed as research texts. In doing this, the researcher seeks the meaning of the narrative and its significance for others and for social issues. The field texts are analyzed for tensions, threads, themes, and patterns either within or across the various stories pertinent to the research (Connelly & Clandinin, 1994; Diekelmann, Allen & Tanner, 1989).

There is not a single "right" way to do a narrative analysis. Polanyi (1985) describes the use of adequate paraphrases as the unit of analysis. Labov (1982) presents a model for analysis of narrative interviews wherein the objective is to abstract the theme or point of the story from the total response of the participant. Agar and Hobb (1982) describe a model for analyzing narrative interviews based on local, global, and thematic coherence. Mishler (1986) outlines an analysis which is directed to the content of self-identity. Consequently, there are a variety of ways of conducting a narrative analysis. The procedures used depends on the intent of the inquiry. The process which I used is described in Chapters V and VII.

Constructing the Research Text

The outcomes of the analysis are presented in a research text. In narrative inquiry, the research text is jointly authored in the sense that it is neither solely the researcher's or the participants' reconstruction. Rather, the reconstruction is mutual because all of those involved have explored the origins and explanations in their interactions and in the narrative accounts as written, reviewed, commented on, and then rewritten (Connelly & Clandinin, 1986a; Mishler, 1986; Noddings, 1986). This raises the issue of voice in the text. The research text should capture both the participants' and the researcher's voices. However, a dilemma lies in how much voice to include. Too much leads to autocratic subjectivity; too little leads to technical objectivity (Clandinin & Connelly, 1994; Connelly & Clandinin, 1994).

Another issue pertinent to the writing of the text is signature. Because the researcher is not an objective by-stander or outsider in the investigation, it is expected that he or she will "be there" in the text. Signature then refers to the researcher's unique writing style. It is this uniqueness that others will recognize and associate with belonging to that particular author. Herein lies another dilemma. Too vivid a signature runs the risk of obscuring the field and its participants; too subtle a signature runs the risk of deception that the research text purports to "speak" only the view of the participants instead of a jointly constructed view (Clandinin & Connelly, 1994).

Ensuring the "Goodness" of the Inquiry

The nature and process of narrative inquiry raises the issue of how to judge its "goodness" or rigor. In contrast to a system of rules and procedures which govern research done within a quantitative paradigm, Noddings (1986) and Van Manen (1990) advocate fidelity to the spirit of qualitative work. Congruent with this, Guba and Lincoln (1989) suggest that qualitative research should be judged for trustworthiness and authenticity. Trustworthiness addresses credibility, transferability, dependability, and confirmability. Authenticity of research is seen in the interactions and outcomes of the work. The criteria which address these aspects are fairness, ontological authenticity, educative authenticity, catalytic authenticity, and tactical authenticity. In the following sections, I deal briefly with these criteria in terms of their meaning and their use in ensuring the "goodness" of my inquiry.

Credibility

Credibility refers to the accuracy, adequacy, integrity, coherence, and verisimilitude of the research (Guba & Lincoln, 1983; Hall & Stevens, 1991; Leininger, 1992; Patton, 1990; Polkinghorne, 1988). Research is judged as being credible when the participants read the descriptions and interpretations of the experiences in the report, and recognize them as their own. Other researchers and readers confirm credibility when they have an experience which they recognize as being like the experience reported in the literature (Sandelowski, 1986). Techniques which I used to achieve credibility included prolonged engagement, peer debriefing, progressive subjectivity, member checks (Guba & Lincoln, 1989), structural corroboration (Eisner, 1979; Guba, 1981; Patton, 1990), and consensus (Polkinghorne, 1988).

Transferability

Narrative inquiry emphasizes the study of phenomena within their natural setting with few controlling conditions. The findings from the study fit the field texts from which they are derived. This means that they are grounded in the life experiences studied. They reflect both typical and atypical elements. They are tied to the time and the context in which the study was done. Consequently, generalizability, i.e., the application of research findings to the population from which the sample was drawn (Burns & Grove, 1995) is not a criterion for goodness in qualitative research. This does not mean, however, that findings are restricted to the situation in which they occur. Instead of generalizability, narrative inquirers look for transferability from one context to another. This requires assessing the degree of "fit", i.e., the similarities and differences between the context of the study and the context for the desired application (Lincoln & Guba, 1985). Thus, transferability is always relative. It depends on the degree to which salient conditions overlap or match (Guba & Lincoln, 1989; Marshall & Rossman, 1989; Sandelowski, 1986).

The major technique used in this study to establish transferability was thick description, a term first described by Ryle and later elaborated by Geertz (Guba & Lincoln, 1989). Another procedure used to enhance transferability was purposive sampling (Baker, Wuest & Stern, 1992).

Dependability

Researchers using narrative inquiry are concerned with dependability or stability of field texts over time. However, because a context cannot be controlled, i.e., it cannot be suspended in time, shifts and changes are both expected and accepted. To achieve dependability, a record of shifts and changes must be kept so that outside reviewers can explore the processes used in the research, judge the decisions that were made, and understand the contextual factors that led to decisions and interpretations (Guba & Lincoln, 1989). The technique used in this study to elicit dependability was auditing as described by Guba (1981), Hall and Stephens (1991), and Sandelowski (1986).

Confirmability

The construction and analysis of field texts in qualitative studies involves subjectivity (Peshkin, 1988). Thus, the researcher remains alert for and strives to reduce bias in narrative inquiry, thereby engendering confirmability. Techniques which I used included prolonged engagement, member checks, and reflexivity (Hall & Stevens, 1991).

Fairness

The need for fairness arises because naturalistic inquiry is value-bound and value-situated (Guba & Lincoln, 1989). A role of the researcher is to seek out and honour values. However, this may not be an easy task because differing value systems may emerge from the various research participants leading to conflict over claims, concerns, and issues. The conflicts should be identified and communicated, opening the way for negotiation using member checks. If this is not done, the findings will be less authentic. Fortunately, differing value systems did not create conflict in my study.

Ontologic Authenticity

Ontologic authenticity pertains to the benefits that the participants gain from taking part in the research (Guba & Lincoln, 1989). They should acquire a greater understanding of their own experiences and an increased awareness of their personal contexts. The researcher will know that ontological authenticity has been achieved when the participants describe changes in their understanding of the issues being studied. It can also be demonstrated in an audit trail where entries which were recorded at different points in the research process reveal greater understanding and/or appreciation of the context by the participants.

Educative Authenticity

Advantages of participating in research should not be limited to a better understanding about personal experiences and situations. Participants should also come to recognize the constructions about the data made by others, and understand how the constructions are rooted in different value systems and how the different value systems evoke different solutions. This "knowing" represents educative authenticity. As with ontologic authenticity, educative authenticity is demonstrated through verbal description by participants and in an audit trail (Guba & Lincoln, 1989).

Catalytic Authenticity

A question which can be heard by readers of research is "So what?" Catalytic authenticity responds to this question (Guba & Lincoln, 1989). It is the criterion which relates to the extent to which action is stimulated and/or facilitated by the research. The type of action desired will, of course, depend upon the purpose of the research and its results. All of the stakeholders should have the opportunity to participate in determining the action to be taken. In addition, there should be follow-up at designated times to assess the outcomes of the actions and their merits.

Tactical Authenticity

The final criterion in this category is tactical authenticity. It represents an essence of naturalistic inquiry, i.e., the reciprocal interactions among the research participants including the researcher. It pertains to being empowered to act. Through member checks which enable participants to be informed and to react to descriptions and interpretations, the significance of their input is verified. Through their active participation, they are able to shape the focus of the research, its strategies, and consequently its outcomes. This is likely to invest them with an interest in what happens next and, for some, a desire to continue to be involved (Guba & Lincoln, 1989)

Various examples of ontologic, educative, catalytic, and tactical authenticity are evident in the narrative accounts. However, because including them here would necessitate taking them out of context and thus possibly obscuring their meaning, they will appear in later chapters.

Collaboration and Quality Control

Guba and Lincoln (1989) also discuss the value of the hermeneutic process as a means of quality control. In this process, data are analyzed very soon after they are obtained. The analyzed data are taken back to the participants for comment, elaboration, correction, revision, and expansion. Thus, the ensuing construction of knowledge emerges as a joint, collaborative undertaking. If the researcher-participant relationship is a trusting and open one, there are few opportunities for errors to go undetected or unchallenged. If the information is also subjected to continuous and multiple challenges from a variety of reviewers, quality is further ensured. The processes of collaboration and quality control which I used are described throughout subsequent chapters.

Conclusion

Polkinghorne (1988) expressed concern that academic research does not meet the needs of clinicians. This signalled the need for nurse researchers to use a methodology which generates knowledge capable of informing nursing practice. Narrative inquiry responds to this need. By listening to the stories which comprise a nursing situation and interpreting them to understand their meaning, knowledge important to nursing can be generated. By using techniques which involve the participants in the process, narrative inquiry is able to meet the criteria necessary for the work to be credible, dependable, transferable, confirmable, and authentic. Because the knowledge evolves out of the practice realm, it has direct relevance both to those who plan and deliver, and to those who receive nursing care.

Narrative inquiry was an appropriate research method for this study. By listening to the parents' stories, constructing both the narrative accounts (Chapters V and VI) to which the parents responded and the research account (Chapters VII and VIII), I gained knowledge which connects with my nursing practice and has implications for my teaching. I also spoke with the unit supervisor at the hospital involved, and changes in practice were initiated based on information from this study (Appendix D). In the following chapters, the narrative accounts and the research account are presented.

CHAPTER V

Exploring The Experiential Landscape

Entering the Landscape

The participants for my study came from four families: four mothers, one father, and four children. I met all of them initially on the pediatric unit at the Meadowfields Hospital[1].

The Meadowfields Hospital, at that time, was a general acute health care facility in a western Canadian city. The pediatric unit accommodated up to sixteen children ranging in age from newborn to adolescence. The children were admitted for a wide variety of health problems requiring nursing care. Their degree of illness was classified as moderate or less. Children who were critically ill were transferred to a different health care centre.

The philosophy of the pediatric unit promoted participation by parents in the care of their hospitalized children. A walk through the unit revealed the presence of parents in the children's rooms, the play room, the day room, and in the corridors. Posted in each patient room was a list of rules regarding unit routines and expectations of parents while they were with their children (Appendix C).

At the time that this study was done, the health care system in the province was undergoing massive budget cuts with reduction of staff and services. These changes had an impact on parent involvement in the care of their children

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[1] Meadowfields Hospital is a pseudonym.

at the Meadowfields Hospital. It was reflected in a comment by the unit supervisor who said to me, "When we first encouraged parents to participate in the care of their children, we did it because we felt that it was good for the children. Now we want them to participate for more selfish reasons. We need their help" (personal communication, March 11, 1994).

To access the families, I initially contacted the Program Coordinator for Pediatrics to determine the feasibility of doing the study at the Meadowfields Hospital. She was very supportive of the research indicating that it would be of value to nursing and specifically to them. The research proposal was subsequently reviewed and given ethical approval by the Research Ethics Review Committee, Department of Elementary Education, The University of Alberta, and the Research Steering Committee of the hospital where the research participants were recruited.

Potential participants were identified by the charge nurse on the pediatric unit using the following criteria adapted from those identified by Morse (1991): the parent (or parents) had a child who was an in-patient, the child did not have a known chronic illness which required repeated hospitalizations, the participating parent was at least 18 years of age, the participant spoke English, the parent's visits were sufficiently long that she/he could participate in the child's care, the parent was willing to critically examine the experience and her/his response to it, she/he was willing to share the experience with me, and the person had time to talk with me. It was not necessary that all of the parents participated in their child's care because they too could have had a story which bore on participation. However, as it turned out, all of the parents did participate in the care of their children.

As required by the Research Steering Committee, permission for the parents to participate was acquired from each child's physician. All participants were given a Parent Information handout (Appendix A) which they read prior to agreeing to participate in the study. At the time of our first interview, I checked that they had read the handout and asked them if they had any questions about it. Three of the parents had questions which I answered. Examples of the questions were: "Why is it necessary to get permission from the doctor?"; "When do you want to do the interview?"; "Where will the interview be done?"; "What will be done with the information?"; Who will read it?" They retained the copy of the handout. They also signed a consent form (Appendix B) of which they received a copy.

All of the participants fit the criteria at the time of selection. One child was subsequently diagnosed with asthma which is a chronic illness. However, at the time of admission, his diagnosis was uncertain. In addition, it was his first hospitalization.

All parents were interviewed twice. The first interview took place at the hospital to hear their stories during the children's hospitalization. This provided me with the opportunity to see the parent in the hospital environment. I saw how tired each of them looked. I watched them interact with the child in that milieu.

Although it was limited, I also saw each of them interact with the staff. Consequently, when I met with them later in their individual homes for the second interview, I was able to visualize the context from which they were speaking. The purpose of the second interview, which was done following the child's discharge, was to hear the parents' stories after they had time to reflect on their experiences.

The initial interview lasted from one to one and one-half hours; the second one ranged from one and one-half to two and one-half hours. All interviews were audio-taped. I transcribed each of them verbatim within two days of doing the interview. The transcripts and cassette tapes were kept in a locked filing cabinet except when I was using them. They will continue to be kept locked until they are destroyed in five years as directed by the Research Steering Committee.

From the transcripts, a narrative account was written and sent to the corresponding participant for review and comment. In the note that I included with the narrative, I emphasized that it was important that the account be an authentic representation of their experience, and that I hoped that they would feel free to criticize. I then talked to each parent on the telephone. Two of the five parents suggested changes and/or additions which were subsequently made. The remaining three agreed that the narrative account was an authentic representation of their experiences. I reiterated that it was important that the account be true to their experiences; that I hoped that they felt free to suggest changes, deletions, and additions. Each of them offered to reread it, but they again affirmed the authenticity and completeness of the narrative accounts as they were written.

Two of the parents asked about similarities and differences between their experiences and those of the other parents who participated in the study. In response to their questions, I wrote the letter which is presented in Chapter VI in which I compare their stories.

In keeping with the requirements for confidentiality, pseudonyms were used for the participants and their families, the staff, and the hospital. The record which identifies each participant's pseudonym is contained on one sheet of paper which is locked in a separate folder in a filing cabinet. It has not been shared with anyone else.

Constructing the Narrative Accounts

Constructing the narrative accounts began by analyzing the field texts. I started by reading each interview transcript in its entirety to get a general sense of the meaning contained within it. Following the initial reading, I read the transcript a second time As I did so, I recorded words and phrases in the margins which described the parent's experiences as a participant in the care of her/his hospitalized child. I followed the same procedure with the transcript from the second interview which was done in the parent's home. I then listed all of the comments from the margins on separate paper and subsequently clustered them into groups. Using the groups as an outline, I wrote a separate narrative account for each of the four families. The narrative accounts are presented in the following pages.

Monica's Story: My Construction

I Meet Monica and Brent

It was Monday morning about 10:30. Approximately two hours earlier, I had contacted Paulina, the charge nurse on the pediatric unit at the Meadowfields Hospital. She said there was a parent, Monica Hane, who was interested in participating in my study. Her fourteen month old son, Brent, was being treated for a respiratory problem. Prior to interviewing Monica, permission to include her in the study was acquired from the family pediatrician thereby complying with the requirement established by the hospital Research Steering Committee.

When I went into the unit, a woman was walking toward me accompanied by a toddler. The child flashed me a wide smile but when I spoke to him, he turned immediately to his mother and clutched her leg. I passed them, went to the nursing station which was close by, and introduced myself to the nurse who was there. The woman with the child overhead me, came over to me, and introduced herself as "one of the mums in your study". I felt comfortable with her immediately.

Our first interview was done in Brent's hospital room with Brent present. During the time that I was there, Brent was active and cheerful although he was wheezing audibly. He continued to maintain a distance between himself and me.

A month later, I saw them again at their home. It was a sunny morning with a wonderful sense of impending spring. The brightness of the day accented the comfortable hominess and the beautiful family portraits which decorated the walls. Although there was no clutter, the toys, a highchair and other accoutrements of childhood revealed that "little people" lived here. As Monica served coffee and cookies at the kitchen table, I noticed how much more rested she appeared as compared to when I had seen her last.

Brent was in his upstairs room having a nap when I arrived. He got up about fifteen minutes before I left. During the brief time that I saw him, he was exuberant with good health and no hint of a wheeze. He was active, laughing, and babbling his infant language interspersed with occasional English words. The distance he had maintained in the hospital was no longer evident. It was easy to see why, as his mother said, "the nurses loved Brent." He was captivating.

My Telling of Monica's Story

"I'm there for him. I'm there to do it for him." These statements capture Monica's beliefs about her role as the parent of a hospitalized toddler. During her son Brent's four day hospitalization, she was his primary caregiver. She did almost 100% of his care which included his usual daily care plus his special health care needs. Being able to do all of this was very important to her because, as she said, "When it comes to children, it (their care) is more than nursing care."

Brent's hospitalization was unexpected. He had, on the whole, been a healthy baby until this illness episode. On Thursday prior to his hospitalization, he had a fever. He was subsequently diagnosed with an infection which was treated with antibiotics. By Saturday, however, he had developed a cold which advanced to a more difficult respiratory problem. Monica took him to Emergency where some tests were done. They were inconclusive in that the physician was uncertain as to whether Brent's underlying problem was pneumonia or asthma.

While in Emergency, Brent was given Ventolin® by means of a nebulizer and a mask. A nurse prepared the medication and left Monica to give it without explaining how to do so. Monica described the experience as very frightening because she had never given Ventolin® nor had she seen anyone else give it. She was uncertain about the best way to hold Brent who was struggling vigorously, whether she could remove the mask during the treatment, or how she would know when the treatment was finished. She described it as "not being in control". However, in spite of her lack of knowledge and experience, Monica did not question the nurse's expectation that she give the medication. Indeed, she viewed it as part of her role. This was evident in her statement, "So when the nurse finally did come back, she goes, oh my goodness, because he was just hysterical and I'm trying to hold him down because I'm trying to do my job." In spite of the anxiety provoked by the lack of instruction, Monica was not critical of the nurse. She said that the Emergency Department was very busy. However, she suggested that it would have been less frightening to give the Ventolin® to Brent if the nurse had shown her how to hold him, stayed with her for a few minutes, and given her feedback that she was doing it correctly.

Back home again, Brent, Monica, and Vernon (Brent's father) spent a terrible night. In spite of the medication they gave him, Brent's breathing got progressively worse over the course of the night. Sleep was scarce for all of them. By seven o'clock on Sunday morning, Brent's breathing was "so scary" that Vernon took him back to Emergency. Monica remained at home with their older son, Darcy, until her mother could come to stay with him. By 10:00 A.M., Monica was at the hospital and the decision was made to admit Brent for treatment.

This was Monica's first experience with having one of her children admitted to hospital as an in-patient. Darcy had been a patient in Day Surgery several years previously. Her only other encounters with a hospitalized child were with her goddaughter, Katy, who as a premature baby was in a Neonatal Intensive Care Unit for three months. Monica visited daily during that period. Katy subsequently developed asthma and was hospitalized occasionally for asthmatic episodes. Through these various hospitalizations, Monica became aware of open visiting hours for parents. Therefore, when Brent was admitted, it was her expectation that she would stay with him full-time and provide his care. A potential restricting factor was that she worked part-time in the family business. However, she said that if it had been necessary, she would have negotiated her hours so that she could stay with Brent.

At the time that Brent was admitted to the pediatric unit, no information was given or sought by the staff regarding his parents staying until, in response to the nurse's question about Brent's sleeping habits, Monica said she or a family member would be there all the time. This was received positively by the nurse.

Although there was still no discussion about parental participation, expectations were posted on the wall in the room (Appendix C) and these were pointed out to Monica.

Monica fed, bathed, dressed, changed, and played with Brent in the hospital. She viewed these actions as a continuation of her mothering role. She had no input into the selection of food sent to Brent from the central kitchen. However, if it was not food that Brent would eat, she could get baby food such as applesauce from the kitchen on the unit. She also had food for him which she brought from home. The physician reassured her not to be concerned about his intake of solids. Rather, it was more important that he have a good fluid intake. Monica was not told how much fluid he should have but she felt that four or five eight ounce bottles a day would be adequate. This would be slightly less than what he usually took when he was well.

Monica participated in the administration of health care treatments which were neither familiar nor comfortable for her to do. She suggested laughingly that her discomfort was because she was "such a wimp". Regardless, she viewed the procedures as "something that had to be done", and that as a parent, she had an active role to perform. Consequently, she assumed responsibility for doing most of Brent's care from the beginning of their stay. Her participation was guided by "what had to be done", what she recognized as being her limitations based on knowing herself, what she felt was best for her child, and what alternatives were available. There was no discussion between Monica and the nursing staff regarding what care she would give.

By watching others and by doing, Monica learned new tasks such as giving Ventolin®, assessing Brent's breathing, and using a stethoscope to listen for crackling sounds in his chest. For example, she watched a nurse listen to breath sounds with a stethoscope. As she repeatedly gave Brent his Ventolin®, she "figured out" the most effective way to hold him. She did not receive specific instructions from the nursing staff. She also learned to do chest physiotherapy. A physiotherapist showed her how to do that.

I had an opportunity to see Monica give Brent his Ventolin®. The nurse brought the medication and put it into the nebulizer after which she left the room. Monica then gave it to him using the mask. Having done it many times myself, I could see that Monica was very adept and appeared confident. When it was finished, she turned off the air flow, placed a towel over Brent's chest and did a short treatment of chest physiotherapy. When I asked her how she learned to give the Ventolin®, she said, "After you do it a couple of times, you know how to give it, how to hold him." However, she did reiterate that procedures should be explained.

Although Monica could not conceive of leaving Brent alone in the hospital, she found it very hard to be present when painful procedures were done. She was aware of her limitations; of what would cause her to become upset. She expressed concern that her upset state would be communicated to Brent who, in turn, would become more distressed. Therefore, she appreciated the nurse in

Emergency suggesting that it would be better for her to leave the room while a sputum specimen was collected from Brent, and then returning immediately afterwards to comfort him. The nurse explained that, by waiting outside, Monica would not be cast in the role of "the bad guy." She was also grateful for the support given by the nurse who gave her a hug when she was upset.

On the pediatric unit, it was her choice to do his total care; she was not "pressured" into it. In relation to doing procedures such as the administration of Ventolin® and chest physiotherapy which Brent fought initially, she said:

> It's better for me to do something like that than a nurse because he's more comfortable with me and why upset him more than he is already. Because it's not good for his asthma so medically speaking, it's probably better.

Knowing that these treatments did not hurt him was an important aspect of being able to do them. She said that she was able to do treatments that did not hurt. However, she also said, "Things that I have to get used to, I can."

A procedure which Monica did not do was to take Brent's temperature even though she was accustomed to doing it at home. A nurse always did it in the hospital. When I asked Monica about it during my home visit, she said she hadn't thought about it; that a nurse would come into the room with the thermometer and say, "It's time." Monica would hold Brent during the procedure, but she did not actually do it herself.

Monica felt that she was a member of the health care team as opposed to being a "guest" or a "visitor" on the unit. She related several instances in which she negotiated his care and participated in decision-making. For example, the first night that Brent was in the hospital, he wouldn't settle. So Monica asked the nurse for Tylenol® which the nurse then gave. On occasion, Monica initiated having Ventolin® given earlier than scheduled when Brent was very wheezy. She said, "I would ask her (the nurse), is it time for his Ventolin® because he's really crackling. So they would come and check him." Another incident occurred when Brent contracted influenza while in the hospital. A physiotherapist came to do Brent's chest physiotherapy. Monica refused the treatment for Brent because he was vomiting persistently. She said, "We just couldn't get this under control." She felt that the treatment would exacerbate the situation. The therapist agreed with her concern and did not do it. Another situation involved Brent's discharge. Monica and Vernon were consulted by an intern regarding the advisability of having Brent go home. When they were unable to determine what was best, the matter was referred to the pediatrician who decided that Brent should stay in the hospital for another night.

The opportunity to participate in decision-making contributed to interactive care. This was evident in an incident which I observed in the hospital. A nurse had assessed Brent's chest sounds in response to Monica's request. As she finished, she murmured, "Um hum", and asked Monica if she wanted to listen. Monica did so using the stethoscope and said that she could hear the crackling. The nurse then went and got Ventolin® which Monica gave to Brent.

It was important to Monica that she continue to participate in Darcy's care during this period of hospitalization. She was able to do this with support from her family; her husband, her mother, and her mother-in-law. They also enabled her to meet her personal needs. For example, on the day that Brent was admitted, Monica had lunch in the hospital cafeteria while Vernon stayed with Brent. At supper time, when her mother was visiting, Monica went home, made supper, ate and went back to the hospital. Later in the evening, "Vernon spelled me off for half an hour so I could lie down because I was exhausted." She then stayed overnight and all day Monday. On Monday afternoon, when Vernon got home from work, he picked up Darcy from a neighbour's home, took him to Tai Kwon Do and then to the hospital. Vernon then stayed with Brent while Monica took Darcy home, prepared his supper, helped him with his homework, and had a shower herself. Then they returned to the hospital; Vernon took Darcy home; Monica stayed with Brent. Consequently, Monica was very tired.

One means of managing Monica's fatigue might have been to negotiate a schedule whereby a staff member would stay with Brent while Monica took breaks. However, even if this had been suggested by the staff, Monica said that she would not have felt comfortable leaving Brent with anyone other than a family member. She said that Brent had never been left with babysitters other than his grandmothers. Although it was infrequent, he had become upset when left with one of them. Consequently, she felt that, "If he was in the hospital, and I left him alone with a nurse, it would have just been disastrous." For her, to have left would have more stressful than relaxing. She said that even though she was tired, staying there was what she wanted to do; what she had to do for her own mental comfort.

Monica spoke very highly of the nursing staff. Just as she depended on her family for support through their help, she depended on the nurses for moral support through their caring, compassion, conversation, concern for her and for her son. They made her feel welcome. Although there was not a bed in Brent's room for her, she was given a mattress to sleep on. A nurse brought her extra blankets so that she would not be cold at night. The only negative event she identified as such involved a nurse who directed all of her attention to Monica and none to Brent. "And I didn't think that was right," Monica said, "Brent was the patient." Monica also commented on the help given by nurses who were able to suggest alternative ways of doing treatments. She related situations wherein a child's special habits were incorporated to make treatments less stressful. For example, one nurse suggested that Brent continue to have his soother during his Ventolin® inhalation. In response to Monica's query, the nurse reassured her that even with the altered method of administration, Brent would receive full benefit of the medication. Another nurse adapted the equipment so that it would not be necessary to wake Brent to give him his Ventolin® one night after they had a particularly difficult time getting him to sleep. Monica described this nurse as "extraordinary". Although Monica did not say so, it was my sense that she was considerate of the staff. She did say that she "didn't want to be a pain; to be a demanding mother."

If it was necessary for Brent to be readmitted to hospital at some future time, Monica would approach it in "exactly the same way." It would once again be made feasible through her support network. If Vernon was out of town at the time, she would receive help from her neighbours in addition to her relatives. However, she would prefer not to have to go back. She emphasized that this was not a reflection on the hospital, but rather she felt that there was nothing that could be done in the hospital that she could not do at home if she had the necessary equipment. She believed that would be preferable "because children do better at home."

In response to my request for suggestions to include in my teaching with nursing students, Monica told me several things based on her experience. She advised me that nurses should have understanding for parents even though the child is the patient. "The parent," she said, "is probably more stressed than the child is." Her suggestions included making it as comfortable for the parents as possible; letting the parents know that whatever they decide to do is okay; never making the parent feel guilty or that they are in the way; being willing to bend the rules. "But number one," she said, "is to make the parent feel welcome." She concluded her comments saying:

> Make it clear the minute the child is admitted that whatever you want to do, just let us know. If you want to stay, you're more than welcome, and if you want to go, just let us know

and we'll make sure that someone is with your child.

Janie's Story: My Construction

I Meet Janie and Penny

The winter of 1993/94 was an old-fashioned Canadian winter. It seemed as though one storm barely stopped before the next one began. The snow banks got higher and higher, and the streets more and more slippery. Falls were common that winter. It was because of a fall that I met Janie and Penny Kancet.

Janie was outdoors carrying her three year old daughter, Penny, when suddenly she found herself lying on the ground curved against a pile of snow. "It wasn't a hard fall," Janie said in a voice filled with wonder and puzzlement. But it turned out to be a significant fall because, in that fall, Penny's leg was broken. At first, it did not seem as though any injury had occurred to either of them. However, Penny would not stop crying. Nor would she let her mother remove her ski jacket or ski pants. When Penny's crying persisted, Janie became very concerned and decided to take her daughter to Emergency for an examination. There it was apparent to Janie that there was a problem when, with the removal of Penny's ski pants, her swollen leg was visible. So began a hospital stay of three and one-half weeks.

I was introduced to Janie by Paulina who was a charge nurse on the pediatric unit at Meadowfields Hospital. Paulina had approached Janie earlier, told her briefly about my proposed study and given her the Parent Information Sheets (Appendix B) to read. In accordance with the requirements of the

Research Steering Committee of the hospital, I contacted Penny's physician and requested permission to include Janie as a participant in my study. After receiving an explanation about the study, the doctor gave oral permission and subsequently wrote an order on Penny's chart enabling Janie to participate. A date was then set for our first interview. However, before we could talk, Janie called to say that she had laryngitis and although she was remaining at the hospital with her daughter, she doubted whether her voice would last for the duration of our conversation. Certainly, it was extremely hoarse.

When I first met Janie, I also met Penny. When I said "hi" to her, she immediately turned her head away from me and pulled a pillow over her face. I was to learn that this was a common response by Penny to strangers. Indeed, although I subsequently saw Penny on two more occasions in the hospital, it was not until I visited them in their home, that I realized what expressive, beautiful brown eyes she had. Until then, she had always covered them!

My Telling of Janie's Story

Eight days after I met Janie initially, we finally had our first long conversation. I arrived on the pediatric unit about midmorning. Janie was sitting at Penny's bedside. Once again, Penny responded to my greeting by turning her head away. Janie told Penny that she and I were going to stay in the room and talk. She gave her a choice of things to do. Penny chose to watch a video on TV. The television provided a barrier between us. Towards the end of our interview which lasted about seventy-five minutes, Penny interrupted with a request for books. She continued to ignore my presence.

Hospitalization was a new experience for Penny who had never been a patient before. Janie had some exposure to children in hospital several years previously when her older son was admitted first with croup and some time later for suturing of a deep cut at the corner of his mouth. Each of those stays was about three days long. Although Penny's stay was to be much longer, those initial experiences prepared Janie for this hospitalization in that she knew that parents could stay all the time with their child, and that they could be involved in the care. The one difference she recalled was that on those other occasions, no bed was provided. Parents had to sleep in a room separate from the child. This time, there was a bed so that she or her husband could sleep in Penny's room which they chose to do for the first eleven nights of their daughter's hospitalization.

Penny's fracture was treated with a Steinmann pin and traction. She was not able to get out of bed. Also, she was confined to lying on her back although she did manage to turn on to her side on occasion. The pin was removed three and one-half weeks after her admission; a unilateral hip spica cast was applied and Penny was discharged.

In the initial phase of Penny's hospitalization, she experienced pain which was often related to muscle spasms. To control the pain, she had an intravenous (IV) morphine drip. The IV also provided her with fluids. While she was having the morphine, her appetite was poor and she had a problem with constipation. She woke up frequently during the night either with pain, or because she had kicked off her blanket and was cold.

Her parents were involved with her care from the beginning of her hospitalization. This included staying with her when any procedures were done such as x-rays. This was important for Penny because of her shyness, and also because she was afraid that whatever was done to her would cause pain. Mitchell, her father, stayed with her the first two nights. After that, Janie stayed overnight until the IV was discontinued and Penny was able to sleep through the night. This was eleven days into the hospitalization. Meanwhile, the demands at home did not stop. Laundry, housecleaning, and grocery shopping still had to be done. The boys played hockey and required transportation to and from arenas. It fell to Mitchell to do the chauffeuring. Because of his job and the responsibilities at home, there were times when Janie was at the hospital for thirty-six hours before Mitchell could come and give her a break. She became very tired and, not surprisingly, she got sick with laryngitis. However, even though she was ill, she continued to stay at the hospital with her daughter during the day. It was an advantage that she was not employed outside the home because she would have had to arrange for time off work.

Janie's increasing fatigue, the family's disrupted home life together with Penny's improved comfort level and uninterrupted sleep during the night led to Janie and Mitchell stopping their overnight hospital stays. Janie said, "We sort of realized that we just couldn't go on like that." However, that was a difficult transition for them. Janie said that she worried about Penny when she wasn't there. "When we're not staying the night, you'll sleep a certain amount of time and then if you, if you wake up, forget it. You hope she's doing okay." To bridge that transition, Mitchell would get up at 6:00 A.M. to be at the hospital by 7:00 A.M. before Penny was awake. Janie would get their two sons off to school, and get to the hospital about 8:45 A.M. Mitchell would then go to work. Once they felt assured that Penny was alright in the morning without one of them there, Mitchell stopped going in so early. A disadvantage of this was that they did not see the physician who made his rounds about 7:00 A.M. This meant that they did not get progress reports on Penny unless they called his office. They also did not see the night nurses for information as to what kind of night Penny had.

Going home at night did not diminish the demands on Janie's time. She continued to spend long hours at the hospital. Penny would have an afternoon nap which had not been her routine at home. Consequently, she would not settle to sleep until late in the evening. As a result, it was usually 10:00 P.M. before Janie got home.

Penny's hospitalization was also hard for her brothers, nine year old Charles, and six year old Kevin. They visited at least once a day. After Penny's IV was discontinued, Janie would drive to their school occasionally to pick them up. They would go back to the hospital with her. Kevin would find things on the unit to amuse him, but Charles was often bored. Janie said:

> He realizes it's hard for her, but he still, after school, he'd rather go to a friend's place. But we just feel that we've

> really used our neighbours in terms of dropping these kids off after school. You just can't ask them anymore. It's too much. Because it interrupts their dinner by the time my husband picks them up.

Janie assumed most of Penny's care very soon after her admission. As I mentioned before, Penny is very shy. She objected to having the nurses do anything for her. She would cry, "You do it, Mummy, you do it." So Janie learned to help Penny eat in a lying position, bathe her in bed, give her a bedpan, change the bed with her in it in traction, and entertain her for hours. She learned how to do the physical care by watching the nurses, rather than by having any direct instruction. It was not easy for her to do it at first. She said, "The IVs were what bothered me the first while and so did the pin in her leg. So the first couple of days, it was hard. I felt so guilty." It was also difficult to lift her at first to put her on a bedpan or to change her sheets. "She had such pain. You want to cry every time she cries but it had to be done."

The pediatric unit was very busy when Penny was admitted so Janie did not have a tour of it. She found out about the unit routine, regulations regarding visitors and parent involvement in the child's care by reading a poster (Appendix C) on the wall of Penny's room. She gradually found out where things were by following the nurses and seeing where they got supplies. The short staff rotations created a problem in that different nurses did not know what Janie had been told. Although she said that nurses were always willing to show her where to find things if she asked, she did not necessarily know what to ask for because she did not know what was possible. For example, she was not aware that Penny's hair could be washed in bed until sometime after Penny's admission when a nurse asked if her hair had ever been washed. It was then that Janie found out that there was a special tray that enabled hair to be shampooed in bed. In the meantime, Penny's hair had become so matted in the back that a large snarled piece had to be cut out.

While Penny was on the morphine drip, she had a problem with constipation. A stool softener was ordered. Janie did not recall the name of it but she vividly described the difficulty she and the nurses had trying to get Penny to take it. Eventually, a nurse was able to get a less distasteful one ordered. Janie assumed the responsibility for determining when Penny needed the medication and informed the nurse. Penny also had a sedative at night once her IV was stopped. Although Janie did not know the name of the medication, she knew that it was to help her daughter sleep. Either she or Mitchell would give it to Penny after the nurse brought it to them. As the time approached for Penny to be discharged, she fell asleep one night without having the sedative. Janie suggested to the nurses that they see if Penny could do without it, and it was subsequently discontinued.

The nurses maintained responsibility for managing the IV although Janie would note the level of fluid in the buretrol and notify the staff when it was getting low. Janie also observed it closely at night so that the beeping noise did not occur and wake Penny.

Noise was a problem. It was particularly noticeable in the evening and during the night. Common sources of noise were the beeping of the IV infusion pump when the fluid level was getting low or there was a problem in the system, the beeping of the cardiac monitor which Penny had during the time of the morphine drip, and other patients in the room.

Once Penny's IV was discontinued, she could be moved in her bed into the playroom. Penny and her parents looked forward to that because there would be different things to do plus it would provide a change of scenery. They did encounter a delay of three days after the IV was stopped until the physician wrote an order allowing Penny to go to the playroom. By then, the recreational therapist was on holidays for a week. However, before she left, she gave Janie keys to the cupboards where toys and supplies were kept. They were able to use these while the therapist was away. The therapist also took music and videos to Penny's room for her entertainment until she could go to the playroom. Janie said that helped because keeping Penny occupied became the greatest challenge of the hospitalization once Penny adapted to the traction and was pain free.

Penny did not like the hospital meals very well. Fortunately, a nurse had told Janie, "She's not on a restricted diet so you can bring in whatever for her. You can bring in her fruit and her cheese and whatever she likes." So Janie kept fruit and cheese in the refrigerator on the pediatric unit. She would get buns from the hospital cafeteria. Occasionally, Janie would have her own meals in the cafeteria. However, she worried when she was away from Penny because, if Penny needed anything, she would not call the nurses. Therefore, Janie was hesitant to leave her. Also, eating in the cafeteria became expensive plus the food was repetitious. However, having sandwiches from home for lunch and dinner was equally boring. Although it was never made clear to Janie what privileges were extended to her, she began to bring her own tea bags and to make tea for herself on the unit using the tea kettle that was in the kitchen. It seemed to be acceptable because no one told her otherwise.

Janie talked about her reasons for doing most of Penny's care. Although the reasons were all interrelated, the primary one was for Penny. She said, "That was my daughter there. I just felt I was helping out and taking good care of her." Helping the staff was also very important. She mentioned several times how busy they were, e.g., "You just can't expect the nurses to do it, do everything because they just don't have the time. And I don't know if they ever did, but they certainly don't have it anymore." She also described it as her nature to do it. She said:

> I'm just the kind of person, if I can do it myself, I'll do it myself. I know there were other parents who would run to the nurses first, but I know how short staffed they were and I just, if I could do it, why bother them...You're here to get well, not to be served and, I mean, when you absolutely need somebody, you call them.

Another reason was that the nurses depended on her. One said to her, "I feel really bad but I know you're here and you do everything. I'm really glad you are here." So, in being involved, she helped her daughter and the staff while being true to herself.

Janie said that she maintained her parenting role in the hospital. She identified several factors that she felt had enabled this. She was there all the time. The staff did not have time to do everything. The staffing rotations which were limited to two to three days in length meant that continuity of personnel was interrupted so that nurses did not get to know a child well enough to take on a parenting role. Finally, she said that some nurses just come in to do their job; they do not take time to talk and get to know the children.

Four weeks after Penny's discharge from hospital, I met Janie in her home. It was a beautiful, sunny, warm afternoon. The smell of spring air coming in through the open patio doors plus the aroma of freshly baked gingersnaps contributed to a comfortable atmosphere. The orderliness of her home, Janie's casual, well-groomed appearance, and the image of Penny playing with her toys on the living room floor suggested to me that they were managing well.

Early in our conversation, I asked Janie to think back over the hospitalization and tell me the first thought that came into her mind. "Boring," she said. She went on to talk about the need to get out, to have a change of scenery. She said, "We had to get out. We were just absolutely going crazy." She welcomed going to pick up the boys from school because that was an hour's outing. To go home and do housework was a welcome change. One night, she went to her son's hockey game which she said, "felt good." However, even though getting out was a welcome relief, she said she always carried the feeling that she should be back at the hospital. In spite of that, though, she remarked that if she had to do it again, the one thing she would do differently is to get out once a day. She said that in hindsight:

> What I should have done is gone and exercised just because of the stress and boredom. I don't think it would have been as bad if I had done that. She (Penny) would have been fine, you know. She would have lived through it.

The transition from hospital to home went well for them. Penny was adept with her wheelchair including getting herself out of her it safely (which came as a surprise to her mother when Janie found her on the floor one day unexpectedly!). She was able to assume a variety of positions; on her back or abdomen on the floor, upright in her walker, and a modified sitting position in her wheelchair. She occupied herself much better than when she was in hospital. Janie managed well with the cast care. On discharge, the staff did not review this aspect of care with her, but they did provide her with an instruction sheet. This, coupled with her own experience of having a cast herself when her arm was broken, seemed to have prepared her well for this phase of Penny's recovery.

During my visit with them, I noticed another change. When I arrived, Penny did not acknowledge my greeting. As at the hospital, she ignored me.

However, as the interview proceeded, she eventually maneuvered her wheelchair very skilfully up to the dining room table where Janie and I were talking. There she played with puzzles and made comments to her mother some of which seemed to be meant for me. She also began slowly to make some eye contact with me. Just before I left, I mentioned that I had never seen a little girl walk with a walker. I asked her if she would show me how she did it. Instead of withdrawing as she would have done earlier, she immediately asked her mother to help her get up and, using her walker, walked across the room. She was amazingly mobile given the bulkiness and weight of her hip spica cast. She also seemed comfortable and content.

Lynn's Story: My Construction

I Meet Lynn and Gary

Lynn and her twelve months old son, Gary, were the third set of participants to join my study. I first met Lynn when Paulina, the charge nurse, took me to Gary's room on the pediatric unit and introduced us. At the time, Lynn was standing at the counter just inside the door. She was eating a sandwich. It was about 3:00 P.M. She spoke in a low voice. She looked tired and sounded tired. Gary was being rocked by a woman who looked like she might be his grandmother. The drapes were drawn and the room was dark. Gary was crying softly so I didn't go over to see him. It was not a convenient time for Lynn to talk with me so we arranged to meet at 6:00 P.M. that evening.

Later, when I returned, Lynn and her husband, Paul, were in the hall pushing Gary who was in a stroller. The older couple, who were Lynn's parents, had left. Gary looked very sick. His eyes were heavy and he was listless. He had intravenous (IV) fluid infusing into his foot which prevented him from standing or walking. When anyone approached him, he reached for his mother, buried his face in her chest, and cried.

When I went to their home three weeks later for our second interview, I saw a very different little boy. Those eyes that were so sick looking in the hospital were now a beautiful, clear blue. I was struck by the beauty of his eyes. Although he was cautious around me at first and wanted to keep his mother within sight, he soon relaxed, made eye contact with me, and brought things to me. He played (and fought!) actively with the dog, demonstrated a hearty, albeit selective appetite, and appeared to have recovered fully from his earlier illness. He was charming.

Lynn, too, had changed. She looked rested and relaxed. Her home was comfortable and casual. Toys and crafts were scattered throughout. Barriers were visible at the bottom of the stairs leading to the second floor and on the bathroom door. Otherwise, Gary's playspace included all of the main floor. While he played, Lynn and I sat in the kitchen and talked at length.

Lynn's Story: My Telling

Gary's illness seemed to come on suddenly with a high fever lasting two days. In retrospect, though, Lynn realized that he had been sick on and off for the previous three and one-half months with a croupy cough and ear infections which were treated with antibiotics. This time, however, chest x-rays revealed a shadow around his lungs which was diagnosed as pneumonia. He also had some diarrhea but this stopped before he was admitted to the hospital. In relation to the pneumonia, the physician decided that the treatment should be IV antibiotics which required hospitalization. Lynn said he told her that "the pneumonia was not serious, but it needed to be fixed."

This was Lynn's first experience with having a child hospitalized. Gary had a circumcision in Day Surgery at a different hospital when he was eight days old. Being that he was in for only a few hours that time, Lynn did not draw any parallel between that hospitalization and this one. She said that taking him to Day Surgery more closely resembled taking a child to Emergency than having him as an in-patient on a hospital unit. A notable consequence of this experience, however, had to do with lack of education about post-operative care. Lynn had not been told that there was a possibility that bleeding from the circumcision site could cause the penis to be stuck to the gauze which in turn could stick to the diaper. As a result, when she changed Gary's diaper for the first time after the circumcision, the pull on the diaper caused the gauze to pull away from the operative site resulting in bleeding. Ultimately, Gary had to be taken back to Emergency for cauterization to stop the bleeding. Lynn's mother, who is a nurse, subsequently suggested an alternative way to care for the circumcision which Lynn implemented. Based on this experience, Lynn remarked that if she has another son, she will look after his circumcision using her mother's method rather than the one advocated by the staff in Day Surgery.

In relation to her experience at Meadowfields Hospital, Lynn said she was not familiar with the policy regarding parental visiting and participation on the pediatric unit. When the physician called her to say that Gary should be admitted, she asked him if she would be able to stay. She could be there all the time because she was not employed outside of her home. Paul, on the other hand, could only be there in the evenings because of his work. He would also have to care for their dog who was at home.

The doctor told her that he thought she could stay; that they would give her a mattress to sleep on. Therefore, she went to the hospital prepared to remain with her son throughout his hospitalization. When they arrived, she saw many parents on the unit. She said that she was surprised by that.

At the time of admission, a nurse told Lynn that they would get Gary settled first and then she would show Lynn where everything was. Because of that, Lynn felt comfortable later in reminding the nurse to give her an orientation. The nurse showed her where the diapers, fluids and food were kept. Although the nurse didn't explain anything regarding expectations about parents participating in the children's care, Lynn assumed that because she was shown where the things were, she was expected to feed and change Gary. Besides, she would be staying there and she was accustomed to doing these things for her son. Therefore, it didn't seem necessary to ask about it. The nurse also showed her where the showers were and got a bed and pillows for her. Lynn was told that the food on the unit was only for patients but that she could buy food for herself in one of the hospital cafeterias.

Part of getting Gary settled included starting an IV so that he could be given antibiotics via that route. Lynn wanted to be with him while the procedure was done. However, the nurse told her:

> No, we have the room all set up and it's better if you don't come in because then you're going to look like one of the bad guys standing there letting us do this to him. So, if you just let us bring him to you when it's all done, he'll be happy to see you and he'll be more comforted.

Lynn said she was feeling so tired and discouraged that she just said, "okay, whatever."

Lynn had arrived on the unit in a tired state. Gary had slept poorly during the two nights prior to his admission which was contrary to his usual sleep patterns. Consequently, his parents had also not had much sleep. Unfortunately, the sleep disturbances continued as Gary was very restless that first night in hospital. In addition, Lynn felt responsible to ensure that Gary did not pull out his IV so she tried to remain alert to his movements even while she tried to sleep. She said, "So I have to be really fast. So the second I hear him waking up, I throw the side of the crib down and grab him." Their initial sleep lasted only an hour after which Lynn spent most of the night rocking Gary. About 5:30 A.M., his IV came out. In trying to reconstruct what happened, she recalled, "He inched his arm out of the IV by pushing against the blanket that I was holding him under, which leads me to believe it wasn't very secure in the first place." Unfortunately, it was necessary to restart the IV. "My heart sank when it dislodged, not to mention all the panic I felt when I saw all the blood."

As with the first IV start, Lynn did not go into the room where the procedure was being done although she would have preferred to. In contrast to the first IV, the staff had difficulty starting the second one. Lynn could hear Gary screaming as she waited outside. When they finished, Lynn took Gary into bed with her. She felt that was the only way they would get any sleep and they were both exhausted. The nurse told Lynn that it would be alright to do that although a different nurse had told her earlier not to. With Gary in bed with her, they slept for about two hours. Later in the afternoon of that day, Lynn was able to have a fifteen minute nap.

In terms of Gary's care, Lynn said that she did his regular care and the nurses did the medical care. She described the medical care as consisting of starting the IV and monitoring it, measuring and giving the medications, taking temperatures, and weighing diapers. In response to a nurse's instruction, Lynn kept track of how much Gary ate. She also kept the used diapers in the room until the nurse had weighed them. Lynn said that she could not have started the IV, given the IV medications, or measured the medications, but she thought she could have done the rest of the medical care. In particular, she would have liked to have taken his temperature because he got so frightened when strangers went near him. "He probably would have taken it better if it was me doing it," she said. However, she did not suggest that she do more because she was uncertain about the nurse's expectations regarding her role. She felt it would have been helpful to discuss what each of them could and should do.

Lynn gradually assumed some responsibility for monitoring the IV. The infusion pump which was being used to regulate the rate of flow displayed the pressure within the vein into which the IV was flowing. Lynn noticed that it fluctuated according to Gary's movements and position. She asked the nurse what the numbers meant and what the numbers should be. The nurse explained them to her after which Lynn then tried to ensure that Gary maintained positions that contributed to an optimal pressure level. Lynn also watched the level of IV fluid in the buretrol. On one occasion when she was walking in the hall with Gary in a stroller, she noticed that the fluid level was getting low. Rather than wait until the machine beeped indicating the low level, she stopped at the nursing station where the nurse refilled the buretrol.

The beeping of the IV infusion pump was a source of stress for Lynn. When it sounded, she felt pressured to find someone to attend to it immediately because, usually, she did not know what the problem was. When she did, she felt that she was not allowed to fix it, e.g., putting more fluid into the buretrol. It also created feelings of ambivalence for her. Although she appreciated that it was a safety feature, the beep was an irritant particularly during the night. Lynn talked about her experience the first night when the beeping occurred repeatedly.

> And it just kept beeping for one reason and another and he was sleeping and I didn't want him to wake up. And here I am running down the hall trying to find someone to come and shut it off...Well, it went off three times and this nurse, this is the middle of the night again and I'm hoping he's not going to wake up, and she kept coming in and just shutting it off. And the last time she came in, I said, well, this alarm went off three times now in a short amount of time. And she said, well, I'll tell maintenance on the day shift and they'll have to fix it or something. And I (Lynn) didn't know anything about what was wrong. And so, the nurse that came in the morning, she fixed it in one second. She said, oh, there's too much liquid in there. She turned it upside down and it was fixed.

Lynn wondered if the night nurse was aware of problems like this and how to correct them. She also recounted an incident that was helpful in relation to the IV.

> And the younger nurse told me; it was quite considerate of her; she said, well, this medication's going to have gone through in about an hour and this was when he was having this really restful nap. She said, it's going to beep so if you want to, she said we have a patient coming out of OR, we're

> going to be busy so I'll try and be here but if I'm not, when it beeps, you can just push the orange button; stop or hold or whatever. And she said, come and get us right away.

This gave Lynn some sense of control.

Lynn expressed concern about Gary's experiences with having the IV started. Until this hospitalization, he had been a very sociable child with no fear of strangers. She said, "He loves people. Um, he plays a little shy boy; he hides. But that's more of a game, you know. But he's very sociable. So I'm surprised that he's doing that." This latter comment was in relation to the very strong, negative reaction that he demonstrated to all strangers within twenty-four hours of being in hospital. Lynn attributed this in part to his illness, but she felt the major factor was the pain he experienced when the IV was started. Because of his emotional responses, Lynn felt it was essential that she not go home and leave Gary. She also felt that to prevent him from pulling out his IV, someone needed to be there with him all the time. She said that it was not possible for the nurses to be able to do that; they were too busy.

Although Lynn wanted to stay with Gary and believed that it was important for her to do so for his emotional and physical comfort, it created stress for her. There was also the pressure of feeling that she must watch him constantly to maintain the IV. This made it difficult for her to leave the room. She was able to have a shower and breakfast while Gary slept following the administration of a sedative. Otherwise, she had to wait for a family member to come in to relieve her so that she could have a break and attend to her own personal needs. For example, when I first met Lynn, she was eating a sandwich. That was her lunch and it was three o'clock in the afternoon. She was eating at that time because that was when her parents came. Her father had gone to the cafeteria and had bought a sandwich and pop for her. She thought that the cafeteria stayed opened until 10:00 P.M. so that she would be able to go later to "pick up something (for supper) while my husband's here." In relation to staying in the room hour after hour, she said, "It was stressful. Yes. It was stressful, tiring."

Lynn described a sense of vulnerability which she attributed to the stress of having a sick child coupled with her uncertainty regarding the nurses' expectations about her role as differentiated from their role. She said she did not want to "bother them (the nurses) and have them get mad at me. Or offend them." However, she was concerned that she had done that in, at least, one instance. She related:

> One of the nurses had taken his temperature in the ear. And then the next one that came in took it under the arm saying that you're not supposed to take it in the ear under two years old because it's not as accurate. So then this new nurse came in with the ear temperature thing and I said, oh, aren't you supposed to use the arm one for under two years old? So I guess I offended her by questioning her. She said,

> well, if you don't want me to use it, I'll go get the arm one. And I said, no, no, I'm just asking cause I'm hearing different things here. But she was obviously offended.

Her concern about this incident was not about the most accurate way to take her son's temperature, but rather the possible negative repercussions that could result. She said that she did not want to offend anyone, "because (even) if you say that it's not going to happen, if you, if somebody gets their feelings hurt, I think it's natural for them to have some resentment."

Lack of role clarification also exacerbated Lynn's worry about offending someone. She said that she did not approach a nurse to negotiate breaks for herself because:

> You don't know what your place is; you don't want to offend anybody and I figured that's why I was there; that's what this new way is all about. That the parent be there to give the child all the care and the nurse only does the medical part.

In relation to what her place was, Lynn said that she felt comfortable asking questions until the incident about the ear thermometer occurred. After that, she was reluctant. She was, therefore, very grateful to a nurse who, unasked, provided Lynn with some relief.

> The nurse, I don't remember any of their names, but the nurse that came on on the last day we were there was fabulous. She's the only one out of all the nurses. I asked

> her, can I take him downstairs so I can go get a coffee or whatever, and she said, I'll take him for you. She's the first one that offered the whole time I was there. And she held him even though he screamed and he cried. She sat in the rocking chair with him. And I thanked her for that. And she also is the only one who took the initiative in wanting to change him. I ended up doing it, but she offered. She was right in there, okay, I'll change him. She was right in there. Nobody else did that. I guess that was partly why I was there because they don't have time to do that. But I really appreciated that nurse.

Lynn added, "(when the nurse) started changing his diaper, I almost felt bad. I didn't want to take up her time. I said, oh, I'll do it. I'll do it." Her concern about the nurses' time was also reflected in a statement that she felt that asking a nurse to stay with Gary (so he wouldn't pull out his IV) while she went to the bathroom was imposing on them.

In response to my query, Lynn confirmed that it would be helpful for the parent and nurse to discuss the plan of care; what needs to be done, what the parent will do, what the nurse will do, and a flexible time frame for doing it. In this way, expectations would be clarified and there would be opportunity for the parent to have breaks. However, Lynn expressed concern that the heavy workload for the nurses and the nature of their shift rotation would make it difficult to negotiate a plan of care with each parent. She noted, "I don't think we had the same nurse for two shifts." She felt that it would be too time consuming for a new nurse to have to read the plan of care that had been negotiated with each individual parent.

Lynn said that she was very tired. She described the fatigue as overwhelming. Because of that, she wondered if staying with a child overnight is a good thing. She said that the only way to have gotten sleep would have been to go home. However, she would not have felt comfortable going home at night and leaving Gary. She reiterated that the nurse could not be there all the time and therefore she would have been concerned that he would stand up and his IV would come out of his foot. She said, "I was told he was not allowed to stand up. Try explaining this to a twelve month old." She was also convinced that a child suffered if a parent was unable to stay because the child did not have the physical contact he needed. In addition, a child did not understand what he was experiencing so he would be even more fearful if his parents were not there. She said that patients needed more than the nursing staff to care for them.

We talked about a cuddler program which has been introduced into some hospitals. Lynn thought that if this resource had been available, she would have felt comfortable leaving Gary for a couple of hours because someone would have held him and rocked him. "That's all he would have needed is somebody to hold him." She felt that would have enabled her to go into an empty room and sleep or read; it would have given her a break.

Gary was in the hospital for approximately forty-eight hours. Although Lynn was eager for him to go home, she had hoped that his IV antibiotics would be discontinued and he would be kept in hospital for a period of observation afterwards to ensure that he had recovered sufficiently to be discharged. She told the interns who saw him that she would prefer to stay another day than to take him home and have to come back.

> This doctor kept saying, well, you'll know within twenty-four hours if it's going to come back, then you just come right back here. And I stressed that I don't want him poked again, that I would rather leave the IV in. So I stressed that. And the response I got was, well, you'll know in twenty-four hours after you go home.

Lynn felt that the first intern who saw Gary regarding discharge seemed knowledgable about his condition, but he wanted a more experienced doctor to see him. However, the second doctor (whom Lynn had never seen before) did not instill confidence in her regarding Gary's readiness to go home. He seemed to think that the primary problem had been diarrhea and his main instruction was that Gary should not have milk. He treated the pneumonia as though it was secondary, not addressing her question when she asked him about it. At home, she was very concerned about Gary. She checked him often but the only problem he seemed to have was unsteadiness. She attributed this to not having walked for two days because of the IV in his foot. She elected to use her own judgement regarding the milk. She chose to give it to him, and he had no problem with it.

Lynn was very concerned that in talking about those aspects of Gary's hospitalization that were stressful, the overtone of this narrative account would be negative. Although she described it as "traumatic to have your child in the hospital" and "a mental struggle", she emphasized that she was happy that he was admitted to hospital for treatment, and that a bed was available immediately for both Gary and herself. She said that she had confidence in the care that he received and, if it was necessary for him to be admitted to a hospital again, she would be very comfortable taking him to the same hospital. However, she said that she would approach it differently now that she knows what to expect. She would plan times with her family for someone to come in and relieve her for meals, etc. She said that she would choose a family member to do it because Gary would know that person, and because she has family in the city who are available. She said that if a nurse was available, "that would be a bonus", but that it was not realistic to expect nurses to do it "because they are too busy."

Lynn also talked about two other hospitalizations and drew some connections between those and her experiences with Gary's hospitalizations as an out-patient and an in-patient. She spoke of the need for a family member to be a caregiver, fatigue experienced by the caregiver, reliance on family support, and inadequate teaching.

One incident that she related involved her father who is deaf and unable to speak. A sign was posted above his hospital bed identifying the need to communicate with him in writing. Paper and pencil were available on his bedside table. In spite of the sign, Lynn said that the staff would invariably speak to him and upon realizing that he did not hear, would repeat their words in a louder tone. For her father and for his family, this lack of recognition and attention to his special needs was both humiliating and frustrating. To her, it demonstrated lack of caring.

The other experience that she spoke about was her childbirth experience when Gary was born. She said, "But my labour and the few weeks after his birth were a nightmare, a traumatic experience for me." She recalled it as twenty-one hours of pain coupled with uncertainty and fear. Her primary source of support was her husband. She expressed disappointment about the quality of support from the professional staff with the exception of a student nurse and a registered nurse who were with her for one shift. About them, she recalled:

> (The) student nurse was so kind and the main nurse that was there for most of it, those two nurses, I can't thank them enough for their kindness. That's the only thing they can do when you're in that much pain, is just be kind to you and that's like a medicine all in itself...The more senior nurse answered all my questions, never got angry at me, never. I never sensed any hostility through the whole time they were there.

In contrast, she described other staff as being unsympathetic, "rough, pushy and rough."

In the post-partum period, she relied on Paul to assist her with her care. She said, "He did absolutely everything for me...they were literally so short of beds, so short of nurses, he had to be there." She recalled his fatigue, "Oh, he was just as exhausted as I was. He fell asleep in the chair for a while and he remembers how tired he was." In relation to teaching about the care of her baby, she said, "They give us too much literature to read just when you've had a baby. There's too much to read. I didn't read it all and it was overwhelming."

As a consequence of her father's hospitalization, her childbirth experience, and her experience with Gary's hospitalization, Lynn questioned what had happened to the caring component of nursing. She wondered if it was no longer emphasized in nursing education programmes. She reflected about her mother saying:

> She's a good old fashioned nurse that rubbed patients' backs...she's very caring, very, uh, a real caregiver. She's very concerned about everything, about how you're feeling and fluffing your pillows, and making the patient comfortable and you don't see that anymore...I guess learning from my mum, I've learned to be there for someone who's in the hospital.

Thomas' and Paula's Story: My Construction

I Meet Thomas, Paula, and Stuart

Thomas and Paula were introduced to me by Maureen, the nursing supervisor for pediatrics at Meadowfields Hospital. They were in a room on the children's unit with their seven and one-half months old son, Stuart. They had previously received a copy of the Parent Information Sheet which described the study. Because they had not had an opportunity to read it, I described the study to them. They were willing to be participants. After obtaining permission from their family doctor, we had our first interview.

Stuart was present while I spoke with his parents in the hospital. At that time, he did not look sick. He had a bandage on his arm which I later learned was covering a heparin lock, a device used to maintain a patent venipuncture for the administration of an intravenous (IV) antibiotic every eight hours. While I was there, Stuart either sat quietly in a highchair or was breast fed by his mother. However, when I saw him in their home two weeks later, I realized that his quiet state in the hospital was not his usual level of activity. At home, in much better health, he was a very different child. He babbled constantly, was either banging his toys and feet on the highchair, bouncing on his father's lap, or maneuvering his walker. He was sociable, entertaining, and delightful.

Thomas and Paula's Story: My Telling

Stuart's admission to hospital was unexpected. Except for a cold which lasted two or three days, he had always been healthy. This illness was different from that cold. On Tuesday, Stuart had a fever and was vomiting. Thomas and Paula took him to their family physician who ordered blood and urine tests. A diagnosis of urinary tract infection was made and Stuart was given antibiotics and

Tylenol®. He seemed to improve a little but then he started having diarrhea. Also, Thomas said, "He just wasn't himself. Normally, he's really alert and observant." On Thursday, he was taken to Emergency where it was determined that he was dehydrated and was developing septicemia. He was subsequently admitted for treatment with IV antibiotics and IV fluid replacement. Having him admitted was difficult. Thomas said, "We didn't expect him to be admitted. We just thought he had the flu. It hits you like a ton of bricks all at once."

In order to diagnose the cause of the urinary tract problem, Stuart was to have an ultrasound. However, it could not be booked until the following Monday. The prospect of waiting three days for the test to be done was stressful for Paula and Thomas. Consequently, they were pleased when a change in scheduling made it possible for the ultrasound to be done the day after Stuart's admission. Unfortunately, it revealed that Stuart had a structural anomaly in his urinary tract. So began an indecisive period regarding the course of treatment for Stuart, an additional tension to an already stressful time.

At our first meeting, Thomas and Paula were uncertain about the plan of treatment for Stuart after the infection was resolved with the antibiotics. They knew that he would require more tests and that he might need surgery. When I saw them later in their home, Stuart had been seen by a surgeon who determined that surgery was necessary. He planned to do it in a couple of months. Concurrently, the family doctor had received more test results which indicated that there was no obstruction although there was hydronephrosis. He questioned whether or not surgery would be necessary. This led to a further month of wondering what would be done because the surgeon was away. During that time, Stuart continued to be on antibiotics with biweekly urinalysis tests being done. Paula described that period of time as living in a state of suspense as they waited to find out what would happen. In a follow-up telephone conversation after our second interview, Paula said that a decision had finally been made not to do surgery.

At the time of Stuart's hospitalization, Paula was on maternity leave from her job as a nurse on an adult hospital unit. On the surface, this might have been viewed as advantageous. However, it also carried disadvantages. Paula said that as a parent of a hospitalized child, "As soon as you walk through those doors, you're in unfamiliar territory," but this was not recognized by the hospital personnel. Knowing that she was a nurse, they took it for granted that she knew about the various tests, procedures, and routines. However, pediatric nursing was not her field, so some of it was new to her. "Sometimes there's just not enough explanation," she said. Also, she felt obligated "to put on a brave front" when, in fact, she felt overwhelmed. She and Thomas concurred that in this situation, she was a parent first and a nurse second.

Prior to Stuart's admission, Paula knew that parents were allowed to stay full-time in the pediatric unit. However, she was not familiar with the unit policies regarding parent participation. Paula and Thomas learned some of the expectations regarding parent involvement by reading a sheet of rules and regulations (Appendix C) which was posted on the wall in Stuart's room. It indicated that parents who stayed were expected to feed and change diapers. They were pleased to do these things because, as Thomas said, "We were there anyway, and we wanted to help out." They also wanted to do them because Stuart initially exhibited stranger anxiety. Paula said, "Because of that, it would have been hard for the nurses to give him care."

Paula and Thomas did not have a tour of the unit. They found out where things were by walking in the halls and observing. A nurse did ask them later if they knew where everything was. Paula told her that they "had been snooping around."

Although a plan of care was never discussed, as Paula and Thomas talked to the nurses, asked questions, and became more familiar with the hospital routine, they gradually assumed more of Stuart's care over the course of his six day hospitalization. From the beginning, they fed, changed, and played with their son. They gave him oral medications which a nurse brought. Later, they found out they could bathe him in the basin in the room. Because they knew that Stuart's diapers were to be weighed, Paula asked a nurse to show her where to do it. After that, they did that task. In an effort to decrease the number of interruptions, and because they were used to doing it at home, Thomas suggested that they could take Stuart's temperature. The device that was being used was an ear thermometer so Paula, who was familiar with the equipment, showed Thomas how to use it and they were able to take over that aspect of his care. They did not do his other vital signs. Because of Paula's familiarity with treatments such as IV therapy and drug administration, she offered to fill the buretrol, flush the IV medication, and reset the infusion pump. Some nurses did not have a problem with her giving this care. She recalled saying to one nurse, "I don't mind if you don't mind. If you're busy when it's done, I'll just fill this up" (the IV buretrol). That nurse was pleased to have Paula help with the IV. However, the nurse they had the next day reacted differently as shown in the following incident which Paula described.

> The nurse who was working with us today, I said, when the IV is through, I'll just fill it. What do you flush it with, five or ten cc's or whatever. And she kind of looked at me like, you know, that I shouldn't even be touching it.

She referred to another nurse with whom she felt hesitant, saying, "This one nurse, I think she would have been insulted by that" (offering to help with care that was perceived as being within the nurse's domain).

Paula was concerned about asking probing questions or offering suggestions because she did not want to "seem pushy" or "to come across as a know it all." Thomas described her feelings as a sense of vulnerability. She did not want to alienate the staff. In contrast, Thomas asked a lot of questions and offered suggestions. He attributed this to two reasons. "I think with Paula being a nurse, I felt more comfortable than the average guy would be." The other thing that contributed to his level of comfort was having the same nurses for three consecutive days. He felt that this allowed them to get to know each other which, in turn, enabled them to build a reciprocal trust. He felt that the nurses valued both his and Paula's opinions. However, the trusting relationship was disrupted when the rotation changed. Thomas described an incident in which he made a suggestion about a different way to apply a urine catcher. He had experience putting them on Stuart before, and he knew that the method that the nurse was using would not work. He said:

> When I made that suggestion about the collection bag, I myself got a little bit upset because it was a new nurse there and she didn't accept the fact that I did <pause> I thought I knew a little bit more than, you know, about the system and his stay. And I wanted to be part, and I wanted to help. And then all of a sudden, this person stopped me in my tracks and said, you can't do that. And I thought, well, maybe I shouldn't be suggesting it. (Until then) I kind of felt like I was part of the system and I was helping.

Thomas felt that if it had been one of their original nurses, she would have said his suggestion was a good idea "just from knowing how we'd helped out."

A major discomfort for them was fatigue. It began before Stuart was admitted, continued during his hospitalization, and for about a week following his discharge until he resumed a regular schedule. They described it as physical and emotional exhaustion. In an effort to combat it while Stuart was a patient, Thomas usually stayed with him during the day and went home at night; Paula stayed at night and went home to sleep during the day. This option was available to them because Paula was still on maternity leave, and Thomas was able to take a week of holidays which he had left over from the previous year. Also, Stuart was their only child. Thomas said it would have been difficult to coordinate the various schedules otherwise. However, even though they could go home for long periods of time, wondering and worrying about what was happening at the hospital interfered with sleep. At the hospital, rest was interrupted frequently by medication administration, vital signs assessments, various diagnostic tests, visits by physicians, and housekeeping. These activities made it difficult to plan a schedule which would allow both Stuart and his attending parent to have an extended period of time to sleep.

Noise was another factor which made it hard to establish a consistent routine. For example, it was difficult to change the position of the crib sides quietly. Cleaning the rooms and flushing the toilet would also waken Stuart. Paula described one incident which was upsetting.

> There was no one else in our room and I'd gotten him to sleep. Thomas had gone down to watch some TV and I was lying down. So I'd heard them come to clean the room next door, and I knew they were coming in to clean the crib. So I asked the girl, could you just maybe come back and do the crib later because my little guy's sleeping. I think she must

> have waited maybe five minutes and then came in. And it's bang, bang, bang. And I finally got him back to sleep and the housecleaning lady comes in and she goes in there (the bathroom) and she flushes the toilet. I know they've got a job to do and they've got to get it done on their shift. But it's just those kinds of things...

Light was another problem. The rooms were designed with windows on the inside walls enabling the nurses to look into the rooms from the halls to check on the children. There were no drapes on the windows. Consequently, at night, the lights from the kitchen, utility room, and nursing station beamed into Stuart's room. Thomas said it made it seem like noon all the time. As a result, when Stuart woke up at night which he often did in the hospital, it was hard to get him back to sleep because it was not dark. Thomas felt that inadequate sleep slowed Stuart's recovery. He said he realized the need for the nurse to see into the room if parents were not there. However, he felt that the need was diminished by his presence and advocated having draw drapes on the windows for such times.

Private rooms were not available, and sharing the room with other patients and their families added to the difficulty of establishing and maintaining a routine of care. For example, it was usually not possible to anticipate when a new patient would be admitted, so that a plan could not be made in advance to incorporate such an interruption. Because of their individual needs, other patients had different schedules for assessment checks and medications. Consequently, it happened that activities that were necessary for other patients resulted in disruptions for Stuart and his parents. Paula and Thomas recognized that these interruptions could not be avoided. Paula said, "You have to respect that they're sick and they're in here for a reason too."

Sharing the room also created pressure to keep Stuart from crying. Paula said, "You know, if he's fussing, you kind of feel bad. You don't want to wake the other mums and their family that's staying with them too."

Trying to meet their personal needs was another source of stress for Thomas and Paula even though they were able to "spell each other off." As Thomas put it, "You're working with the hospital schedule and the nurse's schedule and their routine and the doctor's routine and your own routine and your family's routine and your work routine." Home responsibilities became hard to keep track of. "We missed paying a couple of bills because we just forgot about them." Thomas wanted to be present when their physician made rounds, so even if he went to bed late, he would get up in time to be at the hospital to speak with the doctor. He appreciated that the doctor called him whenever rounds were going to be later than usual. The doctor's thoughtfulness enabled him to sleep longer. Food in the hospital cafeteria was costly and repetitious, so Paula's mother stayed at their home and prepared their meals. When family members visited or when Stuart was asleep, Thomas and Paula took those opportunities to go home or just to leave the unit. Paula said, "It was nice to get off that unit. Just to have some different scenery, just to have a break." However, they did not feel comfortable, initially, leaving Stuart with the staff. Their reluctance was not reflective of their confidence in the staff. On the contrary, Paula said:

> The nurses have been great. They're really good with all the kids. You can tell they really like kids. It's not just a job. They're picking them up and giving them a kiss. If our circumstances were different, if we didn't have a lot of family support, or Thomas was away, or you just had little ones at home, you might be forced to leave your baby for a few hours, or even the night just due to circumstances. And you know in that regard, they're not being left in a crib crying all night. You know the nurse will go in. One little guy was fussing and she took him down to the desk and held him and talked to him. So that's making me feel better to know that if circumstances were different, he'd be well looked after.

Paula explained their reluctance to leave Stuart initially with the staff, saying:

> Not that anyone ever said, no, you can't leave him or whatever. And yet, I sort of felt guilty leaving him. And not that they made me feel that way. I guess because it wasn't offered. If they would have said, well, you know, if you guys want to have a break, or go out, or go home for a break, or whatever, no problem. But I kind of felt that I was imposing

> on them to look after him even though that's why he's there.

Thomas and Paula acknowledged that parents may not recognize when they require breaks. They said that, in such circumstances, it is helpful if the nurse takes charge and tells parents they need time away. Paula spoke about an incident where that happened. She recalled that the nurse said:

> You guys go downstairs. Give me twenty minutes, half an hour, and see if I can settle him. Because we were hovering over him and I was getting more upset and I was just totally stressed out by this time.

Thomas also related a situation wherein a nurse provided him with relief.

> It's like a night that I was staying with Stuart. I had a hard time comforting him when he woke up at night and I couldn't put him back to sleep. And the nurse came in and said, listen, I'm going to take him. I'll put him up at the front desk. We'll take care of him and you lie down, and you get yourself some sleep. You kind of need it. And so I lay down, and I was kind of wondering about whether he was going to sleep or not. But I fell asleep and slept for a good solid hour and a half, two hours. And she took over and I was kind of glad that she did.

As Stuart improved and Paula and Thomas became more familiar with the system, they felt more comfortable about leaving him with the nurses and going downstairs for breakfast or lunch. They described that as "a nice relief because we'd wander downstairs. We'd share a pop or something and just talk about it."

Paula and Thomas were members of the health care team up to a point. They provided all of Stuart's basic care and some of what is traditionally viewed as nursing care. In doing it, they helped the nurses who could then "spend their time doing medical care and taking care of kids whose parents weren't present." However, this was a gradual process. At first, they felt like guests. They were tentative about taking the initiative to do things. Once they became familiar with the routine in the system and with the nurses, they started doing more of the care such as weighing diapers and taking Stuart's temperature. Paula assisted with the IV infusion. This was aided by the nurses gradually "letting go." However, Thomas said that as a parent of a hospitalized child:

> You can basically just suggest things. You say, I think he's running a temperature or you say, I think he's not feeling good; he's not sleeping right. You have to find someone else to do it. You've got to say, nurse, or doctor, or whoever, I think there's a problem here. You can't take care of it yourself. Whereas, at home, you're responsible. Also, even though they want you to stay with the baby and they want you to keep caring for him, you're still kind of on your own for your meals and things like that.

In describing the hospitalization experience, Thomas said:

> It's a strange place, and it's very uncomfortable, and it's all new. It's new as far as the sickness goes and it's scary. All that thinking and no time to do anything else except sit there and think. That's what gets you.

Although Thomas was describing Stuart's first hospitalization, at that time he was anticipating the likelihood of another admission to a different hospital in the city. They expressed uncertainty about what to expect. Paula said she would do as much of his care as "they'll let me do. I'll change his dressing if they'd let me. But I don't know if they would or not." She was not sure if she would ask them. Thomas also wanted to do as much as he could.

> I would sooner stay busy myself and that way keep your mind occupied, help soothe what you're going through, what you could be thinking about if you weren't helping. If someone would show me how to, I'd change the dressing.

As they reflected on their experiences during Stuart's hospitalization, Paula and Thomas spoke about the benefits of parent participation in a child's care. Paula said:

> I think it's really good for us to be involved. It makes you feel better. It made me feel just a little more comforted by the fact that at least I was helping him in some sort of way a little bit...

Thomas then completed Paula's sentence saying, "instead of just sitting back and biting your fingernails wondering what to do and worrying."

They also offered several additional suggestions which would facilitate more participation by parents. They said to ask parents specifically and repeatedly if they have any questions; to inform parents about the plan for the day; to let parents know what they are allowed to do; to help parents feel comfortable with their decision to stay or to leave; to focus on the family, not just the child when the family is doing a large percentage of a child's care; to be aware of how tired the parents are, whether they are taking breaks, whether they are getting any time for themselves; to help parents to participate. Paula said to remember that when a parent is stressed and upset, it is easy to fall into the pattern of "Tell me what to do and I'll do it. You're not really thinking, I'm the parent here. I should be involved in what's going on with him." They also said to be attuned to the personal aspect of nursing. To illustrate this, Thomas described an incident that occurred one night when the charge nurse came to the room, introduced herself, and said, "If you have any problems, come and talk to me and if I can help in any way, let me know."

Thomas concluded by suggesting that if nurses would educate parents to do more, then it would help everyone in the long run. Education and reassurance "would take the edge off of what's about to happen to you. It kind of clears the mystery."

Conclusion

In this chapter, I have presented the narrative accounts which were constructed from the interview transcripts. In each narrative, a different personal landscape is presented. The professional landscape also varies for each family as does the way in which the two landscapes interrelate. However, there are also similarities. These differences and similarities are described in the next chapter in response to a request from the parents to know about each other's experiences.

CHAPTER VI

Connecting Experiences in the Landscape

The narrative accounts presented in Chapter V represented a construction of each individual family's experiences as participants in the care of their children in hospital. Common to all of the families was their presence on the same landscape because their children had an illness requiring hospitalization. Within, and sometimes because of, the common landscape, many of their experiences connected with each other in terms of similarities. Their experiences also revealed common connections to their personal landscapes which extended beyond the hospital. Other aspects of their experiences were indicative of differences. The catalyst for me to write about their commonalities and differences came from the parents when they expressed an interest in knowing how their individual situations compared to the others. The following portrayal, written as a letter to the parents, explores the ways in which their experiences connected as the landscape evolved.

A Letter to the Parents

Dear Monica, Janie, Lynn, Paula and Thomas,

When I talked to each of you on the phone after you had read the story I wrote about your experiences in the hospital with your children, a couple of you expressed an interest in knowing how your story compared with those of other parents in the study. Now that I have written each of the stories and spoken with you about them, I thought I would take this opportunity to let you know what I learned.

First, let me introduce you to each other. Of course, I am using your pseudonyms, not your real names. Monica was the first mother to be part of the study. Her son, Brent, was fourteen months old at the time. His health problem, uncertain when he was admitted, was later determined to be asthma. While he was in hospital, he also got diarrhea and vomiting so his stay lasted six days. Janie was the second mother to join the study. Her three year old daughter, Penny, was in for a broken leg. She was in traction for nearly three and one-half weeks, so they had quite a long stay. Next, there was Lynn. Her son, Gary, had pneumonia. Their stay of forty-eight hours was the shortest in comparison to the rest of you. Finally, I met Thomas and Paula whose son, Stuart, (yes, the balance was in favour of boys for some unknown reason) was also in for six days with a urinary tract infection.

When I think about your experiences over all, one thought that stands out is that your "job" as parents had no boundaries. It did not cease with time or location, but it did take on different dimensions because of the hospitalization. While your activities as parents changed in a lot of ways, they did not stop.

I asked myself why they did not stop, and I realized there were several answers to my question. One reason was that all of you found out in one way or another that visiting hours were open. You could be at the hospital twenty-four hours a day, and all of you chose to do that, at least initially. Ultimately, Janie's situation was somewhat different. As I mentioned earlier, Penny was a patient for three and one-half weeks. After eleven days (and nights) when Penny was not having pain anymore and she was sleeping throughout the night, Janie and her husband, Mitchell, decided that she would be alright by herself once she had gone to sleep, and indeed she was. (By the way, I hope it is alright that I sometimes refer to you in the third person. I feel a little strange doing that, but you each know your own story, and it seems easier at times to speak "about you" rather than "to you" as I tell the others about your experiences.)

You may be interested in hearing that you shared many of the same reasons for staying. One was to provide emotional support for your children because they were in a strange environment filled with unfamiliar people. All of you emphasized how important that was as parents. Monica, you mentioned that Brent had shown some fear of strangers before he got sick, so you expected that it would get worse in the hospital. Lynn, you expressed concern about Gary and you, Paula, about Stuart developing stranger anxiety while they were hospitalized. Janie, you spoke about Penny's shyness and how being with strangers was extremely upsetting for her. So, although each of you used different words, in essence what you told me was that you needed to "be there" for your children to help make it less frightening for them.

Another way in which you provided emotional support, you told me, was by doing some of your children's care. Once again, you had a common concern about this. All of you said that you were uncertain in the beginning regarding what you would be able to do in the way of care. Paula, you surprised me a bit in relation to this. (By the way, for the rest of you, except for Thomas who already knows this, of course, Paula is a nurse and therefore very familiar with hospitals.) Paula, you, too, were not sure about your role as Stuart's caregiver. I was intrigued by your statement when you said, "As soon as you walk through those doors, you're in unfamiliar territory." This was an area of uncertainty that all of you shared regardless of your backgrounds.

Other reasons you mentioned for participating in your children's care were that you were the parents, that you were there all the time, and that you expected to be giving care. You will be interested, I think, in each other's comments. Do you recognize your own?

> "That was my child lying there."
>
> "He's our son and you want to do everything you can."
>
> "I'm just doing it because I'm his mother and I know what he likes."
>
> "It made me feel better. I felt I was helping him."

I was struck by the confidence that you conveyed as you told me that you could do your children's basic care and do it well in the hospital environment.

Thomas, you gave me another reason for being involved in Stuart's care. Do you remember saying that by keeping busy with the tasks at hand, your mind was kept occupied and you worried less?

All of you described the nurses as being very busy which was one more reason for participating. You said that you felt the care you gave helped to reduce the nurses' workload. Here again, you might enjoy reading some of the others' comments.

> "I hate to bother the nurses especially when there's kids that really need their attention. So if it's something that I can do, I will do it."
>
> "They were just going crazy last night. And she (the nurse) said, I feel really bad but I know you're here and you do everything."
>
> "You just can't expect the nurses to do it, do everything, because they just don't have the time."

Also, in relation to the "busy-ness" of the nurses, both Monica and Lynn commented that children needed more than nursing care; they needed physical contact. The two of you noticed that the nurses were too busy to include enough physical contact with the children as part of their nursing care. Hence, by being there, you provided Brent and Gary with that contact. Paula, you had a different experience so that you were confident that a nurse would be able to hold Stuart and comfort him if he was distressed and you were not there. You told me about an incident which you saw wherein a nurse took a fussing baby to the nursing station with her. Janie, your experience was more like Monica's and Lynn's. You also felt that you needed to be there to do what the nurses did not have time to do. You said that once Penny had adjusted to the traction and was pain-free, the most challenging aspect of her care was to keep her entertained. You said that the nurses "certainly" did not have time to go to Penny's room every time she dropped an item on the floor or wanted something different to play with. You spoke about the support of the recreational therapist who provided you with ideas and supplies. As I recall, though, she worked part-time. Not only that, she was on vacation for a week during Penny's stay.

Some of you talked about the special care that children required that could only be done by the nurses. You pointed out to me that, because you were able to do a lot of your children's care, you enabled the nurses to do that special care. I think maybe Thomas explained it better than I can. He said:

> The nurses find it helpful when we're here, because when we're taking care of our child, they can spend more of their medical time and their expertise on the kids that need more help.

Another thing that you all had in common was that from the time your children were admitted, you provided what I call basic care. You each fed, changed, comforted, bathed and played with your children. I was interested in knowing how it came about that you did that. I was surprised when all of you said you found out by reading the regulations which were posted on the wall. None of you found out directly from the nurses. I was also surprised that only Lynn received an orientation to the pediatric unit. Even then, Lynn, you mentioned that you had to remind the nurse to do it. However, in spite of that, you all managed well because, as you said, you felt comfortable asking questions.

I laughed, Paula, when you commented that you told the nurse who asked if you were able to find what you needed that you had been "snooping" around.

You all told me you wanted to do more, and gradually you did take on some of the things that we, the nurses, traditionally view as being within "our domain". There was quite a wide variation among you as to what you did. I think there were several reasons for that. One had to do with what I think of as professional knowledge; the knowledge which, in this case, typifies nursing. As you might expect, Paula was able to draw on her nursing experience so she did aspects of care which the rest of you left in the hands of the nurses. I was intrigued, Paula, that initially you limited your care for Stuart to basic care. You took some time before you expanded the scope of care which you gave to him. When I asked Paula about that, she said that she waited until she felt that the nurses were "willing to let go". I will tell you more about this later, but right now, I want to tell you what Paula did. She maintained the IV or the intravenous infusion, weighed diapers, and took temperatures. She also taught Thomas to use the ear thermometer. The rest of you also did some work with the IV infusions. Although you did not fill the buretrol, you kept an eye on the fluid level and notified the nurse when it was about to empty. When you were telling me all that you did, I wondered about the things you did not do that you would have done if you had been at home. For instance, all of you take temperatures at home. You would also weigh diapers if it was necessary. We did talk about these, but I am still not clear why they are not done by you as parents in the hospital. In talking to other parents, I realize that it does not happen in other hospitals either, and again, I wonder why.

Another reason that you gave for doing some of the care that we think of as being specific to nursing was based on need. Lynn, you learned about the pressure readings on the IV infusion pump so that you could position Gary to ensure his IV was maintained. Monica, you learned to give Brent's medications such as his Ventolin®, and to do his chest physiotherapy. You told me you thought it was important to know how to do these things because you anticipated he might need them at home. Janie, you gave medications except for the IV morphine, and learned to care for Penny in her traction because Penny protested so vehemently if anyone else tried to do it. Three of your children were on IV therapy. You learned quickly to assess the need for the buretrol to be refilled. Otherwise, the infusion pump would beep and wake your children which, of course, all of you found very frustrating. All of you, then, acquired knowledge that you needed for your child's specific care.

You were all self-directed in learning to do the special care. You would be great students to have! You observed, asked questions, and then did it. Monica did say that it would have been better to have had the procedures explained, and to have the nurse stay and watch her do them for the first time. Then she would have known if she was doing them correctly. Janie also said that she worried that she might not be doing things the best way. What I learned from what you told me was that feedback would have served two purposes: you would have known that you were helping your child by giving competent care; and you would have been helped emotionally by knowing that the way you were doing it was indeed the best way possible.

I was interested in whether you felt you had a choice about participating in your children's care; whether you felt pressured into doing it. All of you indicated that you did not feel pressured, but I am still wondering about that. Lynn, you made some comments that I have reflected on a lot as I think about how we communicate to parents that they do have a choice. Perhaps you recall telling me, "I figured that's why I was there; that's what this new way is all about. That the parent be there to give the child all the care and the nurse only does the medical part." You also said, "That's why I was so surprised when the last nurse came in and started changing his diaper. I almost felt bad. I didn't want to take up her time. I said, I'll do it. I'll do it." I did not sense that Lynn resented doing it, but rather she felt that she was expected to do it. If she did not do it, she might be perceived to be shirking her "duty". I hope that my perception is correct, Lynn; that your difficulty and discomfort arose from the uncertainty regarding what the nurses expected because they had not discussed it with you. And so, I wonder if parents might perceive that they are being pressured into giving care. In relation to this, Lynn, you made a comment that was particularly helpful to me. You suggested, "It would be helpful to sit down and say, these are my guidelines, these are yours. Because I don't really know what I'm supposed to be doing or not doing."

Even though all of you described some confusion about role expectations, one aspect about which you were all clear was that you were your children's primary caregivers. The nurses' role was to support you by providing the care that you were not able to give either because you did not have the necessary knowledge or skills, did not receive the teaching that you needed to expand your repertoire of skills, or you were prevented from doing it because of the established unit routines. This latter aspect raised a question in my mind regarding membership by parents on the health care team.

When I think of membership on a team, I think of members negotiating to make decisions. You presented different views regarding the extent to which you were members of the health care team. Monica, you described yourself as an active member of the team. You cited several incidents which entailed negotiation and having a voice in decision-making. For example, you identified a need for Brent to have Tylenol®. You initiated the administration of Ventolin® earlier than scheduled. You refused a physiotherapy treatment for Brent because he was vomiting. Janie, you were involved in decision-making pertaining to medications and deciding that Penny no longer needed you to stay overnight. However, you were not involved in negotiating other aspects of Penny's care. For example, the doctor decided when Penny could be moved to the playroom. It was necessary to wait for him to write an order for that. Thomas, you pointed out that, for the most part, you could identify that something was not right, that there seemed to be a problem. However, you said it was the nurse, doctor, or another staff person who had the responsibility for making the decision. You described the difference between home and hospital by saying, "You can't take care of it yourself. Whereas, at home, you're responsible." Lynn, you also felt excluded from decision-making during a discussion about Gary's readiness for discharge. You told me that you wanted him to stay after his IV was discontinued to be sure that he had recovered fully. However, the resident insisted that he could go home and you could bring him back if he got sick again. I remember the frustration in your voice as you talked about that incident.

Another area in which your experiences differed pertained to having a say regarding whether or not you could stay when procedures were being done. Thomas, Paula, and Janie were given a choice. However, that was not the case for Monica and Lynn. The two of you were not given the option of staying or leaving. A nurse made the decision that it was better for you to leave the room. Monica, you said you were relieved that the nurse preferred it to be that way; it was very stressful to be there. Lynn, you made it clear that you would have preferred to stay. However, you also related how tired you were. It seemed that your fatigue plus the uncertainty you felt about your role resulted in the feeling that you had no choice but to acquiesce to the nurse's decision.

The extent to which each of you were involved in making decisions seemed to be reflective of the relationships that you had established with the different nurses; how well you knew each other, how comfortable you felt to ask questions and make suggestions, and how vulnerable you felt. You identified several factors which affected your relationships with the staff.

One factor had to do with the length of a nurse's rotation. Thomas and Paula, Monica, and Janie all had the opportunity to have the same nurses over several days. Thomas commented on what a difference that made. Once again, Thomas, you said it better than I can when you commented, "They all kind of got to know us and feel really comfortable with us and they basically trusted our opinions, and what we thought." You went on to talk about an incident that happened when the rotation changed and you had a different nurse. The trusting relationship that you and Paula had established with the original nurses did not transfer to the new nurse. The incident you referred to involved getting a urine specimen from Stuart. When the nurse had some difficulty with it, you suggested another way to apply the urine bag. "I rubbed her the wrong way I guess by making a suggestion. And she just rolled her eyes back at me and basically called me an idiot for making a suggestion."

The latter part of Thomas' comment is indicative of another factor that all of you voiced in one way or another, i.e., vulnerability both in terms of adverse effects on yourselves as well as your children. You spoke about it in different ways. Monica, you said that you "didn't want to be a pain; to be a demanding mother." Paula, you expressed caution about offering suggestions regarding different ways to give care and about drawing on your nursing experience to expand the care you gave. You also voiced concern about coming across as a "know-it-all" or as being "pushy." In support of your concern, Thomas said:

> Everyone's vulnerable and you bring a child in there and you want what's best for him so you're willing to do almost anything that they say or, or suggest we should do.

Lynn, you also talked about feeling vulnerable. Part of the problem for you was that you and Gary did not have the same nurse twice. You talked about feeling comfortable with the first nurse you had. You asked her questions. However, you then experienced some conflict with the next nurse who you did not know. As I recall, this latter nurse used an ear thermometer to take Gary's temperature. The previous nurse had told you that type of thermometer should not be used with children as young as Gary. When you asked about it, the nurse responded in a defensive manner. After that, you said you were reluctant to ask questions. You told me, "You kind of feel vulnerable and I didn't want to bother them and have them get mad at me." You suggested that if you had been able to continue with the same nurse for the two days that you and Gary were in the hospital, it might have been different.

Janie spoke about another problem that was created by not having the same nurses over a succession of days (or nights). She expressed concern that the frequent change-over of staff meant that a nurse did not have sufficient opportunity to get to know a child well, or for the child to become comfortable with the nurse. She said that this was a big factor with Penny because of her shyness. Although it was Janie who talked about this, it was true for all of your children because of the stranger anxiety they experienced.

Janie, you also commented that just as the nurses could not get to know the children well, they could not know the parents well. As a result, the nurses did not know what you knew in terms of what care to give, how to give it, or what resources were available. Therefore, they could not respond to your learning needs because they did not know what they were.

Another problem common to all of you were the long periods of time that you spent with your children on the unit. They varied in length anywhere from twelve to forty-eight hours. Without exception, each of you talked about the fatigue. Lynn described it as overwhelming. She said it was an added stress to an already stressful experience. You gave me several reasons why you were there for such long stretches of time. One had to do with the lack of opportunity to take breaks to eat, shower, even to go to the bathroom. Lynn agreed when I asked her if the lack of a negotiated plan of care contributed to that problem. Because none of you was given an opening to talk with a nurse about breaks, no schedule was organized whereby a nurse would relieve you. Thomas, I thought your description reflected this difficulty clearly when you said:

> They want you to stay with the baby and they want you to keep caring for him (but) you're still on your own for your meals and things like that...You're plopped into the situation and you're there to fend for yourself and you gotta learn the routine as you go. If you don't ask the questions, if you're not taught, no one's gonna say you could do this or that.

I wondered about asking the nurses to "cover" for you so you could leave for a while. Paula, both you and Lynn talked about this. You even used the same words. You both said you felt that to ask would be an imposition. Lynn, you elaborated further by saying that you did not negotiate breaks with a nurse because you were not sure if that was acceptable; whether it was reasonable to expect a nurse to relieve you. A couple of you also said you hoped that a nurse would offer. Such an offer happened only twice, once for Lynn and once for Thomas, during the many hours you were there. Consequently, all of you depended on family members to relieve you. I recall, Monica, your assertion that you did not know what you would have done if your family had not been available to come in.

All of you mentioned having mixed feelings about leaving the unit because you worried about what was happening in your absence. Janie, Lynn, and Paula also mentioned feeling guilty. However, at the same time, you acknowledged that the change of scenery was helpful to your mental state. Janie added that if she had it to do again, she would schedule a time away everyday. Paula commented that parents do not always recognize their need to leave. She, Thomas, and Janie suggested that sometimes it is necessary for a nurse to take charge and tell a parent to go, perhaps just to an empty room for a period of time. Janie said jokingly, but perhaps with a serious undertone, "Maybe you have to kick us out."

For all of you, lack of sleep was another cause of fatigue. Brent, Gary, and Stuart were awake often during the night for the entire time that they were in the hospital. Initially, Penny also woke frequently. She did not begin to sleep through the night until she had been a patient for one and one-half weeks. When the children woke up at night, it was a written expectation on the unit that you would tend to them. You did not question this because you would have responded to them had they been at home. However, they woke more often in the hospital. Consequently, you also got less sleep than usual.

Another reason why you got less sleep was being in the hospital environment. Noise emanating from the equipment was a major problem. Brent did not have an IV so Monica escaped it, but for the rest of you, probably the most irritating source of noise was the beeping of the IV infusion pump. You actually got quite ingenious in running interference on it during the day and evening. You told me about anticipating the beep and asking the nurse to refill the buretrol in advance of the noise. However, when you were sleeping, you could not do that. Thomas and Paula also mentioned additional sources of interruptions such as other patients, lights, cleaning staff, routine checks by the nurse, and rounds by physicians. Penny was in a four bed room, so other patients were disruptive for her as well. Unpleasant though they were, you did say that it was not realistic to expect that interruptions would not occur. However, they did create more sleep deprivation which, in turn, diminished your capacity to cope with the stress.

Lynn acknowledged that the only way to get sufficient sleep was to go home at night. However, for those of you who were able to do that, it was only partially satisfactory. You all mentioned that you did not sleep well even though you were at home because you worried. Janie said, "...you'll sleep a certain amount and then if you wake up, forget it. You hope she's doing okay." In addition, Janie and Thomas commented that by sleeping at home, they received less information. The night nurses left early in the morning so there was no opportunity to talk with them. If the physicians made rounds very early, it was necessary to get there equally early to meet with them. For Janie who stayed all day and into the evening until Penny was asleep, the day with few breaks was extremely long; hence, more fatigue. I wonder if you are all nodding your heads as you read this.

Then there were the on-going demands from home. Janie, you brought this issue to light when you commented, "Life continued outside the hospital." You and Monica had other children whose lives were disrupted by their siblings' hospitalization. They, too, continued to need you. Although Lynn, Thomas and Paula did not have other children, they did have responsibilities which required their attention.

So, all in all, it was not an easy time for you. The various demands added to the stress created by your children being ill. However, you pointed out that it was not all negative either. I think I can summarize it collectively as follows.

In the beginning when you were told that your children required admission to hospital, you went to the pediatric unit expecting to stay. Once there, you welcomed opportunities to participate in their care. From the beginning, you provided basic care which included physical, emotional, and social care. Gradually, you expanded your scope of activities to include some procedures which were traditionally viewed as being part of the realm of nursing. You learned the new skills by observing the nurses, asking them questions, and doing the tasks.

You were motivated to participate by your expectations that your parenting role would continue from home to hospital, by your beliefs that you knew best how your children liked things to be done, that your children would feel more secure if you provided as much care as possible, that the heavy staff workloads made it difficult for the nurses to meet all of the children's needs, and by the possibility, or in the cases for Janie, Paula and Thomas, the necessity to continue to do some of the nursing skills following discharge.

Your participation in your children's care was facilitated by the policy on the pediatric unit which advocated parental participation, the positive attitudes by nurses in support of your participation, feedback by staff that you were helping and that your help was valued, sleeping facilities for you, opportunity for you to arrange your home schedules so that you were able to stay at the hospital, and availability of assistance from your family and neighbours.

Your participation was hindered by incomplete orientation to the unit regarding availability of resources including supplies, unclear expectations regarding your role and that of the nurses which led to uncertainty and a sense of vulnerability, lack of a mutually negotiated plan of care, precedence of unit routines over family routines, lack of opportunity to continue doing health care skills which you traditionally did at home, and lack of teaching which would have enabled you to expand your caregiving activities.

Adverse effects of the extended periods of staying with your children were the fatigue that was cumulative to the point of exhaustion, the disruption to home life, and the dependency on external resources such as family and neighbours. However, the negative effects were outweighed by the positive outcomes. You felt good that you were able to help the staff enabling them to continue to provide high quality care. Above all, you were there for your children so that hospitalization was a less frightening experience for them. You truly made a difference.

Last, but definitely not least, I want to thank you for participating in this study. What you have shared with me has added to my knowledge which I will be able to use in my teaching with nursing students. I think it will make a difference. It also has the potential to influence care on the nursing unit at the hospital. Some time ago, the unit supervisor expressed an interest in hearing the outcomes of the study. Although it is not finished, as you see, there is a lot of information now that can be passed on to her. We hope to be able to meet before I return to Calgary. If so, I will write again to let you know what we discussed.[1]

Once more, thanks very much. It was wonderful for me to be able to

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[1] See Appendix D: Follow-Up Letter to Parents

spend all that time with you.

With warm regards,

Elaine

CHAPTER VII

Interpreting the Landscape

Where Do They Fit?

It was March. I was often in the hospital to talk with the parents in my study. As I walked through the foyer and along the corridors, or cast my eyes around the cafeteria, it struck me that the majority of people that I saw had an identifiable, formal connection to the hospital organization. There was one group who wore a uniform or a laboratory coat, had a stethoscope hanging from a pocket or around the neck, or had an identification badge attached to their clothing. They were the staff. They had job descriptions which defined their roles, and policy manuals which guided their activities. There was another group dressed in hospital gowns and house coats, some with IV infusions, some in wheelchairs. They were identifiable as patients. They, too, had a hospital specific role although it was probably less well defined than that of the staff. I also saw a third group, one without a formal connection to the hospital. They were dressed in street clothes. Some looked serious, others concerned, others relaxed and sociable. I surmised that these people were most likely to be family and friends of patients in the hospital. They were visitors. I wondered about their role. If this hospital was like those in which I had worked, then rules and regulations dictated when they could come and where they could go. There was probably an unwritten code of conduct which *dictated what they could do.*

It occurred to me that the parents in my study did not fit any of these groups. They were not staff; they were not patients; they were not visitors as I had experienced being a visitor in hospitals. As participants in the care of their children, "my" parents were workers whose "shifts" were usually longer than those of the staff. Also, their "jobs" had different dimensions. I wondered about their "fit". What was it like for them in the hospital landscape?

Constructing the Research Account

Do not understand me too quickly.

These words by Norman Mailer (1959) were a guiding principle for me as I struggled to interpret the parents' stories. The process that led to the construction of this research account involved reading and rereading the field texts, noting significant words and phrases in the margins as I read, and then constructing the narrative accounts from the words and phrases. In reviewing the margin notes from the field texts, it was apparent that there were both commonalities and differences among the parents' experiences as they participated in their children's care. To gain a clearer understanding, I made margin notes on the narrative accounts as I had on the transcripts. I then clustered the notes and identified thirty-six elements (Appendix E). Some were unique to one parent, e.g., parental illness; some to two parents, e.g., choice; some to three parents, e.g., advanced knowledge about visiting and participating; many to all parents, e.g., breaks, decision-making, expectations, fatigue (Appendix

F). Using these elements as an outline, I constructed a letter for the parents in response to their query about the similarities and differences of their experiences (Chapter VI).

In the process of reading, writing, rereading, and rewriting the letter to the parents, additional elements emerged (Appendix G). Daunting though the growing list was, I took some comfort in thinking that its size must surely mean that I was not understanding too quickly; I was not succumbing to premature closure. Just to be certain, though, I compared it to the notes in the margins of the transcripts and discerned that the elements did indeed represent the experiences of the parents. They were confirmed later by two senior undergraduate nursing students who, as part of the requirements for their research methods course, analyzed the transcripts. I also discussed my interpretations with colleagues in formal presentations and informal talks.

Choice of the term *elements* was confirmed by Carr (1986). Based on work by Dilthey, Carr wrote about the significance of elements of life which stand out and make up a pattern giving meaning to life. In reading and rereading the narrative accounts and the separate list of elements, two storied patterns became apparent to me; patterns of interaction and patterns of care. However, having perceived these, I still sensed that there was something more. Finally, in reflecting further on the experiences described by the parents, I realized that a recurring impression was change. A change in the health status of the children resulted in many changes for the parents. The changes were not contained within the hospital landscape, but reverberated among the hospital, home, work, and community. I perceived that it was change within and around people that crystallized the living out of stories about interaction patterns and patterns of care. In this research account, I will describe the ever changing nature of this storied landscape of patterns and interpret their meaning in relation to parent participation.

Storying the Parents as Participants in the Professional Landscape

People live storied lives (Clandinin & Connelly, 1994). As I reflected on my own life, I saw an image of life as a continuous path. As I subsequently allowed my mind to wander in free thought, specific images appeared on the path. I recognized the images as events, and the events as a connected series. The series that my mind conjured up was one that I recognized as having occurred in grade eleven. As I re-viewed the series, I realized it had not occurred in isolation. It grew out of grade ten and prepared me for grade twelve. In one sense, grades ten and twelve were connected to grade eleven to comprise my high school years making them a chapter in the story of my life. In another sense, they formed artificial boundaries around grade eleven so that it, in itself, became a chapter; a smaller chapter within a larger chapter.

Visualizing a series of events as a chapter resonates with the stories the parents told me. The illness experience with their children can be viewed as a chapter in their storied lives as parents. The chapter began with a picture of their lives flowing back and forth with relative smoothness within a landscape that included home, work, and community. Then their children suffered an illness; their reality was disrupted; their children required hospitalization; their reality was disrupted further. Thomas described the experience as, "(hitting) you like a ton of bricks all at once." The disruption required a reorganization, a reconstruction of a new reality during the time of illness prior to and during hospitalization. Even in the aftermath, the disruption continued because no child had recovered fully at the time of discharge. Each family went home experiencing uncertainty. For example, Lynn was concerned that Gary had not recovered sufficiently to be discharged. She was not reassured by the physician's comment, "...well, you'll know within twenty-four hours if it's going to come back (the illness), then you just come right back here." For Monica, the uncertainty was masked when they took Brent home and resurfaced shortly after discharge when he suffered another asthmatic attack. Janie's uncertainty was linked to managing Penny's care because she would be in a large, heavy, bulky cast. Uncertainty for Thomas and Paula pertained to Stuart's on-going treatment. Would he need surgery? If so, when? What would the outcome be? They asked me about my experiences with children who had the type of surgery that Stuart might require. I was able to describe the surgery to them from a nursing perspective and tell them that I had cared for many children with that surgery, and they had done well. Paula said in a voice flooded with relief, "Yes, that's what our doctor said."

The disrupted reality and the thread of uncertainty were a story of transition (Moos & Tsu, 1976; Selder, 1989). Golan (1981) defined transition as "a period of moving from one state of certainty to another, with an interval of uncertainty and change in between" (p. 12). Selder (1989) also identified uncertainty as a major feature of any transition. Schlossberg (1984), Schumacher and Meleis (1994), and Spierer (1977) supported the attribute of change saying that it is inherent in transitions. The trajectory of illness-related care impregnated by change and uncertainty from home to hospital to home again as revealed by the parents in their stories was representative of one type of transition identified by Chick and Meleis (1986) and revisited by Schumacher and Meleis (1994), that being health-illness. Specifically, it was storied as transitions across levels of care.

The restorying of their lives as a consequence of change continued in another type of transition identified as situational (Chick and Meleis, 1986; Meleis 1991; Reed-McKay, 1989; Schumacher and Meleis, 1994). It involved changes in the scope of care they gave, and in identities, relationships, abilities, and patterns of behaviour. These were also part of the transition story (Brown & Powell-Cope, 1991; Catanzaro, 1990; Imle, 1990; Klaich, 1990; Patsdaughter & Killien, 1990; Pridham & Chang, 1992; Schlossberg, 1984).

The elements of transition experienced by the parents are featured in the following short stories. Together, the stories constitute a constructed version of one chapter in their lives; storying participatory care in the professional landscape.

Parental Identity: A Continuing Story

Within the landscapes of home and community, the parents were living a parenting story replete with history, familiar routines, and evolving expectations. Suddenly, a detour appeared on their landscapes; their children became ill and required hospitalization. In going from home to hospital, they moved into what was for them, the relatively unexplored territory of a different landscape. Their established story had been halted and a new story was being written.

Monica's story was the first one that I heard. As I listened, I found myself nodding occasionally as she told me what I had expected to hear. Life had changed in many ways. But later, in my reflections, I recognized a continuing thread between the "old" story and the one she was now living. As she talked, I realized that she had maintained responsibility for Brent's care during his hospitalization. She had continued to be his primary caregiver just as she had been at home. In the hospital, the nurses provided her with the resources and the emotional support that she needed to continue her parenting story. The nurses' story, as told by Monica, was one of assistance. This surprised me because that was not what I had understood from the literature. Knox and Hayes (1983) and Robinson (1985a, 1985b) reported that parents of children with chronic illnesses who required hospitalization experienced a major shift in their role as primary health providers. Park (1991), whose study included both acutely ill and chronically ill children, wrote about parents relinquishing control to health professionals. Ritter-Brinton (Triska, 1995), speaking about family-centred intervention in the educational process of children with special needs, said, "Many children with disabilities come to us first through the medical system. Parents are not used to having much control in that setting" (p. 3). Both Robinson and Park noted that some parents gradually reclaimed aspects of their parenting role over the time of their child's hospitalization. Others did not regain their role until their child was discharged from hospital. Based on the research, I had expected parents to give up control in the hospital setting and, in doing so, to suspend their identity as primary caregivers to their children at least for a period of time.

Therefore, in the second interview with each of the parents, I checked my perception that their "home story" and their "hospital story" did contain a thread of continuity. Had they remained primary caregivers for their children? They all affirmed that they had. Their reaction to my question was interesting in that their voices all carried a note of surprise. Janie was the most explicit. When I asked her if she was Penny's primary caregiver during the hospitalization, her face and her voice were filled with surprise. She said to me, "Why would you even ask that?" as though why would I even be wondering about it; as though it could not be any other way for her.

As primary caregivers, they provided basic care which included bathing, feeding, changing, comforting, and playing. They knew they were expected to do this because they were staying with their children. However, the expectations were not conveyed to them orally. Instead, they were instructed to read the regulations regarding parental visiting and participation which were posted on the wall in each room. Not having an opportunity to clarify expectations with a nurse created some uncertainty accompanied by anxiety, but it did not diminish their identity as primary caregivers.

As I reflected on the differences between the parents in my study and those in the research by Knox and Hayes, Robinson, and Park, I recalled that these authors were reporting the experiences of parents whose children primarily had chronic illnesses. Children with chronic illnesses had special health needs. Care in response to their special needs was normalized as part of basic, everyday care at home. However, when hospitalization was required, health personnel viewed special needs care as part of professional care and imposed control over it. In contrast, the children in my study had been well prior to the health problem which caused them to be hospitalized. Their parents did perform illness related care at home, such as taking temperatures and giving medications, e.g., antibiotics. However, these were exceptional rather than routine components of care. Therefore, when the children were admitted to hospital and the staff took control of the professional components of care, parents did not see that as relinquishing their responsibility as primary caregivers because those tasks had not been everyday aspects of their children's care. Their story as parents of children with a short-term acute illness was not the same story lived by parents whose children had chronic illnesses.

Restorying the Boundaries of Care

The children were admitted to hospital for care which was not available at home. Their parents viewed the additional care given by nurses, which I call professional care, as supplementary to their basic, everyday care. It was the care which they did not have the knowledge, skill or, for Paula and Lynn, a sense of permission to provide. However, to varying degrees, they all wanted to expand their caregiving stories to include professional care. This was impeded initially by uncertainty regarding how nurses storied participation by parents. What were their expectations? Negotiation might have clarified the issue but that was also lacking in the nurses' stories as understood by the parents. Although negotiation and clarification did not happen, over time trust between parents and nurses was engendered for those who had the same nurses repeatedly. Those parents became comfortable asking questions, making suggestions, and offering help. All parents became familiar with routines, and learned as a result of unintentional role modelling by nurses. This enabled them to integrate aspects of professional care with basic care. However, it fell short of what they would have liked to do. Lynn exemplified this in her statement, "...except for the needles and giving the (IV) medications and measuring the medication, I could have done it" (the rest of Gary's care). Thus, the boundaries of caregiving did expand but within limits.

Parental Care and Professional Care: Stories of Difference

Parents storied their care as being distinct from care by nurses. Initially, the differences were readily apparent because the parents gave basic care and the nurses provided specialized care. However, the parents continued to view their care differently even when they began to integrate aspects of professional care with basic care. Monica explained it by saying, "When it comes to children, it (their care) is more than nursing care...It's better for me to do something like that than a nurse because he's more comfortable with me and why upset him more than he is already." Lynn explained that young children could not understand what was happening to them, so they would be even more fearful if their parents were not there. She said that patients need more than the nursing staff to care for them. Paula spoke about the stranger anxiety which Stuart experienced. She felt because of that, it would have been difficult for the nurses to care for him. Janie unknowingly summarized their comments when she said that nurses did not get to know a child well enough to live a parenting story.

Consequently, the parents perceived the scope of their care to be more inclusive than that of the nurses because of the personal knowledge that they brought to the setting. As Spence (1947) noted, mothers came to the hospital already having knowledge and skills in caring for their children both in times of wellness and in times of illness. In other words, they came with knowledge about their children that was personal to them, that they had gained through their experiences of knowing their children, experiences which the nurses did not have. The parents had a connected knowing (Belenky, Clinchy, Goldberger and Tarule, 1986) that enabled them to respond to the uniqueness of their children and to recognize change intuitively. For example, Thomas spoke about "knowing" that something was wrong based on patterns of behaviour such as, "...he's not sleeping right" and "He just wasn't himself." As Belenky et al. (1986) wrote, connected knowers seek to make "the unconscious conscious, by consulting and listening to the self, by voicing the unsaid, by listening to others and staying alert to all the currents and undercurrents of life about them, by imagining themselves inside the new poem or person or idea that they want to come to know and understand" (p. 141). They seek the points of connection between what they are trying to understand and their own experience. This is supported by Clandinin (1985) who wrote that personal knowledge is the knowledge which participates in, and is imbued with all that goes to make up a person. "It is knowledge which has arisen from circumstances, actions and undergoings which themselves had affective content for the person in question" (p. 362). From personal knowledge, Clandinin (1985) described personal practical knowledge as "knowledge which is imbued with all the experiences that make up a person's being. Its meaning is derived from and understood in terms of, a person's experiential history, both professional and personal" (p. 362).

The way in which the knowledge is manifested or "acted" out is dependent on the landscape. The situation in the hospital, i.e., the hospital landscape, honoured the parents' personal practical knowledge in relation to giving basic care. However, parents had more to offer so it was frustrating for them when their knowledge was not sought by health care professionals. Their frustration increased further when they offered knowledge but did not perceive that it made any difference. Their experience was not unique. Smith (1989) wrote:

> ...how can a medical decision be made in presumably the best

> interests of the child by ignoring those of us who have been responsible until now for the welfare of the child?...Still, the significance of the adult's presence has yet to be recognized medically. Parents, family, community are still regarded as, at best, supportive of the medical processes of child hospitalization. (pp. 146-147, 152)

Consequently, the parenting stories and the professional stories are different out of necessity and out of tradition because each represents different knowledge on the landscape. Therein lies a challenge to create a landscape in which differences are complementary so that within the landscape, the view is one of collaborative integration rather than one divided by artificial boundaries.

Patterns of Care: Storied Relationships

Different patterns of care evolved over the course of each child's hospitalization. All parents experienced each pattern but the range of activities that comprised the patterns varied notably among the parents. The changing patterns reflected stories of relationships which unfolded differently among parents, and between parents and staff.

The first pattern became apparent to me during the period when parents were responsible for basic care and nurses were responsible for professional care. The process reflected parallel relationships resulting in parallel care. Parents and nurses worked independently of each other without negotiating a plan of care. The process allowed parents to continue to story themselves as primary caregivers. At the same time, it inhibited clarification of expectations and any subsequent expansion of parental care.

Cooperative relationships enabled parallel care to happen. The staff cooperated with the parents allowing them to provide the basic care. The parents cooperated with the nurses allowing the staff to give nursing care according to the routine on the unit. Cooperation was not equitable, however, because hospital routines took precedence over parents' routines. This was not always satisfactory. Thomas spoke directly about the pressure to plan his activities around the routines of the health care professionals and auxiliary staff. Other parents also related incidents which seemed to imply a need to submit to the routines of others who were involved directly or indirectly in the children's care.

A second pattern involved storying collaboration. Parents and nurses consulted with each other to determine the need for and to make decisions regarding the administration of medications such as Tylenol®, sedatives, laxatives, and Ventolin®. However, this tended to be limited to medications. Collaboration as described by Bennis, Benne and Chin (1969) and advocated by Shelton, Jeppson and Johnson (1987) did not characterize the experiences of these parents for the most part. Lack of negotiation was one way in which this was evident. Another was in relation to decision-making power. Decisions were made for them with little opportunity for input. For example, the decision was made for Lynn and Monica that they would not be present when their sons were having intrusive procedures done. Lynn expressed concern that Gary was not ready to be discharged but it seemed not to influence the physician's decision to send him home. Thomas cited another example when he said that a parent could "basically just suggest things." In contrast, he said that when they were at home, he and Paula were responsible. They made the decisions. Thus, at best, the parents were members of the health care team without voting privileges.

The third pattern reflected stories of learning in the absence of teaching relationships. Parents gradually undertook activities traditionally assigned to professionals. In doing so, they integrated professional care with basic care. However, even though each parent was motivated to expand the scope of integrated care, achievement varied widely because of different past, current, and anticipated experiences, and because of lack of planned teaching by staff in response to parental learning needs. Some skills that parents performed that were traditionally deemed to be within the nursing domain were part of their personal practical knowledge which they had acquired prior to their children's hospitalization. For example, they were able to assess changes in their children's condition such as fever and discomfort. They came to the hospital knowing how to do interventions which could help. However, they had to take the initiative to continue this component of their parenting story. It was also through their own initiative that they expanded their repertoire of professional skills thereby authoring a new parenting story.

One View of Caregiving: Storying Stress and Strain

Parenting does not have boundaries; it is a twenty-four hour a day job. At home, space and opportunities for a variety of activities can make time seem too short. In the confines of hospital, however, time "hung heavy on the parents' hands". Participating in the care of their children required them to be in one room for long periods of time. Lynn described it as stressful and tiring. Janie called it boring to the point of being consumed with the desire to get out. It could have been to another room for a change of scenery, but her preference was to leave the hospital. However, even when it was possible to leave, she and the other parents expressed ambivalence about being absent because they worried about what might be happening. They also felt guilty about leaving the children in the care of the nurses who were busy with other children.

Another concern was created by the open landscape of the hospital; parents experienced lack of privacy. Unlike home, they had no control over who came and went. When other patients and families shared the room, added stress resulted. Paula spoke about the pressure she felt to keep Stuart quiet so that he would not disturb the other child. Conversely, other children disrupted any routines that the parents had been able to establish.

Because parents were expected to respond to the children if they woke during the night, they were "on call" continuously. This created more stress. The cumulative stress, coupled with frequent sleep interruptions, resulted in overwhelming fatigue. As a result of the stress, boredom, worry, guilt, and fatigue, the parents' stories were poignant with strain. Perhaps that was a contributing factor to Janie's illness.

Strain was exacerbated by uncertainty. Parents were uncertain as to how to story their participation beyond basic care, how the nurses storied their participation, how boundaries were storied, or how permeable the boundaries were in the stories. Because of the lack of negotiation, they did not know if it was part of the nurses' stories to oversee their children so that they could have breaks. Lack of teaching, supervision, and feedback from nurses also created stress because the parents were unable to story the "correct" professional care.

Supportive Care: Co-Authored Stories

To manage the strain created within the landscape, parents depended on support. To some extent, this was provided by nurses. For Monica, it took the form of emotional support through conversation, demonstration of caring by ensuring she had enough blankets, and giving her a hug when she was upset. Lynn described an example of support that she received when a nurse offered to stay with Gary and rock him while she took a coffee break. Because the nurse offered, Lynn did not feel that she was imposing on the nurse's time. For Thomas, a supportive event happened late one night when he was unable to settle Stuart. Without him having to ask, a nurse took Stuart to the nursing station enabling him to have an uninterrupted sleep for approximately two hours. These examples demonstrated that, by perceiving and responding to the needs of parents, nurses co-authored parenting stories.

However, the primary source of support for the parents was family and friends. They enabled the parents to have breaks to attend to their various needs, e.g., eating, resting, responding to home responsibilities. In thinking about the meaning of participation by family and friends, I was reminded that the landscape of care was not bounded by the physical structure of the hospital. It extended to the community through the involvement of others. For example, on short notice, Monica's mother went to stay with Darcy so that Monica could go to the hospital. Paula's mother moved into their home while Stuart was hospitalized so that she could prepare meals and assist in other ways. Janie's neighbours assisted with child care. However, that also contributed to strain. In providing support, family and friends experienced disrupted lives. Janie expressed concern about the disruption for others saying, "But we just feel that we've really used our neighbours in terms of dropping these kids off after school. You just can't ask them anymore. It's too much." In this regard, the restorying of the parenting story caused by each child's hospitalization was a catalyst reaching across the extended landscape. As a result, the lives of others who held significant places in the parents' landscapes were also restoried. Together, they co-authored part of the participation story.

Conclusion

In this research account, I have reconstructed parenting stories and presented them as a collection of short stories. Although separated by format, they interrelate to form a chapter which stories the experiences of five parents as participants in the care of their hospitalized children.

The participatory landscape for this study was predominantly that of the hospital. However, as revealed in the storied accounts, any boundaries that are established can only be artificial because participation by parents neither starts nor stops at the hospital doors. It both affects and is affected by the historical landscape, the visible landscape in which the parents are present, and the extended landscape beyond the horizon.

In the next chapter, I present a different landscape. It is the landscape which has grown and will continue to grow as an extension of the parents' landscape in this study.

CHAPTER VIII

Cultivating the Landscape

Understanding Parent Participation

Cultivate is defined in the New Lexicon Webster's Dictionary of the English Language (1988) as improving, refining, fostering, causing to develop. In this chapter, I describe how the parents' stories about their experiences as participants in the care of their hospitalized children have led me to refine, foster, and develop a changing view of parent participation. As I reflected on the changes, I recalled the set of assumptions which I had recorded during the development of the proposal for this research. Reviewing them helped me to see the evolving nature of my understanding of parent participation. Therefore, where the assumptions connect with my changing views, I have included them to show how my thinking has developed.

I have been an advocate of parent participation in the care of hospitalized children for a long time, but it has not always been part of my beliefs about child health nursing. I think back to the situation of the baby who was scratched so badly by another child. At that time, I accepted the practice that all care required by hospitalized children was done by the staff. That was our job. I wonder now, as I have for many years, whether that baby would have been injured if her mother had been able to story herself as a continuous caregiver from home to hospital to home. If I had co-authored a story of participatory care with the mother, she would have fed her baby. Maybe the baby would have slept afterwards and not upset the other child. I wonder why I did not negotiate that. It was certainly not lack of concern. Did I think that basic care differed somehow when it was situated in a hospital landscape? Was I concerned that parents would think that I was lazy if I asked them to feed, bathe, or change their child? Was I worried about being reprimanded if I encouraged or allowed parent participation? These might have been factors that influenced my behaviour. But even more so, I think that I was living a story which had been written for me; one in which I had been trained to be a follower not a leader, to adhere to the policies and procedures of the employing institution. It was only when I undertook baccalaureate education that I began to restory my understanding about the negative reactions manifested by children in response to hospitalization, and about the strategic role of their parents in preventing or buffering the adverse effects. It was also as a result of that education that I storied nursing, with its responsibility for holistic patient care, as being much more than following orders.

When I returned to work in a different hospital after receiving a Bachelor of Nursing degree, I observed that nurses on the unit where I was instructing students had rewritten part of their story. They were accepting of parents feeding and changing their children. However, I do not recall it happening very often. Possibly neither nurses nor parents took the initiative because it was still not the norm. Certainly, there were no policies advocating parent participation. However, if I asked parents if they wanted to feed their child, and if they chose to do so, the staff seemed to accept the practice. As I think now about those times, I recognize them as the beginning of my conceptualization of parent participation; parents were involved in meeting the physical needs of their children. As I think more about parents participating, I realize that seeing parents giving care to their children in hospital may have been the beginning of my awareness, but it was not the beginning of my experience with parent participation. Even before parents began feeding their children, and then gradually expanding their care to include bathing and changing, they were participating by virtue of visiting. In those visits, their presence provided emotional support. When they held their child, talked and sang to him or her, and read stories, they were meeting social needs as well. That too, I realize now, was part of participation. But, surprisingly, it has only been in doing this study that I have consciously thought about the scope of parent participation. Prior to this, I had thought of participation by parents as assisting with the physical needs of children, i.e., bathing, feeding, and changing. Although I did not state such an assumption, there is an implication that I assumed that meeting the basic physical needs of children constituted the full scope of parent participation. Now, I find it hard to believe that my view was so narrow.

An assumption which I did record pertained to differentiating between the work of nurses and the work of parents. *Nurses see basic care, e.g., bathing and feeding as appropriate for parents to do, but see tasks such as filling IV buretrols, giving medications, and taking vital signs as nurses' work.* Although the assumption was written from my perspective as a nurse, the parents in this study initially viewed it that way as well. However, they were not satisfied with that dichotomy. They wanted to do more which created a tension for me. How much should parents be encouraged to do beyond basic care? If they assume most, or even all of their children's care, what constitutes nursing care? This question led to another concern. If parents are to expand their scope of care within the hospital setting, they will require teaching. However, until I did this study, I did not consciously think about the implications that teaching could have for a nurse in terms of professional identity. When teaching results in parents expanding their participation to include care traditionally viewed as being within the realm of nursing, teaching becomes as central or, perhaps in some areas, more central to nursing than the traditional "hands-on" health-related care perceived as being nursing. This requires a shift in terms of how nursing is storied and subsequently how nurses story themselves.

Another assumption which I recorded was: *As parents spend more time in the hospital and become used to/familiar with the environment, they will want to participate more in their children's care.* This statement was accurate as far as it went, but was incomplete in relation to this study. Parents did want to participate in their children's care and to expand the scope of care which they gave. However, their desire to participate was not something that developed only after their children had been in hospital for a period of time. These parents came to the hospital wanting to be participants. In listening to their experiences, I was reminded to think of participation in terms of past, present and future, of unity and continuity. The parents had established routines with their children at home.

They wanted to continue the routines as much as possible in hospital. Doing so helped to make hospitalization less strange. They also wanted to increase their participation early in the hospitalization period. This made me aware that parents may not need an initial period of time to get used to the hospital environment before they become participants in the health care of their children. They may be motivated to participate right away and so we, the staff, need to be able to identify that motivation and respond to it from the beginning of the children's hospitalization, thereby facilitating increased participation. This would not only be advantageous within the hospital landscape. The knowledge about illness care which parents gain can contribute to a smoother home transition for the whole family following discharge. In terms of parent participation, I realize now that, by confining the illness experience to the hospital landscape, I allowed invisible boundaries to limit my understanding of the participatory path.

Connected to this image of erecting artificial boundaries which confined the parents' experiences to the hospital landscape was the realization that parents continued to have responsibilities at home and/or at work. To meet them, they depended on support from staff within the hospital and from family, friends, and colleagues. This linked, in part, to an assumption that: *Not all parents want to be, or are able to be, involved in their children's care to the same extent both in terms of time and type of activities.* There were minimal differences among the parents in this study in relation to how much they wanted to be involved. They all wanted to be involved as much as they could be. Their participation was aided by their personal circumstances which enabled them to organize their home and work responsibilities so that they were able to be in the hospital for long periods of time. However, two parents acknowledged that, had their circumstances regarding jobs and support systems been different, they might have been restricted in relation to the amount of time they were there. Their involvement was also influenced by personal practical knowledge which differed among them because they had different backgrounds and experiences.

Recognition of the connection between teaching and participation was apparent in my assumption: *If nurses take time to identify what parents want to know and teach them how to do it, parents will do more of their children's care.* The parents in this study indicated that this assumption had the potential to be correct. However, they learned by watching the nurses who did not seem to realize that, through role modelling, they were teaching the parents. It was not part of my assumption that parents would expand their participation in the absence of deliberate or conscious teaching by nurses.

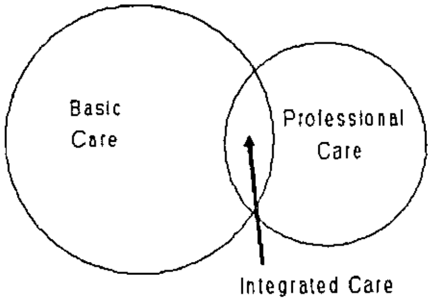
Understanding the illness of a child as creating a transition for parents (Pearlin, 1980) helped me to gain a very different view of how parents might story participation. Initially, I disregarded short-term hospitalization as a transition because Schlossberg (1984) wrote that "the transition process consists of reactions over a period of time..." (p. 63). Although she did not designate the length of time, the implication was that it was long. Her thesis was supported in articles about transition in which the focus was consistently on long-term care (Brown &

Powell-Cope, 1991; Bruder & Cole, 1991; Cohen, Arnold, Brown & Brooten, 1991; Pridham & Chang, 1992). I found no literature on transitions being experienced as a result of short-term acute illness requiring hospitalization. However, the attributes of transition as described by the different authors were reflected in the stories told by the parents in my study. In various ways, they storied uncertainty and changes in identity, relationships, routines, and abilities. This connected with an assumption I had made that: *Parents perceive their parenting role in the hospital as being different from that at home.* This assumption was accurate in that parents did story themselves differently in the hospital. However, the differences were not as great as I had expected. That they would continue to view themselves as primary caregivers was not part of my assumption. In fact, I assumed that they would relinquish that.

Changing patterns of care evolved from the transition experience. Parents began by doing basic care and gradually added some aspects of professional care. As I watched them expand their scope of care, I wondered about the care that parents gave, that which nurses gave, and what enabled each group to do what they did. It became apparent that it was related to how people learn to do what they do which had implications for parent education, both formal, planned education and informal, unplanned education. It also pertained to what each group was sanctioned to do. Parents said they perceived that some health professionals were unwilling for them to do some nursing tasks or have input into decision-making. This perception has been reported in the literature as well

(Brown & Ritchie, 1990; Nielsen, 1990; Stull & Dietrick, 1986) although the reports more commonly pertain to children with chronic illnesses.

The following diagram depicts a pattern of care as I understood it from the parents' stories.



In terms of quantity, parents gave more care than the nurses did. They started by giving basic care drawing on personal knowledge of their child and the care they had been accustomed to giving at home. They gradually restoried their care in hospital by learning to do some of the professional care traditionally given by nurses. In doing that, did they acquire professional knowledge? Seemingly, they did. They assessed their child's condition, decided what was required in terms of health care, and did the interventions. However, they usually had to consult with a nurse before they were able to proceed with the interventions. To that extent, although they had acquired professional knowledge, they were unable to act on it independently in the hospital landscape.

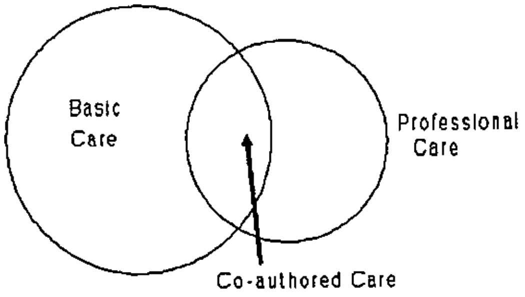
The direction of knowledge movement is noteworthy. What the parents storied and what I observed was:

personal knowledge <------------ professional knowledge
(parents) (staff)

Through their observations and by asking questions, the parents acquired professional knowledge and skills which they integrated into their care. Lacking in their stories was the pursuit of their personal knowledge by nurses. Consequently, their personal knowledge was not integrated into the care nurses gave. What parents would have liked to story was an exchange of knowledge so that:

personal knowledge <-----------> professional knowledge

Here, neither kind of knowledge would be exclusive to parents or health professionals. It would be connected and integrated for use by both groups. It would require collaboration as the basis for shared care or co-authored care. This preferred pattern of care is depicted in the following diagram.



Another result of this study was the expansion of my understanding of parent participation to encompass both direct and indirect components. The direct element was the provision of care by parents to meet the physical, social, psychological, and developmental needs of their children. This was very important to them, but equally important was their desire to be involved in the indirect care. They wanted to have input based on their personal knowledge of their children. They also wanted information which, combined with their personal knowledge, would enable them to influence their children's health care from a nonmedical perspective. However, to do this, they had to be acknowledged as members of the health care team which was limited for them. Although they were not entirely silenced, they had neither a strong voice nor an authoritative voice in decision-making. They were not equal partners in care. This confirmed my pre-study assumption that: *Health care takes precedence in the hospital and parents are not in a position of leadership in relation to health care in hospital.*

The concerns about voice and authority were connected to another assumption I had made. *Nurses' perceptions of parental roles are shaped by issues of control and trust.* Although I did not explore the perceptions of nurses, and therefore do not speak from their perspective, control and trust were issues for the parents in terms of participation. For example, the issue of control was true for Paula who perceived that some nurses did not like her to manipulate the IV even though they knew that she was a nurse in an acute care unit and consequently was well versed in working with IV infusions. Thomas talked about trust and being able to make suggestions to nurses with whom he had developed a trusting relationship.

Consequently, as a result of doing this study, I now story parent participation in the care of hospitalized children differently. I understand it as a complex phenomenon lived out in a multitude of stories. Although the way in which it is lived out varies from one family to another because of the uniqueness of each parent, each child, each illness event, and each personal and hospital landscape, there are common threads to which I, as a nurse, must be attuned. Thus, I view parent participation as involvement by parents in care pertaining to the physical, social, psychological, and developmental well-being of their children. It includes both direct and indirect components. Direct care includes activities of daily living and informed responses to needs generated by health concerns such as illnesses. Indirect care includes collaboration within a health care team so as to effect decisions about health needs. Participation by parents requires a network of support both within and outside of the hospital. Therefore, it cannot occur in isolation; it must be a co-authored story.

This re-definition has caused me to reflect on the final assumption that I made. *Nurses and parents have different understandings about the meaning of parent participation.* I did not explore the meaning of parent participation with nurses. However, speaking for myself, I assumed that I had a clear understanding as to what it was. It was a surprise to discover the narrowness of my view. It would be interesting to find out to what extent my understanding of parent participation is shared by other nurses. In relation to the parents, their knowledge about parent participation prior to their children's hospitalization was limited. They, too, had a different perception of it after their children's hospitalization. I suspect that my new understanding is closer to that of the parents who took part in this study than it is to that of other nurses.

Implications for Nursing

Surprisingly, I do not recall having read a definition or description of parent participation in the care of hospitalized children. Is there a cover story (Clandinin & Connelly, 1995) that professionals know what it is, thus negating a need for any explanation? Could this lack of clarity have been a significant blight retarding the developing story of parent participation? If so, my expanded description of parent participation could seed the growth of a new landscape. It has implications for nursing in terms of practice, education, and research.

The parents in this study acquired new child care skills as a result of unintentional role modelling by nurses. The possibility of other parents learning via the same means is something to which nurses should be attentive. If it occurs, there is a need to convert the unintentional to intentional role modelling so that nurses become aware of the teaching that they are apparently doing unknowingly. Opportunities to reflect on their practice (Connelly & Clandinin, 1991) in combination with inservice education which enables staff to recognize and capitalize on teachable moments rising from parents' readiness to learn would cultivate a landscape supportive of co-authored care. By making parent education a focus of nursing care in response to individual desires and needs of parents, parental knowledge and participation could be reinforced and expanded.

Evident in the narrative accounts is the necessity for parents to be a focus of nursing care even though they are not the designated patients. Nurses must be attuned to and responsive to the needs of parents that arise from the transition that is being experienced. Supportive interventions such as inviting and listening to parents' stories, and negotiating a plan of care which addresses both family and individual needs would be appropriate responses to the concerns of parents.

The current cutback of services in the Alberta health care system has placed new demands on parents to participate in care. In relation to the demands, expectations by staff regarding care by family members must be guided by the capacities and abilities of individual parents.

Parents have knowledge of their children pertinent to health care which cannot be known by health care professionals. Consequently, parents should have a place on the health care team. Their voices must be heard and be allowed to make a difference; they must have "voting privileges" if the best quality of health care is to be achieved for their families.

All of these issues have implications for nurses in terms of their education and its connection to practice, e.g., developing skills as an educator, acquiring effective listening skills, learning how to use presence as an intervention, learning to work effectively in groups. These content areas must be included in undergraduate nursing and staff development programmes. Their inclusion could be done in conjunction with evaluation research to explore the differences that they make to the quality of health care.

The transition experienced by the parents in this study has not been reported in the literature as a phenomenon related to parents of children hospitalized with short-term, acute illnesses. Because of the implications for supportive care, it warrants further study within the home, hospital, and community landscapes.

A "wonder" for me as an outcome of this study on the experiences of parents as participants in the care of their hospitalized children relates to professional knowledge. I am questioning what constitutes professional knowledge and whether there can be boundaries erected around a body of knowledge so that it is designated to "belong" to a specific discipline. For example, if I teach a skill identified as a nursing skill because it integrates nursing knowledge to a parent who is not a nurse, and that parent can then explain and perform the skill, does the parent have a claim on nursing knowledge, on professional knowledge? If so, what constitutes nursing knowledge and the practice of nursing? This is an area which I am interested in studying further.

I am also intrigued by the parents' identification of themselves as their children's primary caregivers. This contrasted with reports in the literature in which the parents' role as primary caregivers was taken over by health professionals. Was the experience of the parents in my study specific to the Meadowfields Hospital? Did it happen because they were able to be there twenty-four hours a day? Would parents on that unit who were not able to stay with their children all the time identify themselves as primary caregivers? Do parents who stay with their children full-time in other hospital pediatric units describe themselves as primary caregivers? What are the circumstances which enable parents to continue to story themselves as primary caregivers?

These issues are those of the future. If, or when, they are addressed, they have the potential to make a difference. However, this study has made a difference already in a number of ways.

Since January, 1995, I have been involved in developing two family nursing courses, one theoretical and the other clinical. In the fall, I will coordinate both courses and teach part of the theory course. The knowledge I have gained from this study has been influential in the development of the courses. For example, the tenets of family-centred care as developed by Shelton, Jeppson and Johnson (1987) will serve as a framework for the child health nursing component of the courses. Using the parents' stories to generate ideas, I have constructed narratives which will be a significant part of the subject-matter for class discussions. Other instructors have said that they, too, will use the narratives. I think that this approach has the potential to embed parent participation in the students' knowledge <--> practice landscape.

I am also working with a master's student whose population of interest is adults who have had heart attacks. In a guided independent study with me, she is exploring the feasibility of identifying patients' learning needs by listening to their stories. In this way, she is opening the door to opportunities for patients to become participants in their learning from the beginning. This process contrasts with the current system on her nursing unit in which learning needs are identified in advance based on medical diagnoses. Consequently, neither learning needs nor patient education programs are framed within individual, contextualized situations. Her hope is to restory the landscape of patient education.

Finally, nursing practice in the pediatric unit at Meadowfields Hospital has already begun the process of restorying parent participation as a result of this study. In Appendix D, I wrote about meeting with the nursing supervisor, Maureen, after I had written the narrative accounts and received feedback from the parents. Maureen was able to connect a number of the experiences storied by the parents with anecdotal comments from other parents. She was also able to confirm them from her own observations. Consequently, she planned to discuss changes with her staff at their meeting scheduled for the following week (Appendix D).

On Training, Narrativity, Dissonance, and Comfort

The process of doing this dissertation has been an expansive learning experience for me. Obvious outcomes relate to my practice as a clinician and an educator. They are visible to others on the landscape. However, there are also changes in my internal landscape which are less visible, and possibly not visible at all. But they too, will affect my practice, perhaps only in tacit ways. I began to be aware of them in writing a journal entry with which I would like to conclude this dissertation.

June 15, 1995

I met with Jean (Clandinin) today and we went through my dissertation page by page. She is so gentle in her criticism that her suggestions (never directives) seem so sensible and easy to do. However, on the bus ride home as I thought about what I had to do, I realized that it is not going to be as easy as it seemed when I sat in her office. It is going to take a lot of thinking, a change in thinking, and I am just beginning to realize something about myself in relation to that.

Jean was moving through the pages of each chapter fairly quickly explaining the comments she had made in the margins. Then we got to the chapter in which I talked about themes. Actually, I had questioned if they were themes, or categories, or something else. I really did not know what they were. She started to move forward to the appendices and then said, "No, we'll wait until we get to them." Eventually, we did, and I could almost feel her holding back a sigh. She asked me why I had made that list. I stammered out a couple of reasons, but I really could not articulate why I had done it. I only knew it seemed important. Now that I have had time to reflect, I think I am beginning to understand why. It had to do with my training as a nurse.

In my training (and training is the right word), I was taught (and I learned it well) to write concisely, objectively, and comprehensively. We did not *write sentences; we wrote phrases. In our charting, we referred to the patient as "Patient", not by name. I would chart something like, "Patient up walking in hall. No shortness of breath apparent." It was so depersonalized.*

So it has not been easy to write narratively. It has been fun, but not easy. I have had to relearn that and I am already seeing positive results in the narratives that I have written for the child health component of the family nursing course. I do not know if I could have written those prior to Jean's teaching and the opportunities I have had to read and discuss her writings-in-progress and other students' projects and theses.

...But back to nursing and the emphasis on comprehensiveness or thoroughness. We were taught and now I teach students that responsibility and accountability require that nurses must not "miss" anything in doing assessments and providing care; that to leave out something could cause a patient to have an extended hospital stay or perhaps even die. I can recall situations where that did indeed happen. I think of giving medications and the requisite five checks that we must make to prevent medication errors. If I never give another medication, I will still remember those five checks. So I think I know why I made that list. It was a product of my training. I just had to check to ensure that I would not have missed anything crucial; that what I chose to leave out was okay to have left out, and what was included needed to be included.

So now I have another story which I had not expected to be an outcome of my research. I would like to restory it because it conveys such rigidity. And even more important, there is no sense of person in that story. There is only an anonymous patient and nursing tasks to be done with an emphasis on thoroughness and safety which seem to add up to accuracy. I would not want to disregard these things (except for the anonymity, of course!), but I must be careful not to emphasize them over and above people. Actually, I am certain that I do not do that in my own practice, but I wonder what I convey to students. I must continue to be aware of them and put them into perspective because I think that, for me, the greatest benefit of having done this research using narrative inquiry is that by taking time to listen to parents' stories, I have experienced the most wonderful sense of communion with them, and surely that is absolutely vital in every caring profession. Thanks, Jean.

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Appendix A

Parent (Participation) Information

Hello. My name is Elaine McKiel. I am a nurse who is a doctoral student in the Department of Elementary Education at the University of Alberta. I have a special interest in the way in which parents participate in the care of their children while they are in the hospital. Because your child is expected to be a patient here for a short time, I am inviting you to be a part of my research study. Let me tell you a little bit about it.

Before the late 1960's, visiting hours on the children's units in hospitals in Canada were limited to a couple of hours each day. After that time, they gradually changed. Now, most hospitals allow parents to stay as long as they are able to. As the rules changed, I noticed that some parents started to help their children with their care. That sparked my interest in finding out more about what parents do while they visit their children. And that is the purpose of my research which has been given the title:

Participatory Care: The Experiences of Parents
of Hospitalized Children

If you agree to become part of my study, I would like to interview you at least once at the hospital while your child is still a patient. The interview will be at a time which is convenient for you. I will not allow the interview to interfere with your child's care in any way. I would like to tape the interview so that I can have an accurate record of our discussion. Examples of the questions which I will ask are:

When did <u>(your child's name)</u> come to the hospital?

What is his (her) illness?

Tell me about that. (I will be interested in what led up to the illness as well as how your child is now.)

How often are you able to visit?

How long are you usually able to stay?

What do you do while you're here?

When you answer the questions above, you might have already told me the following information. If not, I will also askwhether or not you give your child his (her) bath in the hospital, whether you feed him (her), or do any other part of his (her) care. If so, I'll be interested in knowing how it came about that you started to do these things.

Would you like to do more of his (her) care? If your answer is no, I will be interested in why you answered "no". If yes, I will be interested in knowing what you would like to do. What would help you to be able to do it?

I would also like to interview you again about one to three weeks after your child is discharged from the hospital. My reason for doing this is that once people get home and have time to think about what happened, they often see things differently. For example, you may remember something that didn't seem important in the hospital but now does seem to be. Or, perhaps something that didn't make sense at the time looks different now. There could be a variety of different things that relate to the hospital experience to talk about once you get home.

The interviews should not last longer than a hour each time. After each interview, I will write what we call a narrative or story about it. It will be helpful to me if you will read the narrative to ensure that what I have written is correct. If it is not, I will change it. I will not use your name or your child's name in the narratives. Instead, I will use only false names. When the study is finished, I will give you a copy of the final report if you would like one.

There should not be any risk to you if you take part in the study. Should something unexpected happen, however, I will ensure that you are referred to an appropriate person. If you have any concerns or questions at any time during or after the research is finished, you can call my supervisor, Dr. Jean Clandinin, at the University of Alberta or me at the numbers which I will give you.

If for any reason, you change your mind and no longer want to be part of the study, you can stop at any time without any risk of repercussions for you or your child. You just need to let Dr. Clandinin or me know either by calling one of us or writing to us. As well, if you prefer not to participate at all in the study, the care of your child will not be affected in any way.

If you have any questions at this time, please call me. I can be reached at 436-6713 (H) or 492-7770 (U of A). If you think you would like to take part, you can tell the unit manager. She will let me know and I will call you to set up a time to meet. I am looking forward to talking with you.

Appendix B

Participatory Care: The Experiences of Parents of Hospitalized Children

Consent for Parents (Participants)

I acknowledge that the research project described in the preceding information sheet has been explained to me and that any pertinent questions that I have asked have been answered to my satisfaction. I have been informed that there are no known risks associated with this study.

I understand that Elaine McKiel at 436-6713 (H), 492-7770 (U of A) or Dr. Jean Clandinin (Supervisor) at 492-7770 (U of A) or 492-4250 (U of A) will answer any additional questions that I have about the research project.

Should I decide to withdraw from the study at any time, I may do so without prejudice to myself or my child's overall care.

I understand that I will receive a copy of the information sheets and this signed consent form, and that this project will be reported but I will not be identified. I have been assured that my confidentiality will be respected.

I understand that my doctor has been approached and he/she agrees with my participation in this study.

I consent to participate in this study.

Name of Participant (please print)	Signature of Participant
Name of Witness (please print)	Signature of Witness
Name of Investigator (please print)	Signature of Investigator

Date

Appendix C

MEADOWFIELDS HOSPITAL

WELCOME TO 9 SOUTH

WE HOPE TO MAKE YOUR STAY HERE AS PLEASANT AS POSSIBLE. WE ENCOURAGE YOU TO RELAY ANY INFORMATION OR SUGGESTIONS THAT WILL HELP US TO ACHIEVE THIS GOAL. IF YOU HAVE ANY CONCERNS, COMMENTS, OR QUESTIONS, PLEASE DISCUSS THEM WITH YOUR CHILD'S NURSE OR THE NURSE IN CHARGE.

1. <u>SAFETY</u>: - IS ALWAYS A CONCERN WITH CHILDREN. FOR THIS REASON, WE ASK YOU TO CONSIDER THE FOLLOWING POINTS:

(a) HOT BEVERAGES CAN CAUSE SEVERE BURNS IN SMALL CHILDREN. BECAUSE SAFETY IS A CONCERN FOR <u>ALL</u> CHILDREN ON THE UNIT WE ENCOURAGE YOU TO ENJOY YOUR COFFEE IN THE CLASSROOM, COFFEE SHOP OR CAFETERIA. IF YOU FIND IT IMPOSSIBLE TO LEAVE THE UNIT FOR A SHORT BREAK, THEN PLEASE ENSURE CUPS HAVE PLASTIC LIDS ON THEM.

(b) PLEASE ENSURE CRIB SIDES ARE UP AND SAFETY

CATCHES ON WHEN CHILD IS UNATTENDED IN CRIB.

(c) PLEASE DO NOT LEAVE CHILDREN UP AND UNATTENDED IN PLAYPENS, HIGHCHAIRS OR ROOMS. IF YOU ARE LEAVING, RETURN CHILD TO HIS CRIB, ENSURE SIDE RAILS ARE UP, SAFETY CATCH IS ON AND INFORM HIS NURSE.

(d) ELECTRICAL APPLIANCES MUST BE CHECKED BY THE MAINTENANCE DEPARTMENT BEFORE USE IN HOSPITAL.

2. <u>VISITORS</u>: - PARENTS ARE WELCOME 24 HOURS A DAY. SIBLINGS OF ALL AGES MAY VISIT. THOSE SIBLINGS UNDER TWELVE YEARS OF AGE ARE TO BE SUPERVISED BY AN ADULT WHILE VISITING AND ARE NOT TO BE LEFT IN THE PLAYROOM WITHOUT ADULT SUPERVISION. OTHER CHILDREN UNDER 12 YEARS MAY VISIT ONLY WITH PERMISSION OF THE NURSE IN CHARGE. WE HAVE A FEW ROOMS ON THE UNIT IN WHICH PARENTS MAY SLEEP IN THE BED NEXT TO THEIR CHILD'S. THESE ROOMS WILL BE ALLOTTED ON REQUEST AND ON A FIRST-COME, FIRST-SERVE BASIS. HOWEVER, IF THE NEED ARISES, PARENTS MAY BE ASKED TO VACATE THEIR BED IN ORDER TO ACCOMMODATE THE ADMISSION OF A NEW PATIENT. IF

YOU HAVE BEEN GIVEN THE PRIVILEGE OF THIS ARRANGEMENT, WE ASK THAT YOU FOLLOW THESE GUIDELINES:

- ONLY A RESPONSIBLE ADULT, PREFERABLY A PARENT, WILL BE ALLOWED TO STAY. IF OTHER ARRANGEMENTS ARE REQUIRED, PLEASE CHECK WITH THE NURSE IN CHARGE.
- IF EXTENUATING CIRCUMSTANCES ARISE, PLEASE DISCUSS THEM WITH THE NURSE IN CHARGE
- PARENTS ARE TO MAKE THEIR OWN BEDS AND KEEP THEIR BEDSIDE AREA TIDY.
- THE BEDS WILL BE ARRANGED SO THE CHILD IS LOCATED CLOSEST TO THE DOOR AND THE PARENT CLOSEST TO THE WINDOW. THIS WILL ALLOW EASIER ACCESS AND VISIBILITY BY THE NURSE TO THE CHILD.
- MOMS OR DADS STAYING TO CARE FOR AND FEED THEIR INFANTS WILL BE EXPECTED TO CONTINUE THIS CARE DURING THE NIGHT.
- NO ACCOMMODATIONS ARE AVAILABLE FOR INFANTS OR YOUNGER BROTHERS OR SISTERS TO

STAY FOR PROLONGED PERIODS.

- PARENTS ARE ASKED TO KINDLY REMOVE THEIR OWN DIRTY DISHES AND LEAVE THEM ON THE CART LOCATED IN THE NORTH HALLWAY.

3. <u>ACTIVITY</u>: SOME CHILDREN ARE ON ISOLATION TECHNIQUE AND MUST REMAIN IN THEIR ROOM. THIS SHOULD BE EXPLAINED BY YOUR NURSE. IF YOU HAVE ANY QUESTIONS REGARDING THIS PLEASE FEEL FREE TO ASK. PLEASE USE THE SIGN-OUT BOOK AT THE DESK IF YOU ARE TAKING YOUR CHILD OFF THE UNIT AS IT IS IMPORTANT FOR THE NURSE TO KNOW WHERE YOUR CHILD IS AT ALL TIMES. CHECK WITH YOUR NURSE PRIOR TO GOING OUTSIDE ON THE HOSPITAL GROUNDS AS IN SOME INSTANCES OUTDOOR ACTIVITIES ARE NOT ADVISABLE.

4. <u>MEAL TIMES</u>: PARENTS ARE WELCOME TO FEED CHILDREN AT MEAL TIMES. THESE TIMES ARE:

BABY FOOD CART	0800	1130	4:30 PM
TRAYS FOR OLDER PATIENTS	0800	12:00	4:45 PM

JUICES, MILK, JELLO, ICE CREAM, POPSICLES ARE AVAILABLE ON THE UNIT FOR PATIENTS. PLEASE CHECK WITH YOUR CHILD'S NURSE TO MAKE SURE THAT THERE ARE NO DIETARY RESTRICTIONS ASSOCIATED WITH HIS TREATMENT. PLEASE DO NOT FEED CHILDREN OTHER THAN YOUR OWN AS CHILDREN MAY HAVE ALLERGIES OR OTHER DIETARY RESTRICTIONS.

5. BEDTIME: TODDLERS ARE SETTLED AT APPROXIMATELY 7 - 8 P.M. OLDER CHILDREN ARE SETTLED AT APPROXIMATELY 9 - 9:30 P.M. WE ENCOURAGE A REST OR NAP AFTER LUNCH FOR AN HOUR (APPROXIMATELY 12:30 - 1:30). CHILDREN OFTEN HAVE INTERRUPTED SLEEP IN HOSPITAL SO WE ASK THAT YOU AVOID WAKING THEM IF THEY ARE SLEEPING AND WE WILL TRY TO DO THE SAME. WE WOULD PREFER CHILDREN SLEEP IN

THEIR OWN CRIB OR BED RATHER THAN WITH PARENTS. THIS ALLOWS FOR EASIER ACCESSIBILITY TO THE CHILD BY THE NURSE AND ENSURES SAFETY AND COMFORT FOR THE CHILD DURING SLEEP.

6. <u>CHANGING PATIENT:</u> IF YOU CHANGE YOUR CHILD OR TAKE HIM/HER TO THE BATHROOM PLEASE INFORM HIS NURSE. SHE MUST KEEP AN ACCOUNT OF THIS AND MAY NEED SPECIMENS.

7. <u>PERSONAL BELONGINGS</u>: PLEASE TAKE YOUR CHILD'S BELONGINGS HOME SO THAT THEY DO NOT GET LOST. THE ONLY EXCEPTION TO THIS IS A PAIR OF SLIPPERS OR SHOES AND A SPECIAL TOY OR BLANKET. PLEASE LABEL ANY ITEMS THAT YOU LEAVE AT THE HOSPITAL.

8. <u>PHONE NUMBERS</u>: PLEASE LEAVE A PHONE NUMBER WHERE WE CAN REACH YOU AT ALL TIMES. THE DIRECT LINE TO THE 9 SOUTH UNIT IS ______. THE UNIT CAN ALSO BE REACHED BY CALLING THE HOSPITAL SWITCHBOARD AT

______ AND ASK FOR 9 SOUTH. PLEASE FEEL FREE TO CALL THE UNIT AT ANY TIME IF YOU HAVE CONCERNS OR QUESTIONS ABOUT YOUR CHILD'S CONDITION.

9. MESSAGE BOARD: WE UNDERSTAND THAT OTHER FAMILY MEMBERS ARE CONCERNED WHEN A CHILD IS ADMITTED TO HOSPITAL. NURSING STAFF ARE NOT PERMITTED TO RELEASE INFORMATION ABOUT A CHILD'S CONDITION TO ANYONE OTHER THAN PARENTS. WE ASK THAT YOU INFORM YOUR FAMILY THAT YOU WILL KEEP THEM POSTED OF YOUR CHILD'S CONDITION. THE PHONE AT THE DESK IS VERY BUSY, SO IF FAMILY MEMBERS DO CALL WE WILL TAKE A MESSAGE AND POST IT ON THE "PARENTS MESSAGE BOARD" BESIDE THE NURSING STATION.

10. VIDEO, NINTENDO: A VIDEO MACHINE AND VIDEO TAPES ARE AVAILABLE FOR THE USE OF THE CHILDREN. ALSO A NINTENDO GAME AND TELEVISION. WE REQUEST THAT VIDEOTAPES NOT BE BROUGHT FROM HOME OR OUTSIDE THE HOSPITAL AS THERE ARE A VARIETY OF AGE GROUPS IN ONE ROOM AND WHAT MAY BE SUITABLE FOR ONE AGE MAY NOT BE SUITABLE FOR ANOTHER. THERE IS A LARGE

SELECTION OF VIDEOS. PATIENTS MUST TAKE TURNS SO THAT EVERYONE GETS A CHANCE. WEEKDAYS (TUES. - FRI.) NO VIDEOS OR NINTENDO UNTIL AFTER 1300 HOURS AS THE RECREATIONAL THERAPIST HAS PLANNED ACTIVITIES DURING THE DAY.

Appendix D

Follow-Up Letter to Parents

August, 1994

Dear Lynn,

Now that I've finally found and unpacked the box that has your address, I can write you about the meeting that I had in July with Maureen, the Nursing Unit Supervisor of Pediatrics at the Meadowfields, to talk about the research in which you participated.

It was a very positive meeting. Maureen was most receptive to what I had to report at this stage of the data analysis. I left with a sense of exhilaration that research can make a difference to patient care and I thought you might like to know that too.

Maureen and I talked about the aspects that I wrote about in the letter I sent to you about each parent's experiences[1]. As we talked, she made notes. She was really pleased to hear that each of you perceived that you continued to be your child's primary caregiver. (She made no attempt to identify who the parents were, by the way.) She was also pleased to hear that most of the nursing care was viewed as positive by those of you who participated in the research. She was receptive to hearing about the incidences that were not positive so we were

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[1] See Chapter VI: CONNECTING EXPERIENCES IN THE LANDSCAPE.

able to talk openly about why they might have occurred and what could be done about them. Certainly, it helped that the positives outweighed the negatives.

The regular staff meeting of the pediatric unit was scheduled for the week after we met, so she planned to present the research findings to the staff and talk about approaches. In our discussion, we talked about various ones. I thought you might be interested in them so I will summarize them for you.

In relation to orientation for parents, she said that probably all that was needed was to remind the nurses to show parents where supplies are kept. Also, as part of the orientation, parents should be told that the coffee and tea on the unit are available for the parents. They are not intended to be only for the staff.

In relation to negotiation of care, i.e., what care parents would give and what care nurses would give, she suggested that it would be reasonable to take time to discuss with parents what each would do and write it in the Kardex so that it was available for all staff to read. Not only would this clarify expectations, reduce uncertainty, and save time in the end, but Maureen pointed out that it would also respond to the problem of a parent being told by one nurse that it was alright to do something, and then being told by a subsequent nurse that it was not. Also, in relation to negotiation, she agreed that it was important for the staff to arrange with parents when they would have breaks, and that this could be done at the beginning of each shift. If family members were coming to stay with the child, then the staff would know that, or if the nurses needed to cover for the parents, this would be known as well.

We talked about the problem of tiredness which was experienced by all of you; that you realize you need to get away, but that you worry when you are gone. We did not come up with any solutions other than to talk with the staff about the need to watch for increasing fatigue among parents and suggest to them that they get away for at least a short break.

The issue of routines was another thing we spoke about. We talked about the need for parents to be informed about what is scheduled to be done, and when it is scheduled if that is possible. Here again, that can be included in the initial morning talk with parents. I also spoke about the dominance of unit routines over family routines, but apart from drawing it to Maureen's attention, we didn't discuss it to the point of suggesting any action.

We spoke about the way in which you, as parents, expanded the care you gave by gradually doing some of the care that we traditionally accept as being the nurse's job. I pointed out that for the most part, you learned to do it by watching the nurses. We then talked about the need for nurses to realize that they are teaching even though they may not be aware of it at the time, and that they could enhance that teaching if they described what they were doing as they were doing it. (Long sentence, but hopefully you know what I'm trying to say.) If this was done, it would also be a way of negotiating what parents would like to do. Also, in relation to doing new tasks, I reinforced that you really appreciated getting feedback as to whether you were doing the tasks correctly. Maureen noted these things as aspects to discuss with the staff.

We talked about parents staying with children when procedures are being done. We spoke about the fact that some nurses are uncomfortable when parents are present, and that other nurses sincerely believe that it is better for parents to come after the procedure is over and comfort the child. However, we agreed that it should be a parent's choice as to whether they stay or not. So she added this to her agenda for the meeting.

It has just occurred to me that I forgot to talk about the interruptions to sleep especially the beeping of the IV infusion machine. That is written about in the final report so she will be reading it eventually. In the meantime, she does have a very long agenda. She laughed and said that talking about these research findings would take care of the entire meeting.

So that is the latest from this research. I won't be doing much, if anything, with it in the fall because of the heaviness of my workload here at U of C. However, come January, I hope to get back at it again and get it finished next summer.

Speaking of summer, I hope you're having a good one. Bye for now.

Sincerely,

Elaine

Appendix E

Elements Derived From Narrative Accounts

Breaks

Choice

Comfort: physical

    mental

Confidence

Connections with home: A10 B5

Decision-making

Demanding mother

Effects on siblings

Expectations: by staff

    by parents

Explanations by staff

Familiarity with visiting/participation policy pre-admission:

Giving care: basic

    medical: medication administration

        physio

        monitoring IV

        temperature taking/vital signs

    parent attitudes

Home care

Inconsistency among nurses

Information seeking: by staff

by parents

Information giving by staff

Lack of information

Meals

Member of health care team/guest/visitor

Negative reaction to strangers/stranger anxiety

Negotiation

Noise

Workload/Nurses busy

Parental health

Parenting role/Primary caregiver

Presence

Previous experience with hospitalization of child

Shared care

Short rotations

Sleep interactions

Staff reactions to: parents staying

parents participating

Stress

Support: by staff

by family members

by neighbours

Teaching parents

Tired/exhausted

Vulnerability

Appendix F

Examples of Elements with Indicators

Code: Letter = parent, e.g. A relates to Monica

Number = page of narrative account

Breaks B5 B12 C9 C11 C13 C15 D10 D11 D12

B5: Had to keep up with demands of home. J. could be at hospital for 36 hr. without a break to leave hospital. J. got sick.

B12: Needed breaks. However, when away from P., felt pressure to get back.

C9: Difficult to get breaks.

C9: Relied on family members stay with G so she could have breaks.

C13: Would have taken breaks for couple of hrs. if someone could have stayed with G. and rocked him while she was out.

C11: Only 1 nurse offered to stay with G while L. took break. Also, only nurse who did any basic care for G.

C15: If she had to do it again, only change would be to organize schedule with family for them to come and relieve her.

D10: Reluctant initially to leave S. in care of staff bc staff didn't offer to stay with him so they could have breaks. Felt they were imposing on staff; felt guilty.

D11: Nurse may need to take charge and tell parents to leave for a while.

D11: Parents may not recognize their need for breaks i.e. can't see forest for trees.

D12: Was helpful to get away.

Choice: A8 A8 B4

A8: M's choice to give total care.

A8: Nurse did temp. M. accustomed to taking it at home; not an option in hospital.

B4: J/M stayed during procedures provided emotional support for P.

Decision-making A9 A10 B5 B8 B9 B9 C13 D11 D11 D12

A9: Negotiated his care; participated in decision-making.

A10: Participating in decision-making led to shared care.

B5: J/M made decision to stop staying overnight.

B8: J. decided when P. needed stool softener and told nurse.

B9: J. suggested sedative for sleep be stopped.

B9: Dr. decided when P. could go to playroom.

C13: No involvement in decision-making with internes. No negotiation re discharge.

D11: Nurse may need to take charge and tell parents to leave for a while.

D11: Nurse took charge and took over S's care so T could sleep. T was glad.

D12: As parent, can only point out concerns and suggest things. Someone else's responsibility to decide what to do.

Expectations: by staff A5, A6 D4

A5: Expectations re parent staying and participating not discussed but regulations posted on wall.

A6: No discussion re what M. would do.

by parents A5 C3 C5 D4 D13

A5: From experience with goddaughter, expected to stay with Brent full-time and do his care.

C3: No explanation re expectations about parental participation. Because nurse showed her where things were, she assumed she was to feed and change him. Besides, she was there.

C5: Uncertain about nurse's expectations re L's role. Would have been helpful to discuss roles.

D4: Expectations re parent involvement not discussed. Read them from list on wall.

D4: Knew parents could stay full-time but not familiar with policies re parent participation.

D13: Doesn't know what to expect with next hospitalization; what she'll be allowed to do.

Familiarity with visiting/participation policy pre-admission: A5 B3 C2 C3

A5: From experience with goddaughter, expected to stay with Brent full-time and do his care.

B3: J. knew before P. admitted that parents could stay with child 24 hr. and participate in care.

C2: Didn't know hosp. policies re parent visiting and participation in care prior to adm.

C3: Dr. thought she would be able to stay so went to hosp. prepared to stay.

Meals B10 B10 C1 C3 D8

B10: J. brought food from home for P. and kept it in unit fridge.

B10: Worried when away from P. b/c P. wouldn't call nurses. Included being away in cafeteria.

B10: Hospital food expensive and boring.

B10: Made tea on unit but wasn't told by staff if okay.

C1: At 3 PM, L eating sandwich.

C3: Food on unit only for pts. Told she could get food in cafeteria.

D8: Hosp. cafeteria food expensive and repetitious.

D8: Family members provided support by cooking, relieving T & P so they could get breaks.

Parent got sick B2

B2: J. got laryngitis during P.'s hospitalization

Tired/exhausted A10 A11 B5 C1 C4 C9 C12 D7 D11

A10: Exhausted.

A11: Very tired.

B5: Although she went home at night, J. stayed at hosp. 12-13 hr./day.

C1: L looked tired. Sounded tired.

C4: L. tired when G. admitted.

C12: Fatigue overwhelming. Only way to get enough sleep would have been to go home. However, would have worried about him if she'd gone home.

D7: Fatigue major discomfort.

D7: Physically and emotionally exhausted.

D11: Nurse took charge and took over S's care so T could sleep. T was glad.

Appendix G

Additional Elements

Acquiescing

Acceptable (to ask for coverage)

Ambivalence

Asking questions

Basic care

Boring

Collaboration

Collaborative care

Confidence

Cooperative care

Change (in parenting role)

Choice

Comfort

Continuity

Coping

Decision-making

Demands from home

Dependency/Independency

Difficulty

Discomfort

Discontinuity

Emotional support

Emotional stress

Emotional comfort

Enabling

Expanded role

Expectations

Family support

Fatigue

Feeling comfortable

Guilt

Helping

Imposition

Independent care

Interactive care

Interruptions

Knowledge and skills acquisition

Lack of knowledge and skills

Lack of information

Lack of negotiation

Lack of opportunity to take breaks

Learning needs

Lengthy periods at hospital

Letting go

Membership without voting privileges

Negotiation

Non-teaching

Participation

Perceived needs

Personal practical knowledge

Precedence

Pressure

Primary caregiver

Professional knowledge

Reasonable expectations

Receptive

Reluctant (to ask questions)

Role confusion

Role relationships

Routines

Status on health care team

Staying & participating

Strangers

Submission (to routines)

Support

Taking charge

Teaching by unintentional role-modelling

Time

Trust

Unfamiliar territory

Unfamiliar environment

Uncertainty

Unofficial membership

Variable decision-making

Vulnerability

Voice

Worry