

THE PARENT-NURSE RELATIONSHIP IN FAMILY-CENTRED CARE OF THE
HOSPITALIZED CHILD WITH CANCER:THE PARENTS' PERSPECTIVE

by

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DARIA K. ROMANIUK

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Abstract

THE PARENT-NURSE RELATIONSHIP IN FAMILY-CENTRED CARE OF THE HOSPITALIZED CHILD WITH CANCER: THE PARENTS' PERSPECTIVE

Research to date has overlooked the specific relationship between parents and nurses, particularly in the context of caring for a hospitalized child with cancer. The purpose of this study was to describe how parents perceive the relationship with the pediatric staff nurse necessitated by the hospitalization of their child with cancer.

Using a symbolic interactionist framework and a modified grounded theory methodology, this study explored the parent-nurse relationship when a child with cancer is hospitalized. A purposive, theoretical quota sampling method was used to recruit 16 parents. Both parents' and nurses' care were examined from the parents' perspectives; mothers and fathers were interviewed separately.

Analysis of the data led to the development of a conceptual framework describing parent care, nursing care, and the parent-nurse relationship. Conditions influencing the care provided by parents and nurses and in turn the parent-nurse relationship were also identified.

This research described strategies nurses used to enhance the family-centred care they provide and revealed the effect nursing care has on parents' hospital

experiences. Recommendations are made for nursing research, practice and education.

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Last, but far from least, I would like to thank the parents who participated in this study, for taking the time to share their experiences with me.

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CHAPTER ONE
STATEMENT OF THE PROBLEM

Introduction

Each year, an average of 900 Canadian children are diagnosed with cancer (National Cancer Institute of Canada, 1992). At one time, such a diagnosis meant certain death. Cancer in children is no longer an acute, always fatal disease. Developments in surgery, chemotherapy and radiation have led to longer and longer survival times, to the point that some children are considered cured. Care of the child with cancer necessitates looking beyond the disease itself. The ultimate goal in caring for children with cancer is to both cure their disease and ensure that children achieve essential developmental tasks. The child must be prepared to deal with the possible long-term effects of cancer treatment. Significant others (such as parents and siblings) are inevitably involved in a child's fight with cancer and their needs must also be considered when planning care.

Family-centred care (FCC) is purported to play an important part in caring for children with cancer and their families. When children with cancer are admitted to hospital, their parents are encouraged to spend as much time as possible with them and to participate in their hospital care throughout the day and night. Such FCC policies have

been implemented in recognition of the importance of consistent parental contact to children's development. FCC of children with cancer requires that parents and nurses work together to meet the child's needs. However, this cooperation is not always easy to achieve. Research indicates that although nurses support the concept of FCC (Goodell, 1979; Pidgeon & Sander, 1982) they may have difficulty providing this type of care consistently (Brown & Ritchie, 1989; Brown & Ritchie, 1990). As well, parents have expressed dissatisfaction with their roles in caring for their hospitalized child (Knox & Hayes, 1983; Robinson, 1985b), suggesting that parents may not be benefitting from the FCC concept.

Nursing research specific to FCC of the hospitalized child with cancer has been limited. Studies have examined the relationship between parents of chronically ill children and health care professionals in general (Knox & Hayes, 1983; Robinson, 1985b). The specific relationship between parents of children with cancer and pediatric staff nurses has yet to be described. This study will examine parents' perspectives of their collaboration with pediatric staff nurses when caring for their hospitalized child with cancer in the context of FCC.

The Child With Cancer

The diagnosis of cancer brings about profound changes in the life of the child and his\her family. The diagnosis itself is frightening, and often comes as a shock to parents who have sought medical attention for their child's apparently minor symptoms (such as persistent colds) (Cohen & Martinson, 1988). Treatment usually begins soon after diagnosis, and the child and family must deal with the resulting harsh effects, such as nausea, vomiting and weight loss. Treatment may cause physical changes in the child's appearance. Chemotherapy and radiation are well known for causing hair loss; surgery can leave unsightly scars or may involve amputation. The child's perception of his\her body changes. The illness shatters the child's self-image of a body that functions in a well-organized, predictable manner, and the child experiences a loss of control and self-esteem (Griffiths, 1980).

Diagnosis, treatment and monitoring the child's progress often involve frequent and painful procedures. Zeltzer, Kellerman and Ellenberg (1980) reported that adolescents find the treatment and diagnostic procedures worse than the disease itself. The young child may perceive illness and the required treatment to be punishment for bad thoughts or actions (Maul-Mellott & Adams, 1987). As well,

regular clinic visits or hospitalizations necessitate absences from school and other activities. Such absences may increase if the child experiences severe side effects or complications. Clearly, the child dealing with cancer faces several hurdles beyond the usual developmental tasks of childhood.

Cancer treatment occurs in an atmosphere of uncertainty. There is a possibility that the child will be cured, and treatment is undertaken with this in mind. However, the possibility that the child will die cannot be completely ignored. Adapting to life in the face of such uncertainty makes psychosocial care of childhood cancer patients and their families particularly important (Johnson, Rudolph & Hartman, 1979; Koocher, 1981; Koocher, 1985). This uncertainty does not end when treatment ends. Treatment can cause long-term side effects. Each body system is susceptible to late effects of cancer treatment, necessitating life-long monitoring in cancer survivors. Families need to be made aware of this reality from the beginning of treatment (Ruccione & Weinberg, 1989).

Potential late effects of treatment are numerous. The child's growth may be inhibited by damage to bones and soft tissue by radiation (Ruccione & Weinberg, 1989) or by the decrease in growth hormone related to cranial radiation (Hobbie & Shwartz, 1989). Chemotherapy, radiation and/or recurrent respiratory infections can result in pneumonitis

or pulmonary fibrosis several years after treatment is completed. The chemotherapeutic agent cis-platinum and certain antibiotics can result in hearing loss.

Chemotherapy and radiation can also severely damage the heart, liver and kidneys (Ruccione & Weinberg, 1989).

The central nervous system is particularly susceptible to late effects. Cranial irradiation and intrathecal chemotherapy can cause cognitive deficits and brain abnormalities, particularly when administered to a young child. Studies indicate that possible effects include lower IQ and deficits in attention, memory and verbal learning (Kramer & Moore, 1989). Research also suggests that children who have received these treatments are at higher risk for psychosocial difficulties (Hymovich & Roehnert, 1989).

Research examining the psychosocial consequences of cancer in children is inconclusive. In a study of 116 long-term survivors of childhood cancer, Koocher and O'Malley (1981) found that 26 percent experienced mild psychological adjustment problems and 21% experienced moderate to severe psychological adjustment problems. When compared to a control sample of survivors of non-life-threatening childhood chronic illness, the survivors of childhood cancer were found to be at greater risk for psychological adjustment difficulties than the control sample. However, other studies (with samples approximately one half the size

of Koocher and O'Malley's sample) indicated no difference in the incidence of moderate to severe psychological difficulties in childhood cancer survivors as compared to the general population (Hymovich & Roehnert, 1989). Survivors of acute lymphoblastic leukemia (ALL) and Hodgkin's disease appear to experience more long-term psychological difficulties than those treated for other cancers, possibly due to the longer duration of therapy and side effects (Koocher & O'Malley, 1981; Moore, Glasser & Ablin, 1987).

Age at diagnosis may also affect long-term adjustment. Koocher and O'Malley (1981) found that survivors whose treatment began in infancy or childhood had fewer adjustment difficulties. Moore, Glasser and Ablin (1987) reported that 60 percent of children treated after five years of age and 40 percent of those treated before that age reported feeling different from others their age and that "they had missed out on part of their childhood" (p.156).

Moore, Glasser and Ablin (1987) found that teachers appraised ALL survivors as functioning at a level significantly below that of their peers (survivors of solid tumours were appraised as at par with their peers). Survivors of childhood cancer attain education levels comparable to that of the general population except when cognitive or neurological impairments are present. After the desired level of education has been completed, the

survivor of childhood cancer may face difficulties when looking for work. Several studies report that survivors experience discrimination when looking for employment, a difficulty related to the social stigma of cancer (Barbarin, 1987; Hymovich & Roehnert, 1989).

Surviving childhood cancer also has long-term implications for the child's family. Parents of children who have survived cancer have difficulty accurately appraising symptoms and behaviour in their child; symptoms of a cold or a change in energy level are feared to be signs that the cancer has returned. These parents frequently take their concerns to their doctor and are sensitive to any minimization of these concerns (Cohen & Martinson, 1988). Research is needed to determine how such vigilance might affect the childhood cancer survivor.

The child with cancer faces numerous challenges in the fight against cancer during treatment and long past its completion. Care of the child with cancer must include support to help the child meet these challenges, beginning at the time of diagnosis. Research is needed to determine the best means of providing such support to children with cancer and their families. The goal of such research would be to determine strategies to ensure that the survivor of childhood cancer develops the skills necessary to fulfil the responsibilities of adulthood.

Jan van Eys (1977), a pediatric oncologist concerned about the developmental consequences of cancer treatment, coined the term "the truly cured child" to describe the "child who is not only cured biologically but who has incorporated the experience of having had cancer into his or her being so that functioning on a par with peers is possible" (van Eys, 1985, p.160). Van Eys' writings, based on her experience treating children with cancer, stress the importance of providing the child with an atmosphere of normality in which all that must be accepted - be it pleasant or painful - be accepted as a necessary (though disliked) part of the child's life (van Eys, 1977, 1981, 1985).

Maintenance of a normal family life is important to parents raising chronically ill children, including children with cancer (Anderson, 1981; Holaday, 1984; Krulik, 1980; Martinson & Cohen, 1988; Robinson, 1984). McQuown's (1981) conversations with parents of children with cancer demonstrated the importance of maintaining normality:

Get back to normal family living as quickly as possible. Early on in our daughter's illness, I think, we were very, very much under stress because we hadn't accepted the fact that our daughter had cancer. As soon as we were able to come to grips with that, and as quickly as possible get down to more of a normal family life and family involvement, a lot of the stress went away. (p.199)

A return to normal family life is connected with a desire that the child with cancer be able to grow and develop as a healthy child would:

You hope that you have given them the strength and that you haven't clung to them and made them dependent. One of the greatest dangers is that they would become dependent on you and be afraid to go out into the world. (p.204)

In a study of parents of chronically ill children, Robinson (1984) described parents' desires to maintain normality in their child's life during hospitalization. It is not clear from the report of Robinson's work whether the sample included parents of children with cancer. Further research is needed to determine how parents of children with cancer strive to maintain normality and how nurses can facilitate their efforts when these children are hospitalized. Such knowledge could contribute to improving the long-term adjustment of survivors of childhood cancer, as research indicates that families able to maintain normal day-to-day functioning during treatment demonstrated better adjustment in the long run (Spinetta, Murphy, Vik, Day & Mott, 1988).

Childhood Cancer and the Importance of Family-Centred Care

Since the middle of this century, health professionals' increasing knowledge of child development has led to establishment of family-centred care (FCC) policies that encourage parents to spend as much time as possible with

their child and to participate in his or her hospital care throughout the day and night. FCC requires that parents and nurses work together to meet the child's needs. Today, 98 percent of children's hospitals have 24-hour visiting policies for parents (Johnson, 1990), making parent-nurse cooperation a necessary part of life in these hospitals.

Such FCC policies may prove invaluable in fostering the "truly cured child". Van Eys (1977) clinical work with this population led to the conclusion that the family is the most important influence in normalizing the child's life and that care of children with cancer must include care of their families. As well, research with childhood cancer survivors who believed that their cancer experience had a positive, maturing influence on their lives largely attributed this positive outcome to their relationship with their families (Moore, Glasser & Ablin, 1987). Barbarin's (1987) research also indicated that an effectively functioning family life is a resource that can help children resist the detrimental effect of having had cancer.

The Association for the Care of Children in Hospitals (ACCH) has acknowledged the importance of parents in the child's recovery and recommends that the pediatric nurse implementing FCC "respect the unique care-taking role of parents as well as their individual responses, and provide understandable information and support which will enable them to utilize their strengths in supporting their child"

(ACCH, 1980b, p.105). The nurse is the parents' partner in care, assisting them as they care for their child with cancer, a situation that often calls for expertise beyond the parents' daily child-care abilities.

A common belief among pediatric oncology nurses is that parent participation in care of the child with cancer is beneficial (Goodell, 1979). Pidgeon and Sander (1982) found that nurses considered encouraging parents to maintain their parenting role and participate in the child's care to be an important nursing function. Studies of parents indicate that they are extremely willing to participate in their child's hospital care (Beck, 1973; Caldwell & Lockhart, 1981; Jackson, Bradham & Burwell, 1978; MacDonald, 1969; Merrow & Johnson, 1968; Sainsbury, Gray, Cleary, Davies & Rowlandson, 1986; Skipper, Leonard & Rhymes, 1968) and are prepared to participate in tasks that nurses may consider inappropriate to the parental role (such as giving oral medications) (Brown & Ritchie, 1990; Goodell, 1979; MacDonald, 1969; Merrow & Johnson, 1968). Some research suggests that nurses often take on a gatekeeper role in which they specify what the parents can and cannot do. Parents who do not meet a nurse's expectations may encounter disapproval (Brown & Ritchie, 1990). Robinson's (1985a) research suggested that parents of chronically ill children respond defensively to such control, resulting in an adversarial parent-nurse relationship. Research examining

the parent's view of their and the nurses' roles in care of their hospitalized child with cancer may contribute to harmonizing this relationship.

FCC can also involve encouraging parents to look after themselves, because parents of ill children may neglect their own needs for sleep and food. Pidgeon and Sander's (1982) research indicated that nurses consider providing parents with emotional support an important nursing function. Brown and Ritchie (1990) suggested that the nurse's gatekeeping actions prevent optimum provision of emotional support. Research is needed to determine the effects on parents of caring for their child with cancer in the stressful hospital environment and the nurse's role in mitigating these effects.

Ideally, nurses practising FCC provide children with "consistent, emotionally supportive care" (ACCH, 1980b, p.105) when their parents are absent from hospital. The ideal of an ever-present parent is not always possible. Long distances and responsibilities to other children and/or to employers may limit the amount of time parents can spend with their child. Parents have expressed concerns and fears regarding the care received by their child in their absence (Flint & Walsh, 1988; Knafl & Dixon, 1984; Robinson, 1985b). Research examining parents' views of the nurse's role during their absence may facilitate the provision of consistent

family-centred care of children with cancer and alleviate parents' concerns.

Two aspects of FCC have been neglected in the literature. The first of these is the differences between fathers' and mothers' involvement in the care of their hospitalized child. Research indicates that mothers spend more time in hospital with their sick child than fathers do (Knafl, Cavalleri & Dixon, 1988). Knafl and Dixon (1984) described fathers' perceptions of their role with their hospitalized child but did not compare this to mothers' perceptions. Other studies that included both mothers and fathers failed to differentiate their perceptions as well (Knox & Hayes, 1983; Robinson, 1985b). A study comparing and contrasting each parent's perception of FCC would enhance the pediatric staff nurse's ability to provide care that meets the needs of both mothers and fathers. Such care could enhance the parents' abilities to look after their child with cancer and in turn, better prepare the child for life as a survivor of cancer.

Given the research reports indicating that the age at which a child experiences cancer treatment may influence his/her long-term adjustment, the absence of empirical work related to age-specific aspects of FCC is a notable gap in the literature. Although studies have included children of various ages, none have highlighted the differences among parents of children of different age groups (Knox & Hayes,

1983; Robinson, 1985b). Pediatric nurses encounter parents of children of widely varied age and ability. Further research to provide a description of parents' expectations of nurses for children at different ages is needed. These findings could help nurses implement developmentally-appropriate FCC, which might in turn foster favourable long-term adjustment in childhood cancer patients of all ages.

To date, research exploring the relationship between paediatric nurses and parents of the hospitalized child with cancer has been limited. Although Knox and Hayes (1983) included a sample of parents of children with cancer in their study, they did not specify whether or not the concerns of these parents differed from those of children with other chronic illnesses. Research to explore parents' perceptions about how to share their child's care with staff nurses and the resulting relationship is needed. This information will contribute to knowledge about how pediatric staff nurses can provide optimum FCC of the hospitalized child with cancer that better meets the needs of parents.

Purpose of the Study

The purpose of this study is to describe how parents perceive relationships with pediatric staff nurses necessitated by the hospitalization of their child with

cancer. Underlying this study is the assumption that parent-nurse relationships are an inevitable part of parents' lives when their child is hospitalized for treatment of cancer or its complications. The researcher poses the general question: how do parents share the care (physical, emotional and developmental) of their hospitalized child who has cancer with staff nurses? More specifically, the research will be guided by the following questions:

1. How do parents perceive their role in the care of their hospitalized child with cancer?
2. How do parents perceive nurses' roles in the care of their hospitalized child with cancer: (a) when they are present in hospital and (b) when they are absent from hospital?
3. How do parents perceive the nurse's role in caring for parents when their child with cancer is hospitalized?
4. How do fathers' and mothers' perceptions of parent-nurse relationships differ?
5. How do parents' perceptions of parent-nurse relationships vary with the age of the child?

Conceptual Framework

The theoretical framework selected for this study is symbolic interaction, a theory based upon the work of G.H.

Mead. Mead organized the ideas of William James, Charles Horton Cooley and John Dewey into one theoretical perspective, describing the relationship between interaction and society, self and mind (Meltzer, 1967). Various scholars have built on the work of G.H. Mead in developing symbolic interactionist thought, resulting in diverse theoretical perspectives (Turner, 1991). Turner (1991, p.392-394) identified four perspectives common among these writings:

1. Humans create and use symbols to represent their environment and experiences.
2. These symbols have shared meanings, permitting communication among individuals.
3. Interaction is based on the process of role-taking, that is, determining the appropriate response in an interaction by putting oneself in the place of the other.
4. Interaction is the base of both individual development and society. The individual's self develops through interaction and interactions shape society. These are the basic tenets of symbolic interactionism. The following discussion will focus on the aspects of symbolic interactionism pertinent to the interactions between parents and nurses.

In their interactions, human beings assume certain roles. Roles represent society's shared beliefs regarding appropriate behaviour in a specific situation (Burr, Leigh,

Day & Constantine, 1979, p.54). Roles are defined in relation to other roles (Meleis, 1975; Schvaneveldt, 1981). As the context of the situation changes, the role may require modification. Such modification is termed role-making (Schvaneveldt, 1981, p.106).

Blumer (1969) stated that humans interact with objects in their environment. Objects can be physical (a chair), social (a friend) or abstract (an idea). The way an individual sees an object depends on the meaning it has for him/her and that meaning is determined through interactions with others. The individual can also represent him/herself as an object in an interaction. This is termed the self, and as with other objects is defined through interaction. The individual symbolically identifies an object, imagines possible responses and selects the appropriate response. Mead called this process mind (Meltzer, 1967). Through this process, individuals are able to define their situation.

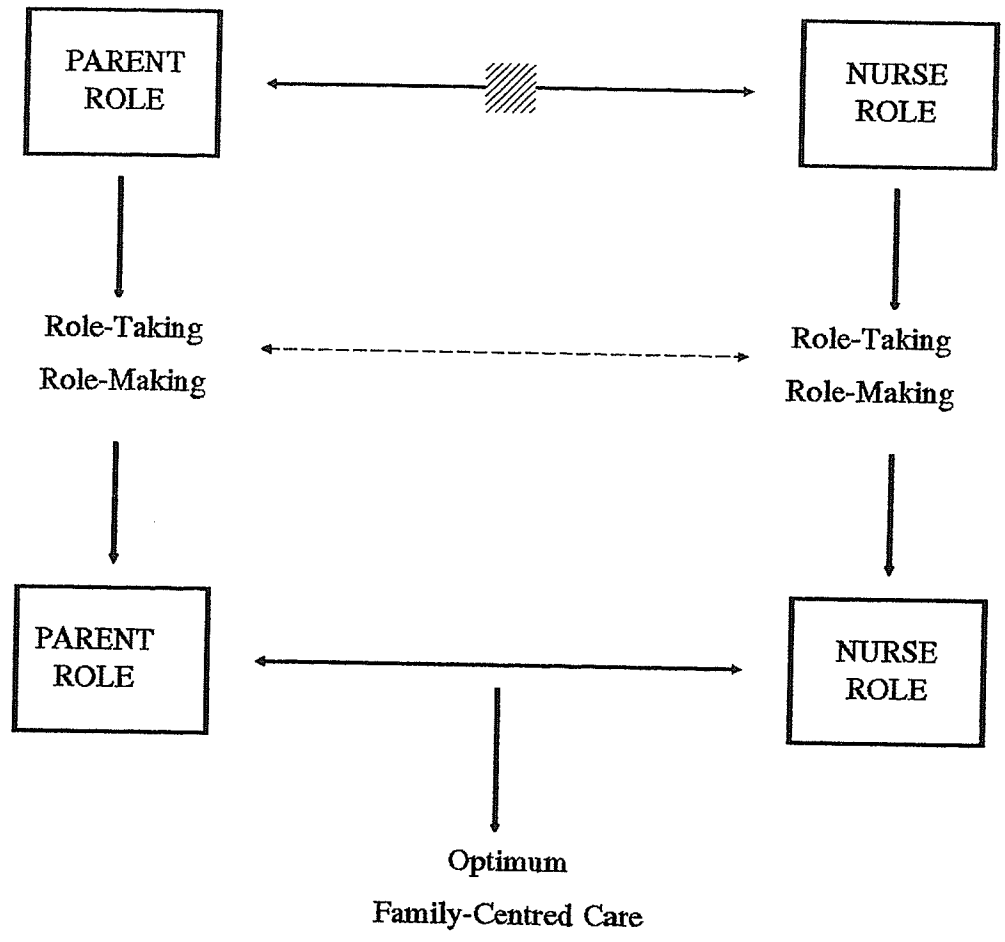
The definition of the situation is the symbolic representation - or meaning - of a situation for an individual (Schvaneveldt, 1981, p.104). An individual's definition of the situation will determine his\her actions in that situation. The process of role-taking contributes to the definition of the situation. Individuals do not simply respond to situations. Instead, they base their actions on their definition of the situation (Blumer, 1969).

Humans can act as individuals or in groups. Blumer (1969) termed such group activity joint action. He describes it as "individuals fitting their lines of action to one another" (p.16). He noted that successful joint action requires that each individual's definition of the situation complement that of the others in the group (p.19).

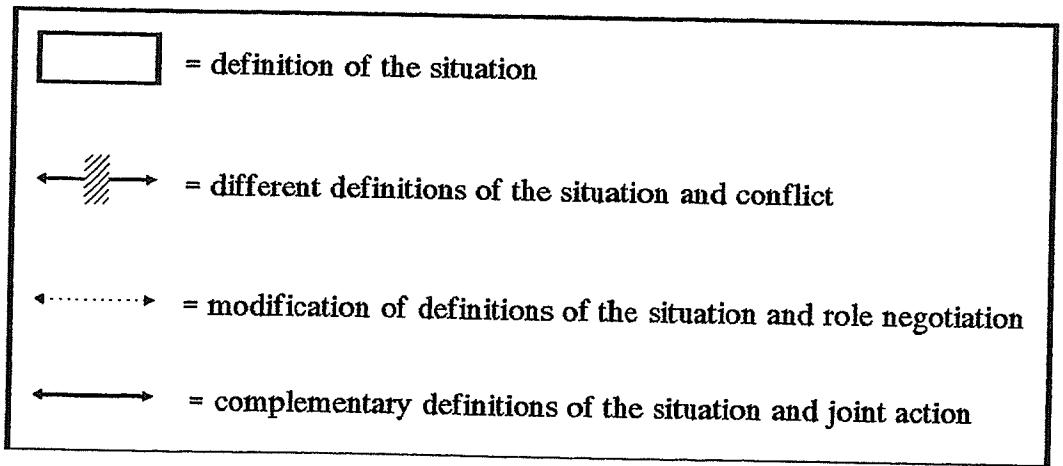
The application of symbolic interactionism to this study suggests that both parents and nurses have specified roles, each defined in part by their relationship to the ill child. The child's hospitalization is experienced differently by each, according to each individual's definition of the situation. Successful family-centred care of the child requires joint action between the parents and the nurse. However, overlap of roles in relation to the child and different definitions of the situation can impede successful joint action.

These difficulties can be overcome through role-taking and role-making. As parents and nurses participate in role-taking, they modify their definitions of the situation, thus making them more complementary. Through role-making, each negotiates his\her role in the situation. As a result, parents and nurses are able to achieve joint action and to provide optimum family-centred care to the hospitalized child with cancer. This process is diagrammed in Figure 1.

Figure 1: Diagram of Proposed Conceptual Framework



Key:



CONCLUSION

Treatment of childhood cancer in the 1990s strives towards cure. Physical cure is possible, but research indicates that curing childhood cancer has immediate and long-term implications (both physical and psychosocial) for child and family. Strategies to deal with these implications must begin at diagnosis. The provision of FCC when children with cancer are hospitalized may be one strategy in helping the child and family deal with their present situation and assist them in preparing for the future.

Relationships between parents of hospitalized children and pediatric staff nurses have many facets. To date, researchers have overlooked this specific relationship, particularly in the context of caring for a child with cancer. Parents' experiences with health care professionals, including nurses, have been examined, but the parent-nurse relationship has not been specifically described. Children with cancer have been included in studies of families' experiences with chronic illness, but the experience of cancer has not been set apart from that of other illnesses. This study will examine the parent-nurse relationship when a child with cancer is hospitalized, examining both parent and nurse roles from the parents' perspectives. Exploring the development of this collaborative parent-nurse relationship can identify factors that may lead to difficulties and uncover possible ways of

preventing them, thus enhancing the FCC provided to children with cancer in hospital.

Symbolic interaction theory provides a useful framework for examining the parent-nurse relationship. Parents and nurses each approach the child's hospitalization with beliefs about their own role and the other's role. The parents' perspective of these roles and their description of how they share their child's care with nursing staff will be studied in an effort to understand how successful joint action between parents and nurses occurs.

CHAPTER TWO
REVIEW OF THE LITERATURE

Introduction

Since the inception of family-centred care (FCC) policies in children's hospitals, researchers have undertaken to examine parental participation in care of hospitalized children from a variety of perspectives. A review of the literature spanning the mid-1960s to the present reveals that specific examination of the parent-nurse relationship has been infrequently attempted. Examination of this relationship in the context of childhood cancer is particularly scarce. However, studies of different aspects of FCC provide valuable background to a study of parent-nurse relationships when a child with cancer is hospitalized. The following literature review has been organized according to three facets of FCC when a child with cancer is hospitalized: parenting the hospitalized child, parent and nurse roles in hospital, and the parent-nurse relationship.

Parenting the Hospitalized Child

Three aspects of parenting the hospitalized child are presented: parents' hospital experiences, perceptions of

nursing care and parental stress during a child's hospitalization.

Parents' Hospital Experiences

A variety of research approaches have been used to determine parents' experiences in caring for their hospitalized child including structured questionnaires, experimentation, semi-structured interviews and observation. Structured questionnaires were used in three studies. Alcock and Mahoney (1990) administered a questionnaire to 22 parents of long-stay children in a Canadian children's hospital to ascertain parents' perspectives on their communication with health professionals and their satisfaction with both their child's care and their role in that care. Results indicated that parents feel comfortable approaching nurses with questions and concerns. The majority of the sample were providing some aspects of care for their child in hospital and about one half were willing to assume more responsibility for that care.

Caldwell and Lockhart (1981) questioned parents (n=155) about their experience in caring for their child on a care-by-parent unit. There were no nurses staffing this unit and all care was provided by parents. Results indicated that parents were satisfied with the experience and felt confident in their abilities to provide care. Both of these studies used questionnaires to determine specific

information regarding the operation of specific units, thus limiting the generalizability of the data.

Sainsbury, Gray, Cleary, Davies and Rowlandson (1986) questioned parents regarding advantages of looking after their hospitalized child; these included an easier adjustment for the child, development of both coping strategies and confidence in their care abilities, and better understanding of their child's care and progress. Parents who had previously remained with their child but had not participated in care preferred active participation. Parents (n=31) answered a questionnaire to determine what they had done, the difficulties they experienced, and feelings about their role. The design of the questionnaire is not detailed in the article and the results presented did not specify how parents defined their roles. Further research utilizing an open-ended interview would be useful to determine role perceptions.

Monahan and Schkade (1985) compared the anxiety levels of two groups of parents: one (n=23) on a care-by-parent unit (CBPU) where parents were responsible for all care for their child, the other (n=18) on a traditional unit where parents were permitted to stay with their child and participate in care as they desired. All children underwent treatment for comparable orthopaedic disorders. A semantic differential scale was used to measure parental anxiety. Parents on the CBPU experienced increased anxiety as

hospitalization progressed compared to parents on the traditional unit. The study did not measure the degree of participation selected by parents on the traditional units. It is possible that these parents participated extensively in their children's care, but had the reassurance of nursing help readily available which lessened their anxiety.

Children may be admitted to hospital for either acute or chronic illness; parents of both groups of children have been studied to determine their hospitalization experiences. Through semi-structured interviews examining how parents (n=24) managed their jobs when their child is hospitalized, Knafl, Deatruck and Kodadeck (1982) found that parents of acutely ill children managed the situation differently than parents of chronically ill children did. Parents of acutely ill children (n=14) believed it was important to alter their daily routines to ensure that at least one parent could spend from seven to 24 hours daily with the hospitalized child. On the other hand, parents of chronically ill children (n=10) were more selective about their visiting, spending time with their child as their daily routine permitted and changing that routine only when hospital procedures considered to be of high priority (e.g., admission, surgery) occurred. Parents also considered the child's level of development, travel time and financial concerns when planning their visits. These parents' repeated experiences with the hospital apparently gave them

the knowledge necessary to make such judgements. Further research is needed to explore how the child's level of development affects parents' visiting patterns and what expectations parents have of nursing staff in their absence.

Knafl, Cavalleri and Dixon (1988) conducted a study of parents' perspectives of their child's hospitalization for non-life-threatening illness or injury. Data were collected through interviews with and observations of families (n=62). Interviews were conducted with both parents during the child's hospitalization and again four to six weeks after discharge. As well, parents were observed during their child's hospitalization. Using a grounded theory approach, the authors identified two levels of parental participation in a child's hospitalization. Parents in Level I approached hospitalization trusting that the nurses would provide the care needed by the child, even in the parents' absence. They perceived that they had no right to hold expectations of the nurses; they did not want to bother the nurses and made requests apologetically. Their participation in care was focused on the child's comfort. Level II parents approached hospitalization with a general mistrust of nurses (and other health care professionals) and assumed a "watchdog" role. They evaluated the nurses continually, increasing or decreasing their trust in them accordingly. They provided comfort care to their child, but also became involved in the initiation of care and tried to influence

nurses' decisions. The two groups were similar demographically except for level of education and income, which were slightly lower for Level I (apologetic) parents than for Level II parents (watchdogs). Future research using a larger sample might prove helpful in determining the extent of the effect education and income have on parent participation. Neither of these levels of parent participation demonstrates a partnership approach to the parent-nurse relationship. This study questioned parents about the hospital experience in general; description of the parent-nurse relationship will require research specifically focused on that topic.

Research suggests that fathers and mothers participate in their child's hospitalization differently, with mothers spending more time in hospital with the child (Knafl, Cavalleri & Dixon, 1988; Knafl, Deatruck & Kodadeck, 1982). Seventy-six percent of mothers (n=62) spent more than half of their child's waking hours in hospital, while only 24% (n=62) of fathers spent that amount of time in hospital (Knafl et al, 1988). The effect that the differing amounts of time spent in hospital has on each parents' perception of the hospitalization is an area for additional research.

Ieni (1977) questioned fathers (n=20) of hospitalized children about their concerns. He administered a questionnaire consisting of a list of possible problem areas, asking fathers to indicate those which were concerns

to them and providing space to list other concerns. Paternal concerns included: seriousness of the child's illness (100%), amount of information received (85%), understanding the information received (75%), and maintaining his father role with the hospitalized child. Lack of detail about the design of the questionnaire and the small sample size suggested that these results be considered cautiously.

Knafel and Dixon (1984) identified two categories of paternal participation according to how fathers carried out their role when their child was in hospital (n=62). Seventy-six percent of the fathers were found to maintain their usual role, while the remaining 24% expanded their role during their child's hospitalization. Fathers in each group demonstrated a different relationship with the nurses. Those who maintained their usual role in hospital trusted the nurses to do what was needed to ensure their child's recovery and provide parents with necessary information. They did not actively participate in their child's hospital care. Fathers who expanded their role in hospital participated actively in their child's care and "did not express a great deal of trust in or value a close working relationship with the nursing staff" (Knafel & Dixon, 1984, p.280).

Although this information about fathers was taken from a larger study including mothers, a comparable discussion of

mothers' responses was not provided. Such a comparison could provide helpful information in planning care to meet both paternal and maternal needs and warrants further study. Because this research only addressed the acute illness perspective, generalizability of the results to parents of chronically ill children is not possible.

Kasper and Nyamethi (1988) used semi-structured interviews to determine the needs of parents of children hospitalized in a pediatric intensive care unit (PICU) (n=15). Of the needs expressed by parents, the most frequently voiced need (80%) was to be with the child in the PICU. Also important were needs to receive frequent and honest information about the child's condition (73%) and to participate in the child's care (67%). Parents also expressed individual physical needs, noting their own needs for sleep (67%), for food and drink (47%) and to take a break away from the child (47%). These findings provided some useful indicators of parental needs, but may not represent the needs of parents of children hospitalized for treatment of cancer or its complications.

Robinson (1984; 1985(a), 1985(b); 1987) conducted semi-structured interviews with nine parents of chronically ill children and found that these parents faced a dilemma when their child was admitted. Their participation in care was encouraged, but the extent and nature of their participation was controlled by hospital staff. Parents who took an

assertive stance were often viewed as demanding and their presence became less welcome. Many parents found it difficult to maintain their efforts to normalize their child's life because of the sick role orientation prevalent in hospitals. Parents were chastised for spending too much or too little time in hospitals. Some parents were reluctant to leave their child because they were unsure of the quality of nursing care he/she would receive in their absence. Robinson's subjects were families with chronically ill children. The report did not specify whether or not any of these children had cancer. The extent to which parental needs are disease-specific is not known, therefore parents of children with cancer need to be studied specifically to describe their experiences in hospital.

Perceptions of Nursing Care

Studies indicate that nurses and patients place importance on different aspects of care (Gardner & Wheeler, 1981; Larson, 1984, 1986, 1987; Mayer, 1987). Gardner and Wheeler (1981) reported preliminary results of a study comparing patients' and staff nurses' perceptions of supportive nursing behaviours. They administered a questionnaire ranking the importance of 67 nursing behaviours to 74 nurses and 119 patients from medical, surgical, and psychiatric areas. To compare cancer patients' and oncology nurses' perceptions of caring behaviours, Larson (1984, 1986, 1987) administered the CARE-

Q (a Q-sort ranking caring behaviours) to 57 nurses and 57 patients. A replication of Larson's study, with the administration of the CARE-Q to 54 patients and 28 nurses, is reported by Mayer (1987). All three studies produced similar results. These researchers found that for patients, sound clinical skills were most important (e.g., monitoring IV's, managing equipment, assessing the patient). Nurses placed more value on their psychosocial support skills. Calderwood and Koenen (1988) questioned parents (n=64) of pediatric oncology patients regarding the nursing services they deemed important from a clinic nurse, and found that technical skill rated highest. Psychosocial support was valued by the parents, but as in previous studies, technical skills received consistently higher rankings.

These findings may have implications for the nursing care of children with cancer and their parents, however further study comparing parents, children's and nurses' perceptions of nursing behaviours is necessary. In particular, a study examining parents' perceptions of services provided to their children diagnosed with cancer by pediatric nurses is needed.

Research suggests that parents perceive staff nurses as too busy to care for and comfort a child (Elfert & Anderson, 1987; Flint & Walsh, 1988). In a study of 31 families of children with chronic health problems, Elfert and Anderson (1987) found that parents perceived nurses as too busy to

provide all the physical care and emotional support needed by the child and parents. These results are considered with caution however, as the methodology for the study is not detailed in the report. As well, the results appear to be part of a larger study pertaining to health care concerns other than nursing care, but this is not definitively stated in the report. Flint and Walsh (1988) interviewed 30 parents of hospitalized children to determine their perceptions regarding hospital visiting policies. They found that one reason parents chose to stay overnight was their perception that the nurses would be too busy to comfort their child when he\she cried. The extent of this perception among parents of children hospitalized for cancer and its implications for FCC require further study.

Parental Stress During a Child's Hospitalization

Studies indicate that changes in the parent-child relationship necessitated by hospitalization are stressful for parents (Hayes & Knox, 1983, 1984; Knox & Hayes, 1984; Miles, Carter, Spicher & Hassanein, 1984). Miles et al. (1984) studied the stress reactions of 36 mothers and 36 fathers of children hospitalized in the PICU. Using Spielberger's State-Trait Anxiety Inventory they determined that mothers and fathers were equally stressed by the PICU experience. Parents were asked to rate stressful PICU stimuli using the Parental Stressor Scale: Pediatric Intensive Care Unit (PSS:PICU). Scores obtained on the

parental role alteration dimension of the PSS:PICU indicated that change in the parent-child relationship is the most stressful aspect of PICU admission for both parents.

Hayes and Knox studied families of chronically ill children, including families of children with cancer (n=24), to determine their perceptions regarding stress experienced during their child's hospitalization. They found that the change in parental role - from primary caregiver to co-caregiver - was the major stressor. The lack of a clearly defined role leaves parents unsure of what they should do. Parents' participation in their child's care is aimed at making the experience a positive one for their child. To do this, parents need consistent, honest information from staff together with assurance that their special knowledge of their sick child will be used in care planning (Hayes & Knox, 1983; Hayes & Knox, 1984; Knox & Hayes, 1983). This study has important implications for pediatric nursing, but the approach taken (i.e., looking for stressors) results in an emphasis on the negative, stressful aspects of the parent-nurse relationship. A research approach that examines the parent-nurse relationship itself may reveal both positive and negative aspects of that relationship.

In summary, parenting a child in hospital is difficult for many reasons. Examination of parents' experiences in hospital indicate that parents do want to be involved in their child's care and that the form such

involvement takes can vary between individuals. Parents' and nurses' views on nursing care can be different. Parents' unfulfilled expectations of nurses may influence the parent-nurse relationship and therefore these perceptions require exploration. Parents' difficulty adjusting to changes in their caregiving role with their hospitalized child necessitates an examination of both parent and nurse roles.

Parent and Nurse Roles in Hospital

In the following section, parent and nurse roles will be discussed separately.

Parent Role

Knafl, Cavalleri and Dixon (1988) studied parents' perspectives of their child's hospitalization. They found that parents included in their role: providing the child with emotional support; basic care; and entertainment. However, they also found that parents at Level II, who demonstrated a general mistrust of nurses, considered monitoring the child's professional care as part of their role as well. Snowdon and Gottlieb (1989) observed mothers (n=12) with their children in the PICU and after transfer to the hospital ward to describe the role they played in their child's care. They identified six roles played by mothers: 1. Vigilant Parent (observing, watching out for and talking to the child; 2. Nurturer-Comforter (soothing the child,

relieving discomfort); 3. Medical Parent (participating in technical care); 4. Caregiver (attending to physical needs and appearance); 5. Entertainer (playing with and amusing the child); and 6. Protector (guarding the child's safety, protecting from self-harm). Of these roles, that of Vigilant Parent was most frequently observed both in the PICU and on the hospital ward, followed by the role of Nurturer-Comforter. The role of Medical Parent was observed more frequently in the PICU, while that of caregiver was seen more often on the ward. Further research is needed to confirm the existence of these roles in various units of the hospital and to determine whether fathers' behaviours are consistent with these roles.

The role of parents in the care of their hospitalized children has been studied from both parents' and nurses' perspectives. Studies by Algren (1985), Beck (1973), Hill (1978), Jackson, Bradham and Burwell (1978), MacDonald, (1969) and Merrow and Johnson (1968) all indicated that parents are prepared to assume a variety of care responsibilities, including helping with activities of daily living (ADL), providing emotional support and assisting with some technical tasks (e.g., recording intake and output, giving medication). Jackson et al. (1978) questioned parents about their desired participation in their child's care on days one and three of hospitalization. They found that although parents' desires changed very little from day

one to three, the most frequent change that did occur was that parents were more willing to increase their participation in technical tasks. Methodological aspects of these six studies are described in Table 1.

Table 1. Summary of Research Examining Parents' Roles

AUTHORS	N	DESIGN
Algren, 1985	20 parents (18 mothers, 1 father, 1 parent pair)	2-part questionnaire: 1. Likert-type scale measuring amount of information received from nurse about parent role (development of scale not detailed); 2. Checklist of 30 child care items indicating who would perform task (adapted from Merrow & Johnson, 1968).
Beck, 1973	38 parents (mothers & fathers, numbers not specified)	Parents attitudes toward participation in care measured using Seidl Parent Participation Attitude Scale (originally designed to measure nurses' attitudes, adapted for parents in this study).
Hill, 1978	18 mothers	Interview; asked to categorize 37 child care items according to what they would do themselves, with the nurse's help or not at all (development of procedure not detailed).
Jackson, Bradham & Burwell, 1978	31 parents or parent substitutes (no other details of sample provided)	Questionnaire; asked to categorize child care items according to what they would do themselves, with the nurse's help or not at all (adapted from Merrow & Johnson, 1968).

AUTHORS	N	DESIGN
MacDonald, 1969	76 parents 71 nurses (no other details of sample provided)	1. Interviews; asked how parents might care for their child and what help they might need 2. Observations of parent- nurse interactions. (Development of procedures not detailed).
Morrow & Johnson, 1978	50 mothers	Questionnaire; asked to categorize 30 child care items as to whether or not a mother would want to include them in her role in caring for her hospitalized child (developed by researcher, pilot tested prior to study).

The small samples used in these studies limits external validity of the findings. Interpretation of the results is limited by the lack of differentiation between fathers, mothers and other caregivers as well as the variety of approaches taken to questioning parents. Three of these studies used a similar tool for data collection (Algren 1985; Jackson, Bradham & Burwell, 1978; Morrow & Johnson, 1968) but applied different data analysis techniques, thus limiting comparison among these studies.

Pediatric nurses have also been questioned regarding their perspective of parental roles in care of hospitalized children. Pediatric nurses believe that encouraging parental participation in care is important (Pidgeon & Sander, 1982). MacDonald (1969) and Morrow and Johnson (1968) found that nurses agreed parents could be responsible

for assisting with ADL and providing emotional support, but were reluctant to have them take more responsibility for technical aspects of care. A study of pediatric oncology staff nurses (n=46) also revealed similar concerns about parents' abilities to safely attend to technical aspects of care (Goodell, 1979). A recent study by Brown and Ritchie (1990) (n= 25) indicated that nurses

expected parents to be active in providing routine nonmedical care, but that they had reservations about parental involvement in many technical and medical activities. They also indicated that a parent's level of involvement in care was determined by the nurses, and that they disapproved of parents who did not provide the type of care that they expected. (p.32-34)

Algren (1985) found that 60% of parents reported nursing staff did not ask parents about the role they desired to play during their child's hospitalization and 70% reported that nursing staff did not explain to them the role they expected them to play. These discrepancies between parents' and nurses' views of the parent's role in caring for the hospitalized child together with the apparent lack of communication suggest potential for, if not actual, conflict. Further research is needed to determine strategies for bridging these differences.

Nurse Role

Studies examining the nurse's role in caring for the hospitalized child are fewer in number than studies examining the parent's role. Pidgeon and Sander (1982) administered a questionnaire to 125 pediatric nurses. They were asked to rate the importance of 43 pediatric nursing functions on a 9-point scale (9 = highly important, 1 = not at all important); reliability of the scale was not determined. The mean score for each function was calculated. The most important pediatric nursing function was found to be providing children with emotional support. Encouraging parents' involvement in care and providing parents with emotional support received the next two highest mean scores, suggesting that nurses consider facilitation of FCC an important part of their role. However, the fact that 49% of the sample of nurses had Master's or Doctoral degrees, together with the lack of a reliability measurement, makes generalizability of these findings to pediatric staff nurses questionable.

Through analysis of interviews, Brown and Ritchie (1990) identified six roles performed by nurses: 1. providing routine nonmedical care (e.g. ADL); 2. providing technical or medical care (e.g. giving medication); 3. being a gatekeeper (controlling parents and children); 4. being an advocate; 5. providing psychosocial care (e.g. emotional support); and 6. providing general care (e.g. coordinating

care or information) (p.30). The role most frequently described by nurses was that of providing psychosocial care. However, the authors noted that this role was often overshadowed by the gatekeeping role. This research suggested that although nurses understand the importance of FCC for children, they have difficulty implementing it. Possible reasons for this include insufficient knowledge of FCC principles, poor communication and conflict management skills, and a hospital environment more conducive to controlling families rather than cooperating with them (Brown & Ritchie, 1990).

Only one study examined the nurse's role from the parent's perspective. Knafel et al. (1988) found that parents' perceptions of the nurses' role differed according to their level of participation. Level I parents, with their greater trust of nurses, believed nurses would determine needs and provide care when necessary, particularly in the parents' absence. These parents gave the nurse the authority to discipline their child in their absence. Level II parents, who generally mistrusted nurses, saw the nurse's role as very traditional and limited to carrying out doctors' orders. The nurse was to be friendly, provide information and help allay the child's fears. Parents at both levels included taking vital signs, giving medications, making beds and providing food and drink as part of the nurses' role. Neither group described a

teaching role for nurses, although any teaching that was done was appreciated.

In summary, research findings indicated discrepancies between parents' and nurses' views of their roles that can result in parent-nurse conflict. Nurses appear uncomfortable with the active roles parents are willing to take in caring for their hospitalized children. The parents' perspective of the nurse's role has rarely been studied and thus is an area for further research.

Parent-Nurse Relationships

Four studies examining the relationship between clients and nurses were found. Of these four, three included parents of ill children as subjects. Brown and Ritchie (1989) identified five types of relationships between pediatric nurses and parents of hospitalized children: 1. reciprocal (parents and nurses responded to each other in a mutually acceptable manner); 2. adversarial (parents and nurses were unable to interact constructively); 3. negotiated (parents and nurses overcame initial difficulties to establish a mutually acceptable relationship); 4. asynchronous (the nurse was able to meet parents' needs despite ongoing difficulties in assessing their needs); and 5. ineffective (the nurses expressed dissatisfaction with their ability to care for the family). Of 49 relationships

described in the interview, 23 were reciprocal and 19 were adversarial. Nurses' care was limited to establishing social rather than therapeutic relationships and that nurses were unaware of the impact their behaviour had on parents.

Role negotiation between parents and nurses was studied by Callery and Smith (1991). Each nurse participating in the study (n=64) was asked to provide written accounts of two critical incidents: one describing an incident where the parent wanted more involvement in care and the other describing an incident involving a parent's desire for decreased involvement in care. A total of 112 accounts were collected and analyzed, resulting in three categories: 1. encouragement (parents encouraged in certain behaviours according to the nurse's expectations); 2. explanation and/or advice ("the nurse either explained why a parent should behave in a certain way or advised the parent to behave in a certain way" (p.778) according to the nurse's expectations; and 3. negotiation (nurse reached an agreement with the parents about their behaviour and did not impose his/her own expectations). The most frequently reported interaction was negotiation, but the authors noted that inter-rater reliability was lowest for this category (reliability score not specified). As well, one of the raters was not involved in or familiar with nursing, and the authors suggested that this different background preparation might have negatively influenced the inter-rater reliability.

Morse (1991) described the development of relationships between nurses and adult patients using a grounded theory approach. Eighty-six interviews with 12 nurses were analyzed; those nurses who had experienced being patients were interviewed from both nurse and patient perspectives. Morse identified two main categories of relationships: mutual and unilateral. Mutual relationships, in which both nurse and client desire the same type of relationship, can be further categorized as follows: 1. clinical; 2. therapeutic; 3. connected; and 4. overinvolved. Each type is characterized by its duration, interaction, the patient's needs, the patient's trust in the nurse, the nurse's and patient's perspective of the patient and the nurse's commitment to the relationship. To increase involvement in the patient-nurse relationship the nurse may break rules for the patient or try to get to know a patients' family, while the patient may assess the nurse to determine if she is a "good person" and "good nurse" or make friendly overtures. In unilateral relationships, one individual desires a deeper relationship than the other. Unilateral relationships can be categorized as 1. grateful; 2. coercive; 3. manipulative; or 4. withdrawn, according to the patient's attitude towards the nurse and towards his\her illness and\or hospitalization. To decrease involvement, the nurse may refuse to chat with the patient and focus interaction on physical aspects of care, while the patient may avoid

personal conversation or become demanding. Although both nurse and patient perspectives were sampled during this study, the fact that the patients were also nurses may have influenced their perspective on being a patient. Similar research with a sample of parents of hospitalized children is needed to determine factors relevant to the development of the parent-nurse relationship.

Research by Knafel et al. (1988) and Knafel and Dixon (1984) indicated that parents often lack trust in nurses' abilities to care for their child. Thorne and Robinson (1988b) combined data from their two studies and identified the importance of reciprocal trust between health care providers and clients. Robinson's study was described earlier in this chapter. Thorne (1985) conducted group interviews with families of middle-aged or older adults diagnosed with cancer; data collection and analysis was done from a phenomenological perspective. Their combined data indicate that "trust from health care professionals fosters trust in health care professionals" (p.786). When professionals trust their clients' abilities to look after their health care needs, clients respond with increased confidence in their abilities. There are three proposed stages in the development of this reciprocal trust (Thorne and Robinson, 1988a). Clients begin with a naive trust that the health professional will always provide the care the client desires. In the second stage, this trust is

shattered when clients realize that this is not always so - information may be difficult to get, and the professionals' goals may differ from the clients'. Clients' anger and frustration at this stage may be seen as interference (Robinson & Thorne, 1984). In the final stage, labelled "guarded alliance", clients develop a realistic trust in health care providers that acknowledges strengths and weaknesses. Nurses can facilitate the development of trust by negotiating mutually acceptable care decisions (Robinson & Thorne, 1984).

Thorne and Robinson (1989) undertook a larger study that upheld the validity of the previously-described three-stage process of development of relationships between the chronically ill and health professionals. Through interviews with 77 adults with a variety of chronic illnesses, the authors identified four types of relationships that can arise out of guarded alliance: 1. hero worship (placing all trust in one individual); 2. resignation (continued to seek health care but did not believe they could be helped); 3. consumerism (sought health care for essential services and did not expect personal needs to be met); and 4. team playing (a negotiated relationship between client and professional, based on reciprocal trust).

Thorne and Robinson's work considered health care providers as a group, from the perspectives of chronically

ill adults, their families and parents' of children with cancer. Further research is needed to specifically explore the development of trust between parents and pediatric staff nurses.

In summary, the relationship between client and nurse can take many forms. All these studies, except those by Thorne and Robinson, looked at this relationship from the perspective of the nurse. Further research is needed to determine parents' perspectives on the parent-nurse relationship.

Conclusion

Research examining the parent-nurse relationship when the child with cancer is hospitalized has been almost non-existent. Studies of the parent-nurse relationship that have been undertaken are predominantly conceptualized from the nurse's perspective. Particularly noticeable is the absence of research examining the parents' view of the staff nurses' role with their hospitalized child. The review of literature provided support for pursuing the research questions previously discussed. The scarcity of research in this area indicated that the application of a qualitative research methodology was appropriate.

CHAPTER THREE

METHODOLOGY

Introduction

A modified grounded theory methodology was selected as the research approach for this study. This chapter will outline why a qualitative methodology in general, and grounded theory in particular, are suited to answering the research question. The application of modified grounded theory techniques in this study will be described. Measures to enhance rigour in the study will be detailed. Ethical considerations will be addressed as well.

Selection of the Research Methodology

Qualitative analysis is defined as "the nonnumerical organization and interpretation of observations for the purpose of discovering important underlying dimensions and patterns of relationships" (Polit & Hungler, 1987, p. 535). There are two reasons for its suitability to a study of the parents' perspective of the parent-nurse relationship when a child with cancer is hospitalized. Firstly, a qualitative approach is recommended when knowledge about a phenomenon is sparse (Field & Morse, 1985; Sandelowski et al, 1989; Stern, 1980). The review of the literature indicates that although

research has examined a variety of aspects of parents' participation in the care of their hospitalized children, the specific phenomenon of the parent-nurse relationship when a child with cancer is hospitalized has rarely been studied. Thus, a qualitative examination of this phenomenon was appropriate.

Secondly, a qualitative approach allows the investigator to examine a phenomenon from the emic perspective, that is, from the perspective of the individual experiencing it (Field & Morse, 1985). Therefore, it was appropriate for a study of the parent-nurse relationship from the perspective of parents of children hospitalized for treatment or complications of cancer. Lutzen and Tishelman (1991) supported the need for qualitative examination of patients' perceptions of nursing practice, arguing that whereas quantitative research tends to separate affective aspects of nursing practice from instrumental aspects, a qualitative approach allows for examination of links between them.

The qualitative method selected for this study is a modification of grounded theory. Grounded theory is a research approach developed to study social processes (Chenitz & Swanson, 1986). As such, it is suitable for the study of the relationship between parents and nurses when children with cancer are hospitalized. Stern et al. (1984) suggested that grounded theory is particularly suited to

studies in nursing, likening the constant comparison integral to grounded theory with the nursing process. The grounded theory approach is described in the following section.

Description of Grounded Theory

The grounded theory approach is associated with the symbolic interactionist perspective (Chenitz & Swanson, 1986). Symbolic interactionism holds that humans interact using symbols, and that such interaction influences human behaviour. Grounded theory provides the researcher with a means to study human behaviour and interactions (Chenitz & Swanson, 1986).

Grounded theory methodology was first developed in the 1960s by sociologists Barney Glaser and Anselm Strauss. They identified a need for a research approach that would allow for the development of new theory, rather than the verification of existing theories (the prevalent sociological research activity at the time). To meet this need, they advocated the generation of theory from data obtained in social research. They argued that such a theory, "grounded" in data, would most accurately reflect the social process studied (Glaser & Strauss, 1967).

Both quantitative and qualitative data may be used to develop grounded theory. However, in studying social

processes, a qualitative approach often produces data that better reflects the intricacies of human interaction (Glaser, 1978; Glaser & Strauss, 1967). Appropriate methods of data collection include interviews and participant observation. Analysis of data in grounded theory is characterized by "constant comparative analysis" and "theoretical sampling" (Glaser & Strauss, 1967).

Grounded theory requires that data collection and analysis occur simultaneously. Constant comparative analysis involves comparison of each incident in the data with all other incidents in the data, resulting in coding and categorization of the findings. Newly collected data is compared with previous data. As data is collected, coded and categorized, the researcher begins to identify relationships among categories and poses hypotheses about these relationships. Memos - the researcher's theoretical notes to him/herself- are written as these ideas emerge, forming the beginnings of the eventual theory. Hypotheses are tested through theoretical sampling (collection of data specific to the questions raised by previously-collected data). This process continues until saturation occurs, that is, data collection ceases to yield new information. The final step is development of theory from the analyzed data (Charmaz, 1983,1990; Corbin, 1986a; Glaser, 1978; Glaser & Strauss, 1967; Lincoln & Guba, 1985; Stern, 1980; Strauss,

1987). Strategies for data collection and analysis will be described in detail in the following section.

Design of the study

This section describes the application of a modified grounded theory approach to the research question: How do parents share the care (physical, emotional and developmental) of their hospitalized child with cancer with staff nurses? It includes descriptions of prospective participants, plans for data collection and methods used for data analysis. Data collection and analysis are discussed separately in this section for ease of description, although during the course of the study they occurred simultaneously, as is consistent with grounded theory methodology.

Study participants

The study population consisted of parents (mothers and fathers) of children who had been hospitalized for treatment or complications of cancer. A purposive, theoretical quota sampling method was used to recruit 16 parents. This approach was selected because it provided objective means to recruit participants whose experiences with nursing staff may have been very different owing to the variations in their children's illnesses. It allowed for a more complete comparative analysis than a convenience sample would have permitted.

An attempt was made to recruit two categories of parents: (a) uncomplicated (parents of children admitted to hospital only for regularly scheduled treatment) and (b) complicated (parents of children admitted to hospital for a period of greater than one week and/or for reasons other than regularly scheduled treatment). Parents suitable for recruitment to each category were identified by the pediatric oncology team at Children's Hospital. Ultimately, the parents who chose to participate in the study were all categorized as "complicated", making comparisons of "complicated" versus "uncomplicated" parents impossible. However, data analysis did reveal some differences among parents related to the frequency and length of their child's admissions; these are discussed further in this report.

The limitations placed on this sample, described below, are one aspect of the modification of grounded theory for this study. The study sample consisted of 16 parents of ten children. This sample size is appropriate for a qualitative study because of: (a) the expectation that a large volume of data would be produced, (b) the limited time available for this study, and (c) the expectation that such a sample would produce sufficient data to allow categories to emerge.

The children of the parents who participated in the study were younger than twelve years of age. This limitation was placed on the sample to permit comparison of parent-nurse relationships according to developmental level.

Adolescents were excluded because the developmental tasks facing teen-agers affect their relationship with their parents and this, in turn, could result in changes in the parent-nurse relationship (Whaley & Wong, 1983). Too wide a range of developmental differences could impede the saturation of categories.

For the purpose of sample selection, hospitalization of the child referred to a minimum of two hospital admissions for scheduled treatment and/or unexpected complications of cancer. As well, the child must have experienced at least one admission within the previous year. These specifications ensured parental experience in working with pediatric staff nurses. However, these admissions did not include the admission during which the diagnosis of cancer was confirmed. No limitations were placed on the type of cancer diagnosed in the child, however, parents of children for whom a quick, downward trajectory was anticipated were not admitted to the study. These limitations were made on the basis of ethical consideration for participants, by not making demands on parents at an extremely stressful time.

Parents recruited into the study also met the following requirements:

1. Fluency in English, both written and spoken
(ensuring that parents understood the study and were able to participate in the interview);

2. Accessible by phone to arrange interview (for ease of conducting study).

Potential participants were recruited through the Manitoba Cancer Treatment and Research Foundation (MCTRF). Letters from the researcher explaining the study and requesting participation (Appendix A) were addressed and mailed to parents by a secretary at the MCTRF. Care was taken not to include parents of newly-diagnosed or dying children in this mailing. This initial letter explained to parents that they would be contacted by a secretary at the Foundation to ask for their permission to release their name and phone number to the researcher. The researcher then telephoned the parents who gave their permission, providing them with a more detailed description of the study (Appendix B). Interested parents were admitted to the study once it was determined that they met the criteria previously outlined.

Data Collection

Interview.

This study explored parents' perceptions of their experiences in caring for their hospitalized child with cancer. The selected method of data collection reflects the other modification of grounded theory made for this study. Rather than combining interviews with participant observation, data were collected through interviews. This method is best suited to eliciting parents' descriptions of their perceptions. Mothers and fathers were interviewed separately, in an effort to obtain unique, individual perspectives that may not have been revealed in a joint interview. After both interviews were completed, parents were given the opportunity to meet with the researcher as a couple to discuss their interviews.

Unstructured interviews, as described by Swanson (1986) were used for data collection. The interview guide developed for the interview provided a general outline for questioning, but it was not rigidly adhered to. This allowed the interview to take the form of a conversation (Schatzman & Strauss, 1973).

Each interview was tape-recorded. The interviews were conducted in the participants' homes. Each interview was between 45 and 90 minutes in length. Each participant was interviewed once.

The initial interview guide was developed through a review of the literature and the researcher's previous experience with this population (Appendix C). Pilot-test interviews were conducted with the parents of a child who had been hospitalized for treatment or complications of cancer in the past (i.e., more than one year ago) to allow for refinement of the interview guide. As data collection occurred, theoretical sampling led to modification of the interview guide (these are included in Appendix C).

Theoretical sampling proceeded along two lines: firstly, to examine and compare parents' experiences and perceptions and secondly, to examine differences among age groups. This latter line of theoretical sampling was limited by the fact that the majority of parents participating in the study had children in the same age group.

The interview began with social talk to establish the conversational tone of the interview (Swanson, 1986). Then, the disclaimer was read to participants; participants were encouraged to ask questions before proceeding with the interview. Following a brief introduction to the research, participants were reminded that the interview could be stopped at any time, that they could refuse to answer any question, and that they could feel free to ask the researcher questions if they arose during the interview. Tape-recording of the interview then commenced.

The interview took Gorden's funnel approach, as described by Swanson (1986). The first question was general, and the participant's response determined the direction of further questioning. A variety of probes were used throughout the interview. These included silent probes and neutral probes (e.g., hmmm...) that indicated to the respondent they have been heard and permitted them to continue voicing their thoughts (Swanson, 1986). Other probes included those to determine chronology (And what happened then?), examine detail (Tell me what it was like), clarify a statement (I'm not sure I see what you mean) and request explanation (Why?) (Schatzman & Strauss, 1973, p.74).

The interview was closed in a tentative fashion, informing the participant that telephone contact or another interview may be required (such interviews proved to be unnecessary). After completion of the interview, participants were given the opportunity to discuss concerns that arose during the interview.

Cowles (1988) noted the importance of considering in advance the possible emotional reactions of participants when they are interviewed about a sensitive topic. In this study, it was possible that the interview could be emotionally difficult for parents, as it revolved around the fact that their child has a life-threatening illness. When a participant become distressed, the tape-recorder was shut

off and the interview was resumed when the participant felt comfortable continuing. If necessary, referral to an appropriate professional was made: these referrals are addressed in greater detail in the discussion of ethical considerations. Nursing interventions (e.g., correcting misinformation) were implemented on completion of the interview when necessary. Such actions may have affected the data collected. However, efforts to maintain validity of the data could not overshadow the nurse researcher's ethical obligations to participants (Robinson & Thorne, 1988).

Demographic Tool.

A demographic questionnaire was administered to participants verbally upon completion of the interview (Appendix D). The information collected provided a description of the sample and it was useful in guiding data analysis and theoretical sampling.

Organization of Data

Qualitative research produces large amounts of data, necessitating a well-planned approach to data organization. Data were collected in two blocks of eight interviews each to facilitate thorough analysis of data. One set of interviews was analyzed before the second set of interviews commenced, allowing the researcher to examine the data and determine the direction of theoretical sampling in subsequent interviews. Interview tapes were transcribed by

a clerical assistant as soon as possible after the interview. The researcher used the computer program Ethnograph® to facilitate data management. The following organizational system was used: 1. When arrangements for an interview were made, the participant's name, address, interview location, and phone number(s) were recorded on an index card. Each participant was assigned a number, which was recorded on the card; 2. Upon completion of each interview, an interview summary sheet was filled out with the following information: interview number (indicating participant number and interview guide used); date, time and place (e.g., home, work) of interview; and notes regarding the interviewer's general impression of the interview; 3. Tapes were labelled with the interview number; 4. Transcripts of interviews were kept on computer disc and printed as needed. Transcripts were labelled with the interview number; and 5. The demographic data sheet was labelled with the participant number. Measures to ensure confidentiality were used when handling all data; these measures are detailed further in this chapter.

Data Analysis

Data analysis began after transcription of the first interview and continued throughout data collection. Data analysis reflected four phases outlined by Corbin (1986b, p.111-117).

Phase one: Corbin's phase one corresponds with Glaser's and Strauss' descriptions of "open coding" (Glaser, 1978; Strauss, 1987). In this phase, the initial coding and categorization of data occurred. Coding involved examining the transcript line-by-line and word-by-word and placing conceptual labels on facts and incidents in the data. Coding was guided by the coding paradigm suggested by Strauss (1987), in which data are coded for conditions, interaction among actors, strategies and tactics, and consequences (p.27-28). Soon after the initial coding, data were re-coded to reflect a slightly higher conceptualization of the data. Categorization involved grouping together codes that have similar properties. In this phase, memos were directed towards the grouping of codes into categories.

Phase Two: The next step was to build up the categories. This occurred through "axial coding", which involves "intense analysis done around one code at a time" (Strauss, 1987). The coding paradigm previously described was used in this process. Theoretical sampling was directed towards getting the data necessary to build categories, making them dense.

Phase three: At this stage, the researcher began to hypothesize about relationships between categories. Theoretical sampling was used to test these hypotheses. This was accomplished through modification of the interview questions. For example, the hypothesis that a parent's

involvement in care varied according to characteristics of their child led to questions about the child's response to hospitalization and the child's previous experience with being away from his\her parents.

Phase four: Finally, "selective coding", in which coding and theoretical sampling are geared towards identifying the core category (or categories), occurred (Strauss, 1987). The core category is the one to which all the other categories can be linked; it is "a category that is central to the integration of the theory" (Strauss, 1987, p.21).

Throughout this process, the researcher kept theoretical memos that reflected the codes, categories and relationships between them and helped to determine the direction that theoretical sampling must take. These memos formed the basis of the developing theory.

Measures to Enhance Trustworthiness

Quantitative studies are judged according to their validity and reliability. These criteria have been deemed inappropriate for use with qualitative data (Kirk & Miller, 1986; Lincoln & Guba, 1985; Sandelowski, 1986; Yonge & Stewin, 1988). Lincoln & Guba (1985) suggested that rather than assessing a qualitative study's validity and reliability, it be judged for the trustworthiness of its data. They propose four areas for consideration in making such an assessment.

1. Truth value. The truth value of a study is judged according to its credibility. A study is considered credible when the description of phenomena it provides is such that individuals experiencing the phenomena would recognize it as their own (Sandelowski, 1986). Three strategies to enhance credibility, proposed by Lincoln & Guba (1985), were used in this study.

The first strategy to enhance credibility is prolonged engagement, that is, spending sufficient time in the field to recognize and overcome distortions in the data and to gain trust from study participants. Secondly, peer debriefing was used. This involved discussions with the thesis advisor and with nursing colleagues about emerging hypotheses and the direction of data collection, and provided an opportunity to clear "the mind of emotions and feelings that may be clouding good judgement or preventing emergence of sensible next steps" (Lincoln & Guba, 1985, p.308). Thirdly, member checks were implemented throughout the study. This involved presenting data and interpretations from previous interviews to the participants for their feedback.

2. Applicability. A study's applicability is judged according to the "fittingness" of its results, that is, their ability to describe the phenomenon outside of the context of the study situation (Sandelowski, 1986). Although such transferring is difficult to do with

qualitative studies, it is necessary that a sufficiently detailed description of the results be provided to allow readers to judge whether or not the findings fit in other situations (Lincoln & Guba, 1985; Kirk & Miller, 1986). The final report of this study provides such a description.

3. Consistency. Consistency is assessed by examining a study's "auditability". A study is "auditable" when its methods are described in sufficient detail to permit another researcher to follow those methods (Sandelowski, 1986). These methods are detailed in the final report of this study.

4. Neutrality. A study's neutrality, that is, freedom from bias, is judged according to its "confirmability". A study that is found to have truth value, applicability and consistency will have achieved neutrality (Sandelowski, 1986). Lincoln and Guba (1985) also advised the use of a reflexive journal in which personal reflections and the methodological decision-making process can be recorded. Along with the theoretical memos inherent in the grounded theory method, this researcher made notes of a more personal nature. The interview process brought to mind previous experiences in working with parents of children with cancer. Writing these experiences helped to reveal researcher assumptions and biases that may have influenced the study.

Ethical Considerations

Ethical treatment of participants was considered throughout the study. Prior to commencing the research, ethical approval was obtained from the Ethical Review Committee of the University of Manitoba Faculty of Nursing (Appendix E). Ethical concerns with this study included: 1. ensuring informed consent; 2. maintenance of confidentiality; and 3. minimization of risks.

Informed Consent

Parents contacted by the researcher over the telephone received a verbal description of the study. Participants were reminded that their participation was voluntary and that they could withdraw at any time during the study at three points: 1. in the phone explanation; 2. in the consent form; and 3. at the beginning of the interview. A disclaimer was read and signed by the participants (Appendix F). Participants were encouraged to ask questions about the study before beginning the interview.

Maintenance of Confidentiality

All data and personal information received during the study were kept confidential. Initial recruitment letters were sent by a secretary at the Manitoba Cancer Treatment and Research Foundation; names and addresses were not released to the researcher. Access to data (summary sheets, tapes, transcripts (on disc and printed) and demographic

information) were limited to the researcher, her advisors and the clerical assistant transcribing the interviews. The secretary assisting with the recruitment procedure knew the names of parents who consented to being contacted by the researcher, but did not know the names of parents who agreed to take part in the study. Members of the pediatric oncology team knew the names of parents recommended for recruitment, but did not know who of these individuals ultimately chose to participate. Identities of participants were known only to the researcher.

Data organization methods ensured confidentiality. Names, addresses and identification numbers were written on index cards and kept locked in a safe place. Other data were labelled with an identification number, and kept locked separately from the index cards. All data will be retained for seven to ten years and will be kept in a safe place during that time. This data may be used in secondary analysis during future studies. Confidentiality has been maintained in this report and will be guarded in future publications and presentations that arise from this or subsequent studies (e.g., pseudonyms have been used and other identifying details have been changed).

Minimization of Risks

Efforts to minimize risks to subjects were implemented beginning with recruitment of subjects. Parents of newly diagnosed or dying children were not recruited so as not to

add to parental anxiety at an already difficult time. Efforts to minimize risk were particularly evident during the interviews.

It was possible that participants would experience psychological distress during the interview. This was because their participation in the study revolved around the fact that their child had been diagnosed with cancer, a potentially life-threatening illness. To protect participants, parents were reminded (at the beginning of each interview) that should they wish to stop the interview at any time, their request would be honoured. If a participant became distressed during the interview, the tape-recorder was shut off and the interview resumed only when the participant agreed. Professional referrals to the pediatric oncology team at Children's Hospital were to be made if necessary. The researcher suggested that the participant speak with the appropriate team member (e.g, nurse clinician, doctor, social worker). The interview ended with a debriefing session, in which parents were offered the opportunity to discuss feelings or concerns that may have arisen as a result of the interview. Although there were no direct benefits for participants, some may have benefitted by feeling that their participation would help others experiencing the same situation. Parents were offered the opportunity to request a report of the results of the study (Appendix G).

Conclusion

This chapter has described the grounded theory approach to qualitative research, demonstrating its suitability for examining parents' perspectives of the parent-nurse relationship when a child with cancer is hospitalized. Descriptions of participants, data collection methods and data analysis techniques were presented. Strategies used to enhance the trustworthiness of the data were described. Ethical considerations were addressed as well.

CHAPTER FOUR

FINDINGS

Introduction

This chapter includes the results of the study. In the first section, a description of the study sample is reported. The second section consists of an analysis of the interviews, presented as a conceptual framework that describes the parent-nurse relationship in family-centred care of the hospitalized child with cancer. Parents' perceptions of the care they and the nurses provide to their hospitalized child with cancer are discussed. Specific factors influencing this care are also presented. Finally, the relationship between parents and nurses is examined. Throughout this discussion, excerpts from the interviews are used to illustrate the findings.

Description of the Sample

The study sample consisted of sixteen parents of ten children with cancer. The term "parents" refers to the individuals with primary responsibility for day-to-day care of the child. In all but two cases, this care was provided by the child's natural parents. Ten mothers and six fathers were interviewed. All six fathers were employed full-time

outside the home; of the six mothers employed outside the home, four worked full-time and two worked part-time. Ten of the parents participating in the study had a high school diploma or lower level of education. Of the sixteen parents interviewed, fifteen lived within the City of Winnipeg. All but one parent were Caucasian.

The children in the study were between 21 months and eleven years of age at the time of the interview. Five of the children had leukemia; six had been diagnosed less than two years ago. Two of the children were only children, while the remainder had between one and six siblings. Three of the children lived in single parent households headed by the mother.

All of the children were admitted to the same tertiary care children's hospital; three of the children had also experienced admission to other hospitals. The frequency of admissions ranged from a low of three to a maximum of greater than ten (three of the children had been admitted so often that their parents had lost count of the number of admissions). All of the children had been admitted at the time of diagnosis, and all had been admitted at least once for treatment of complications. Eight of the children had been admitted for chemotherapy treatment. The duration of admissions ranged from overnight to eleven weeks. The characteristics of the sample are detailed in Table 2.

Table 2: Demographic Profile of Study Participants

CHARACTERISTIC	CHILDREN n=10	MOTHERS n=10	FATHERS n=6	SIBLINGS n=23
<u>Current Age</u> <u>Children/siblings</u>				
< 1	0			1
1-5	6			9
6-10	3			7
10-15	1			2
16-20	0			2
<u>Adults</u>				0
21-30		3	1	
31-40		6	4	
> 40		1	1	
<u>Age at Diagnosis</u>				
< 1	1			
1-5	8			
6-10	1			
<u>Education</u>				
Some high school		3	1	
High school diploma		3	1	
Post secondary		4	4	
<u>Employment</u>				
Homemaker		3	0	
Employed outside home:				
full-time		4	4	
part-time		2	0	
Other (self-employed, student)		1	2	
<u>Diagnosis</u>				
Leukemia	5			
Brain Tumours	3			
Other	2			
<u>Duration of Illness</u>				
<1	1			
1-3	8			
>3	1			
(Range = 6m-11yrs)				
<u>Frequency of Admissions</u>				
<3	0			
3-5	3			
6-10	3			
>10	4			

CHARACTERISTIC	CHILDREN n=10	MOTHERS n=10	FATHERS n=6	SIBLINGS n=23
<u>Number of Siblings</u>				
0	2			
1-2	5			
>2	3			

The Conceptual Framework

The analysis of interviews resulted in the development of a conceptual framework of the parent-nurse relationship in family-centred care of the hospitalized child with cancer. This conceptual framework consists of three main themes: Nurses and the Care They Give; Parents and the Care They Give; Parents and Nurses: The Care They Give. These themes are detailed below. The conceptual framework is summarized in Figure 2.

Figure 2: Summary of the Conceptual Framework of the
Parent-Nurse Relationship

Theme #1

Nurses and the Care They Give

I. Nursing care

A. The Basics

1. Organizing Physical Care
 - (a) Providing Illness Care
 - (b) Providing Everyday Care
2. Providing Information

B. The Human Touch

1. Individualizing Nursing Care
 - (a) Individualizing children's care
 - (b) Individualizing parents' care
 - (c) Individualizing children's and parents' care
2. Sharing Information
 - (a) Informing
 - (b) Inviting
3. Going Above and Beyond the Call of Duty

II. Nursing Care: Outcomes and Effects

- A. Going Through the Motions → Just a Number
- B. Caring Incompletely → Unsafe
- C. Caring Completely → Special Care

III. Nurses

- A. Time-Clock Punchers
- B. From-the-Heart Caregivers

IV. Conditions Influencing Nursing Care

A. Hospital Life

1. Nurses are busy
2. The Ward
 - (a) Specialty
 - (b) Familiarity
3. Hospital Hierarchy
4. Secret Information

B. The Parents

1. Parents' Presence
2. Parents' Behaviour

Figure 1 (cont'd)

Theme #2

Parents and the Care They Give

- I. Parent Care: Making it Better
 - A. Just Being There
 - B. Providing Everyday Care
 - 1. Attending to Nutrition
 - 2. Attending to Hygiene
 - 3. Attending to Elimination
 - C. Providing Illness Care
 - 1. Medicating
 - 2. Performing Procedures
 - 3. Keeping Comfortable
 - 4. Monitoring
 - D. Providing Supportive Care
 - 1. Easing Trying Times
 - 2. Interpreting
 - 3. Being a Voice
 - 4. Making it Fun
- II. Parent Care Profiles
 - A. Intensity of Involvement
 - B. Constancy vs Change
 - C. Routine vs Unpredictability
- III. Conditions Influencing Parent Care
 - A. Life Outside the Hospital
 - 1. Responsibilities
 - 2. Supports
 - B. Life Inside the Hospital
 - 1. Surroundings
 - 2. Nurses
 - 3. What's Allowed
 - 4. Familiarity
 - C. The Way I Am
 - D. The Way My Child Is
 - 1. Development
 - 2. Behaviour

Theme #3

Parents and Nurses: Working Together

- Working Together
 - A. Territorial Caring
 - B. Sharing Care
 - C. Making Friends

Nurses and the Care They Give

The first theme, Nurses and the Care They Give, consists of four components: Nursing Care, Nursing Care: Outcomes and Effects, Nurses, and Conditions Influencing Nursing Care. The following section describes each of these components.

Nursing Care

Nursing care was defined as what the nurse did to look after the hospitalized child and his/her parents. Parents described two types of nursing care: A. The Basics and B. The Human Touch. These are summarized in Table 3. Each of these types of care will be discussed separately.

Table 3: Summary of Nursing Care

A. THE BASICS	B. THE HUMAN TOUCH
1. Organizing Physical Care (a) Providing Illness Care (b) Providing Everyday Care 2. Providing Information	1. Individualizing Nursing Care (a) Child (b) Parent (c) Child and Parent 2. Sharing Information (a) Informing (b) Inviting 3. Going Above and Beyond the Call of Duty

A. The Basics. This type of nursing care was defined as the provision of the bare necessities of nursing care. Parents described the activities that the nurse must

undertake to keep the child and parents safe and informed.

Two strategies for providing The Basics were identified:

1. Organizing Physical Care, and 2. Providing Information.

1. Organizing Physical Care - This strategy included nursing behaviours that ensured that the child's physical needs were met during hospitalization. These nursing behaviours were categorized as: (a) Providing Illness Care, and (b) Providing Everyday Care.

(a) Illness Care. This was defined as the nursing behaviours necessitated by the child's illness. This care included administration of medications and treatments, maintenance of IV infusions, moving a child post-operatively and monitoring the child's status.

...they always seemed to know how to move him. And they'd set things up, they didn't just come in to move him, there was a method...you had to move this pillow, or move that, and get this sheet ready. They were organized, they knew what to do. And then when he had chest tubes in, and they had to drain, and so they were measuring the fluid...when they come out of surgery there's so many things you're watching for. They'd check his B.P., then the last surgery they had problems, he was on oxygen for a week afterwards. And they were checking his oxygen levels...

Parents expected that a nurse will have the skills necessary to provide the care their child needs. In the words of one mother: "...that's a given...that's your profession, that's what I consider a basic requirement in all nurses".

(b) Providing Everyday Care. This was defined as nursing behaviours related to the child's activities of

daily living. Providing Everyday Care included feeding and bathing the child and changing diapers.

2. Providing Information - The second strategy for providing The Basics was labelled Providing Information. This was defined as giving the parents the facts required to function during the hospitalization and afterwards. At the time of admission, the nurse introduced parents to the ward. During the hospitalization, he\she taught the parents necessary aspects of technical care required in home or hospital: "...that's part of their job too. They teach you [to care for the central line], they know you have to do it..." Throughout their hospital stay, the nurse answered parents' questions and updated them on their child's condition and treatment plan. "I think they should be able to answer any question that you may have and let you know what's happening. If there is any inkling of anything else happening, you want to know." One father described a negative experience when provision of information did not occur: "The nurse told me it was nothing to worry about, but then I thought I overheard her saying that it was a concern to the doctor, it was like she didn't want to tell me the truth..." Parents reported that they did not want to be "protected" from the truth.

In summary, The Basics included two strategies: Organizing Physical Care (composed of Providing Illness Care and Providing Everyday Care) and Providing Information.

B. The Human Touch. This type of nursing care was defined as the provision of humanistic aspects of nursing care. As described by one father, "...there has to be that human element involved...you have to have an understanding and draw an association or a bonding with the family and particularly the patient..." Three strategies for providing The Human Touch were identified: 1. Individualizing Nursing Care; 2. Sharing Information; and 3. Going Above and Beyond the Call of Duty.

1. Individualizing Care - The first strategy for providing The Human Touch referred to nursing behaviours that take into account the unique personality and circumstances of the child and parents. These behaviours can be directed at (a) the Child; (b) the Parents; or (c) Both Child and Parents.

(a) Individualizing the Child's Care. Parents identified three nursing behaviours which individualize a child's care:

(i) Interacting. Interacting referred to the nurse's developmentally appropriate interactions with the child. Parents appreciated the nurses who made the effort to speak to the child when providing care. One mother noted the different approaches:

You'll see them come in and joke and they play, at the same time they'd be giving medicine. And others will come in and they're in a hurry or they're cheesed off at what the kid next door did. It's funny for me, but not for the child in the bed, where it's "Here's your medicine, I'm out".

Sometimes my child would start interacting or play a game or ask a question, or do something silly, and some nurses would stay and acknowledge what she was doing, and others would just "OK, yeah, goodbye".

Talking to the child is also important when his\her level of consciousness is poor, or when the child is developmentally disabled. The mother of a child with Down's Syndrome said:

...the child needs to know that this person...coming into the room is going to be somebody who cares about me, and how you care about me is you talk to me face to face, you're not going to talk at mom and say, "Well, do you think he understands this?...and I say, "Well, ask him", and they'll ask..."Well, how will he let me know?", and I would tell them...Now the nurses mostly know him, they don't ask me anymore. They know he has his ways of communicating.

Taking a kind but firm approach with the child when he\she misbehaves was also seen as an important interaction, particularly by parents who could not be with their child all the time.

There was a time when he would ...strike out at nurses. There was one nurse...she was quite good and she was very firm with him. She told him, "Look, you don't do that", I was really impressed with her professionalism...I definitely appreciate that. I mean, we want our child to grow up to be a good person...you shouldn't hit people, and he should be told.

Familiarity with the child's world (e.g., knowing which toys, cartoons or sports are popular with the child) was seen as an asset to successful interactions with the child. Parents reported that interactions should also recognize the child's developmental needs, for example, giving the child as much control as possible over daily activities,

intervening to make sure a child is not bored or lonely and, when a child's first language is not English, assigning a nurse who speaks that language whenever possible.

(ii) Befriending. The second nursing behaviour identified pertains to the nurse's efforts to take the time to get to know the child and develop a relationship with him\her. In the words of one mother: "They'd come in and just talk to him...try to make friends with him. I mean, you have to take care of them, it's good to know your patients, and that was what they were trying to do." One father particularly appreciated the nurses' consistent effort to befriend his daughter:

...their constant trying to break through her shell was something that was important...she was very withdrawn, not at all her own personality. She would just stare at the walls and when a nurse would come in...she would just turn away and not acknowledge them, not answer them...it took a while, but over a period of time they finally gave her confidence and became friends with her. Even though they were doing all these horrible things to her, they became friends with her...Just them never giving up on her was something else...was important for me...

Parents believed that the development of a relationship with the nurses made their child's hospital experience a more positive one.

(iii) Overcoming Reluctance. The third behaviour identified involves taking the time to try to overcome a child's reluctance toward's care. Much of what the nurse must do in providing care can be scary, painful or unpleasant for a child. Nurses' efforts to minimize the

fear and discomfort experienced by a child were appreciated by parents. Parents identified many ways to accomplish this. Giving a child medication was made easier by providing the child's medication in the preferred form (e.g., pill or liquid; mixed with ice cream or jelly). One father, noting his son's strong negative reaction to white lab coats, green operating room uniforms and surgical masks hanging on a person's neck, felt that nurses and other hospital staff could help to ease a child's fears by wearing less-threatening clothing. A mother appreciated a nurse's coaxing her daughter to brush her teeth: "...this one nurse would just make her brush her teeth, took time out and talked to S....and finally S. would brush her teeth, instead of just giving up on her and letting her not brush her teeth." A father described how a nurse's explanations and gentleness gained his son's cooperation:

She would explain, she would come over and tell him, "Look honey, this is not going to be pleasant but we have to do it" and he'd start to cry and this and that, so she would calm him down a little bit and she'd tell him what we were going to do and how we were going to do it, and then she would make use of things, like a pillow or whatever, to try to make the situation as palatable as possible. She would tell him that "We have to move you because we have to change your bed. We've got to get this changed, we've got to get your dressing changed because it's not clean, it's dirty. It needs to be taken care of and we want to get you up walking, get you moving around so you can get out of here so you can go play in the sandbox or go ride your bike or whatever". And of course he still didn't want to it, but he was not as set back in his ways or as fearful...He was persuaded into doing it, reluctantly, but he did it. Once he started, he would want to pull out.

But at least he was motivated to the point where he would start. He had a trust or a confidence in this person, that this person wasn't going to be too rough with him, or hurt him or whatever.

A nurse can overcome a child's reluctance to cooperate with care by preparing a child for what he\she will feel, by explaining what must be done and why, and by performing the care gently.

(b) Individualizing the Parent's Care - Parents identified three nursing behaviours which individualize care for parents:

(i) Providing the Best Care Possible. Parents stated that the nurse's first responsibility is the child, and that meeting this responsibility translates into care for the parents. "Whatever they do for your child, they do for you. I don't know if there should be special considerations, I think it's there the same time that they're there for the child....Everything they do for her, they do for you." Parents felt most comfortable knowing that their child was receiving the highest standard of care.

(ii) Demonstrating Sensitivity to Feelings and Concerns. Parents stated that it was important for them that the nurse be sensitive to their feelings. "You really need nurses to be considerate of maybe that you are tired and give you that extra grace of being a little bitchy or a little annoying...they understand the child is going through a lot, sometimes the nurses have to realize that the parent

is going through a lot too." A mother described how one nurse helped her:

And I was just hysterical...And she just calmly talked to me...She didn't start yelling or screaming at me or anything. She was just calm and loving and caring... And she told me what I needed to hear ...and then she sat with me, she probably sat with me for about an hour and half in that room while I cried and cried, just let me get it out...

Parents valued nurses' efforts to make them feel that they were welcome to participate in their children's care and that their involvement was appreciated: "...They told us ahead of time...so we knew what they expected. [We] were helpful, not a hindrance". Parents appreciated nurses' encouragement and praise of their efforts.

Parents also wanted nurses to take their concerns about their child seriously. A parent who thought that his\her child's physical status had changed (e.g., warm forehead) and asked the nurse to check the child (e.g., take temperature) expected that the nurse would meet this request. One mother described how it felt when the nurse did not take her concern seriously:

...there was air in the line...and I was terrified and when she looked at it...the nurse said, "No, no.", and I said, "But...", and she said, "No, no." And I said, "Fine! I'll get it done at the cancer clinic then". So I'm trying to rush to the cancer clinic and running with the thing because I'm so scared this air is going to go into my daughter's system...and scared that I'm somehow going to hurt the portacath because I want to clamp it off...and I was just nuts...I can understand them being annoyed with me for the little ones, but this wasn't a little one...All she had to do was take it apart and run this into

a towel, run all that air out for me, and I would have been happy.

By taking the parent's concerns seriously, the nurse demonstrates that he\she values the parent's observations and participation in care.

(iii) Demonstrating Concern for Parents' Physical Well-being. Caring for a child in hospital could be extremely tiring for parents, and they appreciated nursing care that took this into consideration. Nurses could do this by entering the child's room quietly at night, so as not to wake the child and parents; putting a "Do Not Disturb" sign on the door the morning after a difficult night; or giving the parents an opportunity to take a break and encouraging them to do so. A father talked about spending nights sponging his feverish child: "I don't think I should have been doing it all the time...I think there could have been some form of assistance for some of those times when we were doing it consistently...when you're dogtired as we were on occasions, I think somebody else should have just taken over." Nursing actions that allowed parents to attend to needs such as eating, sleeping or simply getting away for a break were valued by parents.

(c) Individualizing both Child's and Parent's care - Parents identified four behaviours to individualize care both for them and for their child:

(i) Speaking on the Child's and\or Parent's Behalf.

This involved assisting the parent and child in dealing with

the hospital system. Parents stated that at times they needed the nurses' support in dealing with other health professionals regarding their child's care.

I can remember quite clearly circumstances where there were things that they were rushing, the doctors rushing them in to do because it was convenient for the doctor, but the child wasn't ready for this yet. To put him into the position of some more needles yet and he's just finished some needles...you know that your child needs this thing, and you try to persuade them to go along with this thing, but even then there are occasions where you get mad and say no. And where self-admittedly I did on many occasions, I said, "No. You're not doing this now". But you need that nurse to also stand up and support you and say, "Yeah, this is the wrong time, out. Enough is enough".

An older child, who is dealing with other health care professionals directly rather than through a parent, may also need such nursing support. By speaking up in this way, the nurse eased the distress of hospitalization for the child, and provided both child and parent with an ally. At other times, a parent may need the nurse's moral support:

I had this one remark from one doctor, "Oh, God, are we spending a lot of money on this kid!" and I wanted to ask him "Is it because he's Down's Syndrome that you're objecting to this?" because sometimes there's this stigma...And I got angry about that, but the nurse defended me. She said, "Wait a minute here, this mother's going through enough right now. She doesn't need this garbage." I'm really glad she said that.

Parents appreciated nurses' efforts to speak on their and their child's behalf.

(ii) Bending the Rules. This referred to efforts made to accommodate families. As one father said, "...rules are

one thing and rules are meant to be broken. They don't have to be broken, but they can be bent somewhat. Be flexible in that regard." Bending the rules could make the hospitalization experience a little more pleasant for the family. In the interviews with parents, examples of nurses bending the rules included allowing both parents to stay overnight with a child, giving parents access to the kitchen by telling them the lock combination code, and allowing a non-family member to stay with the child overnight. The nurse who was inflexible and did not provide a good reason for his\her adherence to the rules was seen as unfair. "One time [the child's mother] wanted to take a shower late at night...and she told her she couldn't. And M. was the only patient in the room...they have these little contained rooms, they have doors, wouldn't disturb anybody else outside of the room. So it was like she was pushing her power then". Bending the rules helped to make the family more comfortable during their hospital stay.

(iii) Looking in on the family frequently. Parents appreciated nurses who came into the room just to see how things were as well as to provide care. A mother described her son's favourite nurses as "the ones that just pop in and say, 'Hi, M.!', smile...not necessarily do anything but just make him aware that they're there..." Regular visits were seen by the parent as a sign of the nurse's involvement in care, and provided a sense of reassurance. One mother

described a negative experience with nurses, saying "they were never in the room, they'd maybe come in once a day. And here's this kid that hadn't eaten for ten days, you know, sick, and nobody's saying nothing. I was so frustrated... it's like 'What's going on here!'". Coming into the room frequently made the nurse more accessible to the family, and was interpreted as a sign of caring.

(iv) Maintaining Caregiver Continuity. Parents appreciated seeing the same nursing staff at each admission. This was accomplished in two ways: firstly, admitting the child to the same unit for each admission and secondly, assigning the same nurse to care for the child as much as possible. Such continuity helped the child, parent and nurse get to know each other. This provided for smoother care, as this familiarity helped the nurse to anticipate the child's and parents' needs. For parents, caregiver continuity resulted in less repetition (e.g., parents did not like answering the same questions over and over) and a chance to develop a rapport with the nurse. For the child, caregiver continuity resulted in the development of a secure, trusting relationship with nurses.

"If there was always a different nurse...she would have felt less secure. But when you go back there is always one nurse there for sure...that she knows really well and she can joke with and run around the halls with. So I think that is a big thing, a difference."

Only one mother felt that assigning the same nurse was not vital; she believed that her developmentally delayed child

benefitted from the variety of nurses by learning social skills, and that always having the same nurses would make it more difficult for him if at some future time he had to be assigned an unfamiliar nurse.

In summary, Individualizing Nursing Care (the first strategy for providing the Human Touch) included nursing behaviours directed towards the child, the parents or both child and parents. Nurses could individualize a child's care by Interacting, Befriending, and Overcoming Reluctance. Care for parents could be individualized by Providing the Best Care Possible, Demonstrating Sensitivity to Feelings and Concerns, and Demonstrating Concern about the Parents' Physical Well-Being. Both the parents' and the child's care could be individualized by Speaking on the Child's and/or Parent's Behalf, Bending the Rules, Looking in on the Family Frequently, and Maintaining Caregiver Continuity.

2. Sharing Information - The second strategy for providing The Human Touch pertained to anticipating the family's information needs and assisting them in developing the knowledge base necessary to care for their child at home or in hospital. The nursing behaviours that characterize Sharing Information were divided into two categories:

(a) Informing; and (b) Inviting.

(a) Informing - Informing was defined as the behaviours used by nurses to ensure that parents have all necessary

information. Parents identified three behaviours nurses used to inform them:

(i) Making an Effort. The first behaviour involved making an effort to provide answers to parents' questions. Parents sometimes asked a question that the nurse could not answer immediately. The nurse who was making an effort to inform parents did what was necessary to answer the question (e.g., call the doctor, consult the chart).

If you don't have an answer to the question, that's fine, so now, what's the next step, who does. And with some questions there is nobody who has the answer to the question, but if it means taking a step further, to the resident on-call doctor or oncologist involved, let's take the necessary steps to secure the answer.

Taking these extra steps demonstrated to the parents that the nurse recognized the importance of parents' need for information.

(ii) Offering Information. A second behaviour used by nurses to inform parents was to offer information without being asked. Parents cited various ways nurses did this. One way was to explain all nursing actions as they were done. Parents appreciated being told why a procedure was being done or what medication was being given. Not explaining something could make parents feel uncomfortable and reluctant to ask questions about the activity.

"The other ones weren't wearing [masks] and she'd come in with this mask and I always felt like there was this barrier. Are you afraid you're going to catch something from my kid? And she didn't say, 'Oh, I've got a cold, that's why I'm wearing this'".

Parents appreciated nurses' efforts to elaborate on their responses to parents' questions, rather than simply answering the question. "You'd ask a question and you got an answer - which was good, but, obviously there was a reason that a parent was asking that question, there was something wrong, and they would never even elaborate, or sit down at the end of the bed and say 'This is why...'" Providing parents with available options in the child's care allowed them to choose the best approach for the child. "They'd tell us, they have lots of experience with what the options are. And so we'd pick one that was good for N., just knowing what he is like." Parents valued nurses' efforts to anticipate their information needs and offer information.

(iii) Preparing for Discharge. Preparing parents for returning home was the third behaviour used to inform parents. This was of particular importance to the parents whose child was going home with a central line or other complex care requirement. Aside from simply teaching parents the care required, parents valued nurses providing "tips" to make care at home easier. For example, the parents of a child going home on IV antibiotics appreciated the nurses' help in developing a dosage schedule that would fit into their home routine. The nurses also provided parents with a valuable resource after discharge by offering to provide assistance over the phone.

It seemed whenever I called...they were always quick on the answer. And it was somebody who knew you. So if you called emergency or something like that, they don't know you, they don't know what you have at home. These girls at least knew what you had, and what your set up was. They were helpful that way.

For many parents, providing the technical care their child needed at home was a daunting task that was made easier through the support of staff nurses.

(b) Inviting - The behaviours nurses used to provide an atmosphere in which parents were comfortable seeking and using information were labelled Inviting. Three inviting behaviours were identified:

(i) Taking Questions Seriously. Parents asked numerous questions, and many parents reported feeling that they must have been "a pain" to the nurses with all their questions. The nurses, however, answered all questions. As a result, parents felt comfortable asking even "silly" questions. They received the message from the nurses that any question they had was important and worth asking.

(ii) Taking Time. This behaviour pertained to demonstrating a willingness to take the time for questions. Parents appreciated nurses' verbal encouragement to ask questions, but their body language could either reinforce or weaken this encouragement.

...they would come into the room and rattle off a million things, 'Got any questions? Just ask me!' as they're running out the door...[other nurses] would come in and they'd sit...on the bed, or sit on the chair, and it didn't look like they were in

a hurry to leave, which gave you a little time to think...

Having parents help with nursing procedures provided opportunities for parents to ask question. "That's where a lot of questions would come in and you'd talk to them... 'What would happen if we did this?' You just had a better understanding of why they were doing things... I think they liked to share why they were doing it." Parents needed to feel that the nurse had time for their questions and enjoyed answering them.

(iii) Increasing Involvement Gradually. The third behaviour was to gradually increase parents' involvement in technical care. This was a concern primarily for parents who had to learn to care for their child's central line. Parents learned this care while their child was in the hospital, and all reported that initially they felt frightened and did not want to do it. Parents needed to learn the skill at their own pace.

I remember the nurse saying to me, "Well, do you want to be dirty person or clean person?"... I remember saying, "I don't want to be either! I didn't want this stupid central line in!" and they said, "Oh, we'll come and ask tomorrow." Because I was too emotional, I didn't want to do it. I needed to have time to adjust to it, I think.

Once parents were ready to learn to care for the central line, the nurses' instruction and ongoing support were vital. "The best way to do it is to show someone how it's done and watch over them, and just be there for the questions."

In summary, the strategy of Sharing Information with parents was characterized by two categories of behaviours: Informing and Inviting. Informing included Making an Effort, Offering Information, and Preparing for Discharge. Inviting included Taking Questions Seriously, Taking Time, and Increasing Involvement Gradually.

3. Going Above and Beyond the Call of Duty - The third and final strategy for providing The Human Touch involved nursing behaviours that extend care beyond the walls of the hospital. When the child was in hospital, nurses went out of their way for the child. For example, nurses brought small gifts for the child, or lent him\her movies from their home collection. Nurses also showed they cared about the child even when they weren't at work: "...it was their day off, yet they'd come in just to see how things were going. Or they knew you had surgery...they called to make sure everything was O.K. or to find out what happened." This care could also continue after discharge, as in the case of the nurse who accompanied a child-life therapist to a child's day-care to prepare his classmates for his return. Parents also appreciated nurses' continued interest in the child's progress after discharge. These actions, which extended beyond a nurses' work hours and responsibilities, were seen by parents as signs that the nurses truly cared about their child, and this enhanced their hospital experience.

In summary, The Human Touch was provided through three strategies: Individualizing Care, Sharing Information and Going Above and Beyond the Call of Duty. The Human Touch and The Basics were the two types of nursing care described by parents.

Nursing Care: Outcomes and Effects

This component referred to parents' perceptions of the care they and their child received. The care given by a nurse could take one of three forms: only The Basics, only The Human Touch, or a combination of the two. Each of these forms could result in one of three outcomes: A. Going Through the Motions, B. Caring Incompletely, or C. Caring Completely. Each outcome affected the parent\child unit differently. In the following discussion, each nursing care outcome and its effect on the parent-child unit is examined.

A. Going Through the Motions. Nurses who provided only The Basics were Going Through the Motions. Their care focused on the child's physical care needs, and provided the parents with basic information, but did not apply the principles of The Human Touch.

...you just move him and that's all there is to it, and they didn't really give a shit ...how much it hurt or whatever. They would say it... "It's o.k. honey, I'm sorry we have to do this"...that's one of those things where I say that they're going through the motions, and you knew damn well that they didn't mean a word they said, it's just something they said all the time. And they get the job done, and away they go.

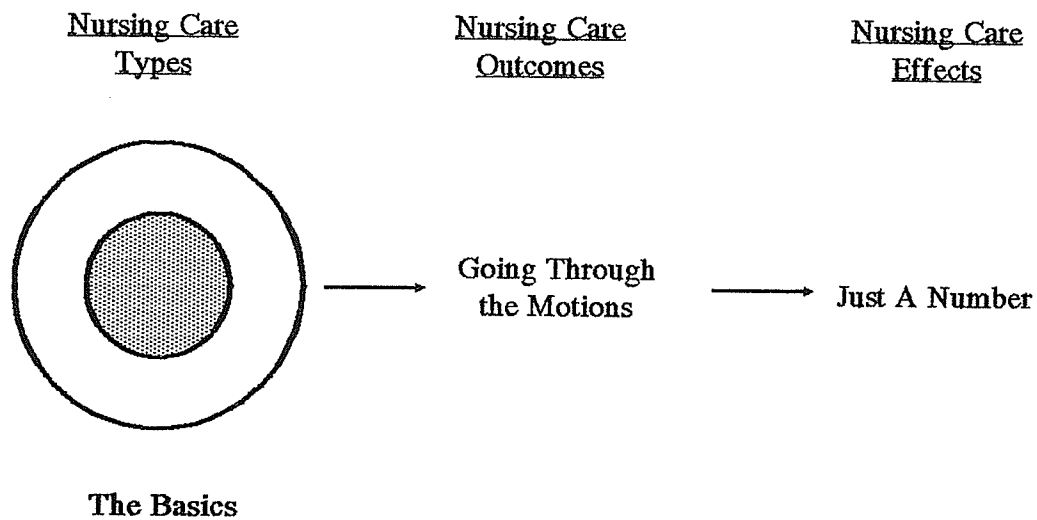
Going Through the Motions was very business-like care. It gave parents the sense that they and their child were simply the recipients of a service. The effect of Going Through the Motions reported by parents was that they felt they were Just a Number. "It was...as if [my son] wasn't important...it was just her job...it was hard to know that my son was being treated like a number." Parents who could not be with their child constantly had a particularly difficult time leaving the child behind when the nurse was Going Through the Motions. Parents recognized that the care provided was of a high calibre technically, but the lack of humanistic elements made parents feel uncomfortable.

...there's a couple of nurses, I get a feeling like I'm always bothering them or they're too much in a hurry to sit and...I don't particularly care for them as much and sometimes I hope they're not there when I'm there but they're very efficient and I know that they're doing the best job.

Parents generally did not complain about this nursing care to hospital authorities. One father reported an unpleasant exchange with nurses when he felt their care was too rough. In most cases, however, they tolerated this care, believing that the lack of The Human Touch was not a valid complaint: "...she didn't do anything very, very wrong. It was just the whole attitude felt very condescending.." Parents did not like receiving such care, but took solace in the fact that basic needs were being met. Going Through the Motions is diagrammed in Figure 3(a). In this diagram, the incompletely darkened circle, with only the core filled in,

represents the presence of The Basics and the absence of The Human Touch. This was the second most frequent form of care reported by parents (n=9).

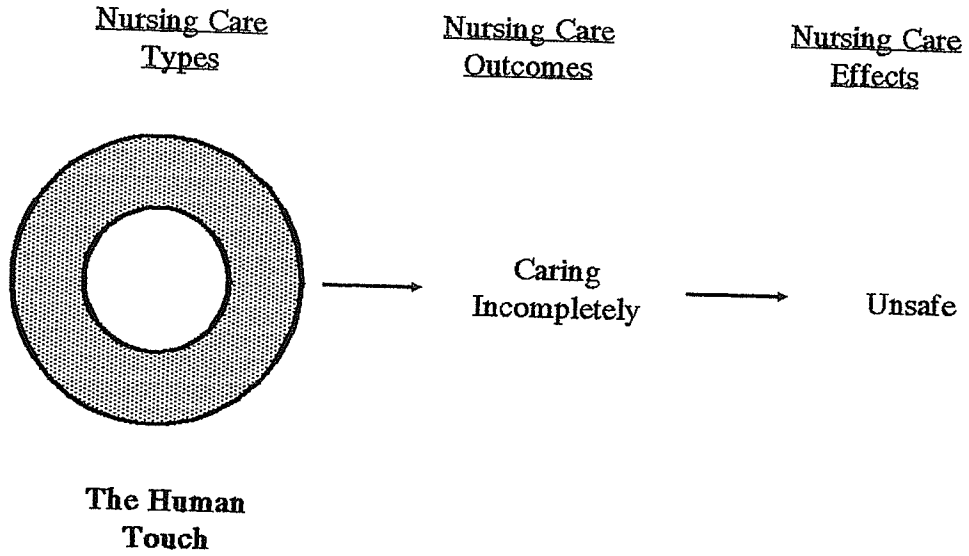
Figure 3(a): Diagram of Nursing Care: Outcomes and Effects



B. Caring Incompletely. The nurse who did not provide The Basics but did provide The Human Touch was Caring Incompletely. The care provided was humanistic but failed to meet the bare necessities of care. "She's a very good person, her heart's in the right place...But I just noticed that when she was really tired, that she could forget really easy, and you can't do that when you're a nurse." This care was not acceptable to parents. Going Through the Motions was preferable to Caring Incompletely: "...if you're endangering patients or just not providing them with the care...then it doesn't matter what little personality treatments come into it. That's why even mean nurses - O.K., they can do their job." The effect of seeing such care was that parents felt their child was Unsafe. "It just bothered us...you have enough to worry about, then when you see people slip up, you know then that there's something wrong. You just don't want to worry about that". Parents were more likely to take action against Caring Incompletely than Going Through the Motions. Most often, this action took the form of discussing the gap in care with the nurse involved. In one case, a mother took over all responsibility for a procedure after recognizing a nurse's mistake in performing it. One couple took their concerns to the head nurse, requesting that a certain nurse not be assigned to their child. Caring Incompletely is diagrammed in Figure 3(b). Here, the incompletely darkened circle,

with only the periphery filled in, illustrates the presence of The Human Touch and the absence of The Basics. This was the least frequently reported form of care (n=6).

Figure 3(b): Diagram of Nursing Care: Outcomes and Effects



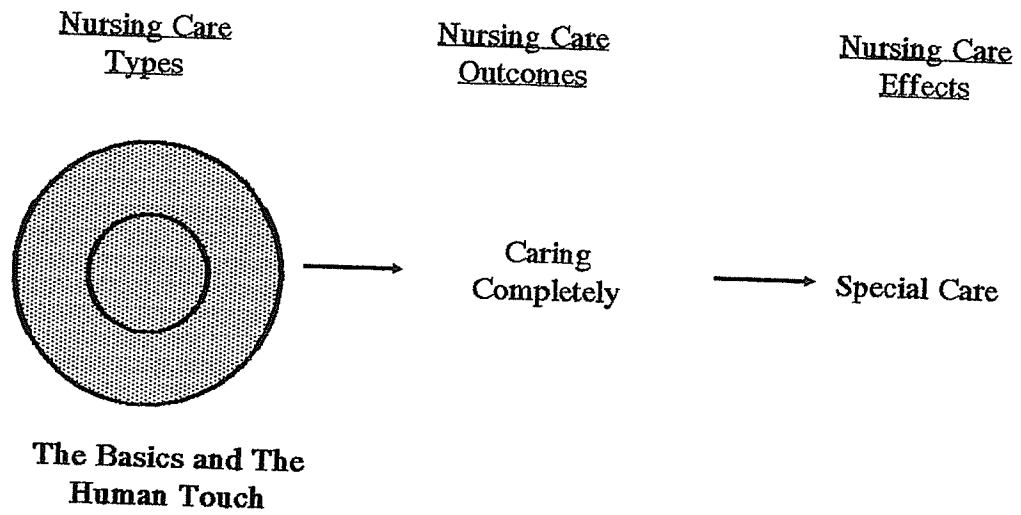
3. Caring Completely. Care that combined The Basics with the Human Touch was Caring Completely. "Care means one thing, administering medication, washing, cleaning, you name it. But it also means, it should mean, interaction". The Human Touch enhances The Basics. The effect of Caring Completely reported by parents was a feeling of receiving Special Care: "you weren't just a number, there was some special care there". It was reassuring to the parent to see that the care given by the nurse was warm and loving.

...it really consoled me to think that I don't have to be up there changing D.'s diaper and being loving to him, this nurse is. And that was great. And not all nurses, but I would say the majority of them are very kind, ...saying wonderful things, "You're such a good boy! Oh I love you", or "Oh, you're so sweet", "Oh, you're getting to be a big boy", things like that, that really makes a Mom feel good. Made me feel like D. is really loved and cared for, and he's not just a patient, he's really a human being who's cared for.

This care was a particular comfort to parents who had to leave their child alone in hospital for extended periods of time: "...knowing that he was with a good nurse was...a comfort, so that I could sleep at night, at home here, knowing that he was O.K." Caring Completely helped to make the difficult experience of hospitalization for cancer much easier for both parent and child by providing Special Care. The parent and child came to trust the nurse and feel safe in his\her care. Caring Completely is diagrammed in Figure 3(c). In this diagram, both the periphery and core of the circle are filled in. The completely darkened circle

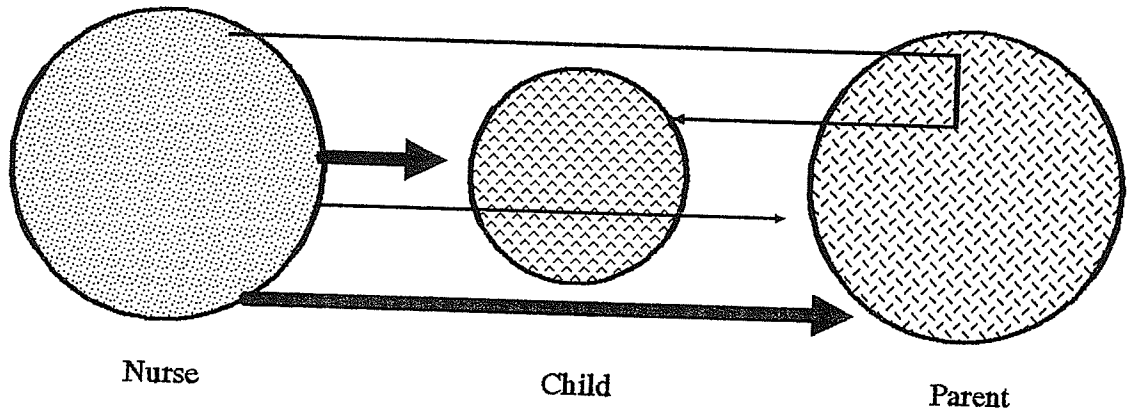
denotes the presence of both The Basics and The Human Touch.
This form of care was reported by all the parents (n=16).


Figure 3(c): Diagram of Nursing Care: Outcomes and Effects




The nurse who was Caring Completely could provide care to the child and parents both directly and indirectly. Examples of direct care include explaining a procedure to the child before performing it and sitting down with parents to answer their questions. Indirect care includes caring for the parent by providing the best quality care for the child, and caring for the child by giving the parents the information and support necessary to look after their child. This is diagrammed in Figure 4.

Figure 4: Nursing Care: Direct and Indirect Care



Direct Care = 

Indirect Care = 

In summary, the type of care provided by the nurse could have one of three outcomes: Going Through the Motions, Caring Incompletely, or Caring Completely. Each outcome had a certain effect on the parents, respectively: Just a Number, Unsafe or Special Care.

Nurses

The interviews with parents yielded descriptions of nurses whose care resulted in the two most common outcomes, Going Through the Motions and Caring Completely. These nurses will be profiled in this section. Because Caring Incompletely was so rarely reported, it was not possible to compile a profile of the nurses who provided this care.

A. Time-Clock Punchers. These were the nurses who were Going Through the Motions. They provided The Basics, without The Human Touch.

...she was professional with no personal input, I guess that's the best way of putting it. There was nothing wrong with the way she did her job, but it was just, "bang, bang, bang, bang", no personal interaction with the child. She had a job to do and that's what she did, and that's the extent of it.

Personal characteristics that parents used to describe these nurses included efficient, thorough, cooperative, and usually pleasant. In some cases, Time-Clock Punchers came across as rude, unfriendly or moody.

B. From-the-Heart Caregivers. These were the nurses who were Caring Completely. They were able to combine The Basics with The Human Touch. Parents often commented that

these nurses obviously enjoyed their chosen profession: "...they were doing...the job because they liked doing the job, and they had an honest and sincere care and interest in the well-being of this child..."; "It wasn't a job, it was more of a pleasure...to be looking after little kids up there". Personal qualities characterizing these nurses included:

- kind, compassionate, comforting, supportive;
- sympathetic, empathetic;
- understanding, sincere, gentle;
- good sense of humour, positive, upbeat;
- friendly, cheerful;
- even-tempered, accommodating, calm;
- knowledgeable, consistent.

These were the nurses who became the child's and parent's favourites. One mother offered this comparison of Time-Clock Punchers and From-the-Heart Caregivers:

Some of them had such a good sense of humour...They were so happy and jovial, jolly and happy and did their work in such a happy manner. You knew they were happy doing the work they were doing. There were other nurses that you sensed that they were just there because it was their job. You didn't feel like they really cared. Maybe they did, but it didn't radiate out of them. For some nurses, it would just radiate...you could tell they cared, you felt the caring, you know...In their attitude toward the parent and toward the child.

All the parents stated that the majority of nurses they encountered were From-the-Heart Caregivers.

Conditions Influencing Nursing Care

In describing the care they and their children received from nurses, parents also recognized conditions that influence the care provided by the nurse. These conditions

are all external to the nurse, therefore he\she cannot control them but must work around these conditions to provide the child and parnets with the best care possible.

Two types of conditions were identified: A. Hospital Life and

B. The Parent. The characteristics of each condition are outlined in Table 4. The two types of conditions are detailed in the following section.

Table 4. Summary of Conditions Influencing Nursing Care

A. HOSPITAL LIFE	B. THE PARENTS
1. Nurses are Busy 2. The Ward (a) Specialty (b) Familiarity 3. Hospital Hierarchy 4. Secret Information	1. Parents' presence 2. Parents' behaviour

A. Hospital Life. Parents identified four characteristics of the hospital and its system that can influence nursing care: 1. Nurses are Busy; 2. The Ward; 3. Hospital Hierarchy; and 4. Secret Information.

1. Nurses are busy - Most of the parents interviewed commented that the nurses they encountered were very busy (n=15). "You could really tell that they were going from room to room...it was just a hectic place. You could see that everybody was busy". Of these fifteen parents, eleven believed that the fact that nurses were so busy had a negative effect on the care they gave. Parents described how Nurses are Busy affected the care that they and their

child received. Most frequently cited were effects on The Basics of nursing care, primarily physical care. Illness care was affected in that IV pumps beeped for a long time before someone responded, nurses were too rushed to do proper physical assessments, and medications and procedures were late, rushed through, or missed completely.

...he had an infection in the incision where his surgery was...it took quite awhile before it healed. And I felt very frustrated because it was hard to see that the incision wasn't healing. And when the nurses were really busy, that's what was harder. You knew that they couldn't, they were suppose to wipe it with peroxide with q-tips. And sometimes they wouldn't or they didn't have the time, or it would be missed every now and then...

Parents also had to wait a long time for someone to respond to their call for assistance.

I find there's a nursing shortage and I can't blame the nurses at all. I see a lot of the nurses really work hard, I see them running from room to room, I see them try to be a help to you, but I also see that they can't always be there when you want them. And sometimes, especially like an instance with D, he was puking and pooping at the same time and he was passing out, I couldn't control him...and you know, you yell for help, "Well, I'll be there in a minute, everybody's on coffee..." and there's only one nurse or two nurses and they're running around doing IVs...Sometimes you felt so angry, like...I can't do this on my own, you're so tired at times, you really need a nurse now, you don't need a nurse half an hour later....

The type of nursing care provided was also affected. Nurses' ability to provide The Human Touch was limited by their busy workload. Because nurses were busy, they had less time to interact with the child and parents, making it more difficult to develop a rapport. It limited the amount

of time a nurse had to talk with the child and parents about how to individualize the child's care. As one mother said:

...you have to be realistic, I mean, they're busy up on that ward where we were, there wasn't a lot of time to...get into...details like that. Sure, it would have been nice...to have gone through stuff like that, but, realistically, you could see that they don't have time to get into those types of things.

Three parents also recognized gaps in the care that other children received. These were children whose parents could not be there all the time, and the nurses were too busy to interact with them. "You see the stainless steel bars and you see the child there and nothing is happening...if the parents aren't there to address the needs of the child, somebody should be doing it. And not in all cases...is that happening...it just didn't seem right". Nurses' "busy-ness" was attributed to insufficient numbers of nurses, ultimately the result of government cutbacks.

2. The Ward - The children of fourteen of the parents interviewed had been admitted to different hospitals or to different wards within the same hospital. Of these, ten recognized that nursing care varied depending on the hospital unit. There were two characteristics associated with these variations. The first characteristic was Specialty, that is, the types of illnesses and treatments commonly seen on that unit. Parents recognized that nurses were best able to meet the need of those children with the illnesses and treatments they saw most often. Nurses on

medical floors were adept at meeting the emotional needs of children with cancer and their parents, and at providing the physical care involved in dealing with cancer treatment and complications. However, they were less adept at meeting the physical needs surrounding surgery.

When we were on the [surgical floor], there were incidents that came up, I guess because of being a cancer patients, that they went to P. to ask questions. And then when he had to have surgery again on the [medical] floor, they had to deal with nurses [on the surgical floor] to get information about how to treat the chest tube and things like that. But yet they seemed to treat him as a cancer patient better, I guess because that's where the cancer patients were. So I guess that's what it pretty well came down to, is the third floor was just surgery, not cancer patients. It was just different, they just deal with people different because if someone goes in for an appendix operation, well it's just an appendix, they're in and out, I mean...they're not going to be back again. Where I think on the [medical floor] the nurses are somewhat different because there's the very good possibility that those kids will be back again. They build a relationship.

Parents recognized that a nurse's knowledge about an illness\treatment and experience with it affected the care they gave.

The second characteristic was Familiarity, that is, how well nursing staff know the child and family. The children in the study were admitted to the same unit each time they were hospitalized. As a result, the nurses and families got to know each other quite well. On occasion the child was admitted to a different unit. Parents recognized that the lack of a relationship with the nurses on a different unit resulted in different care.

I remember once I had to go see another floor, and it was terrible, it was just awful. Then I didn't see anybody. I think I saw one nurse, once, and that was it. Because they didn't know you, and you didn't know them. It was awful.

In these situations, care was characterized by The Basics, rather than The Human Touch.

3. Hospital Hierarchy - Eleven parents recognized that the staff nurses' place in the hospital's organizational structure could affect the care they gave. Two individuals in particular could affect nurses' care. The first of these was the head nurse. The head nurse was seen as "in control" of her ward and had the final say about how the ward was run. "The person in charge of the ward...had complete control and command of her staff. It was pretty obvious who was responsible for the ward and who was in control". If a nurse was trying to bend the rules for a patient, the extent to which he\she could do this was limited by the head nurse. The head nurse was also seen as having an influence on the manner in which the staff nurses on the unit did their work. "I really believe the head nurse makes a big, big difference. I think if nurses can feel like they can be themselves, they can joke, and they can find humour and are easy-going and have an easy-going head nurse, I think there's an easier flow." The head nurse was seen as an example for the staff nurses.

Also in a position to influence care were the doctors. This included all the doctors that had contact with the

patients, such as oncologists, surgeons, and residents. The doctor was seen as the "top of the pyramid". Parents observed that doctors wrote the orders and nurses carried them out. They stated that although a nurse who disagreed with an order could and would discuss it with the physician, the ultimate decision about whether or not the order was changed rested with the doctor. One mother who disagreed with a doctors' decision recognized the nurses' attempts to help her: "...the nurses can't do anything. They can try and they'll phone everybody...they phoned anybody I'd ask...they were wonderful, but they can't do anything".

Parents also related apparent difficulties with nurse-doctor communication that affected the child's care. The doctor would tell the parents that something could or should be done, but the nurses didn't know about it. This left the parent in an uncomfortable position of go-between. "I guess you expect communication between doctors and nursing staff to be...I don't think as a parent you ever expect to be in a position of having to pass a message". Parents did not lay blame for poor nurse-doctor communication on either party, but did recognize that better communication could contribute to better nursing care.

4. Secret Information - Parents recognized that efforts to keep information about their child's condition from them affected their child's care. This mainly occurred at times of uncertainty, such as when the diagnosis was not yet made

or when there was a change in the child's condition. It was a particularly vivid experience for the parents of three children whose diagnosis took days or weeks. Parents recalled sensing that nurses knew what was going on, but could not tell them. "It's kind of a tense situation and nurses cannot always say what it is because a lot of the time it has to be the doctor who tells you." As a result, nurses seemed to avoid the child and parent. "The girls [sic] weren't staying in the room long enough because I think they were afraid they were going to be trapped into saying something." The absence of a diagnosis seemed to limit the care provided. "There was more care for the girl beside us because they knew what she had, I found. So they were often in the room, but not with us. I think if they knew what she had maybe then they would have done something." Two of the children were moved to a different unit immediately after diagnosis. The father of the third child, who remained on the same ward after diagnosis, sensed an improvement in care, with nursing staff increasing their involvement.

In summary, characteristics of Hospital Life that could affect the care a nurse gave included: Nurses are Busy, The Ward, Hospital Hierarchy and Secret Information.

B. The Parents. The second type of condition identified by parents was the parents themselves. Parents believed that their own actions could affect the care nurses

gave their child. These actions can be divided into two groups: 1. Parents' Presence; and 2. Parents' Behaviour.

1. Parents' Presence - Ten parents expressed a belief that their presence or absence could influence nursing care in a number of ways. One belief was that nurses were more diligent in their care when the parents were present: "...I know for sure that because I was there and [my wife] was there, that they were more attentive to needs and concerns." Other parents believed the reverse to be true: that as long as they were there, the nurse was less involved in caring for the child. These parents also trusted that when parents were away, nurses would be more attentive to the child.

Well, we were there a lot. So I don't think they cared as much about her cleanliness, that sort of thing because they knew we were there most of the time so we were taking sort of care of that sort of thing. They mainly just took care of her health. The usual check-ups and the constant temperature, and that sort of thing...But I think cause we were there all the time, I think they mostly watched her health and to make sure that she was going to get through this. If we wouldn't have been there I'm sure that they would have taken care of all her other needs.

Parents also recognized that a parents' presence could make a nurse nervous and cause him\her to make a mistake.

It's hard to work when there's somebody around all the time and you know quite clearly that they're watching everything that you do with this child. I mean, this is their child, you have to make sure, "Jesus, I have to do everything right. I can't screw up at all here". So in a lot of ways that's perhaps unfair...

Parents believed that their presence could influence the amount of time it took nurses to do their work. One belief

was that parents' presence increased a nurse's workload, because of the questions and concerns the parent would pose to the nurse. A more common belief was that a parents' presence eased the nurses' workload because parents provided much of the care a nurse would have provided. Parents' presence also helped in that the child felt more calm and secure, making it easier for the nurse to do the necessary care. In some cases, the nurses came to rely on the parents a great deal: "...they have it on the kardex...and they'll put in whatever they have to do. But they don't even have it in, so it's not slotted, there's not a time allowed for that... 'Cause I always do that".

2. Parent's Behaviour - Two parents expressed a belief that how they conducted themselves in the hospital could affect the care nurses gave their child. These individuals feared negative reprisals, in the form of lower quality care for the child, if the parent displeased the nurse.

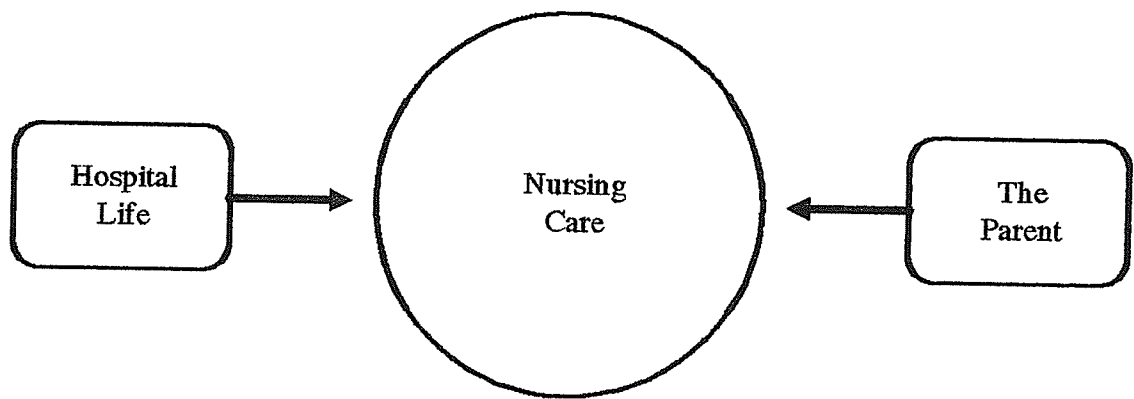
...like we got along really well with them. I saw some parents though that had a hard time. They were trying to buck the system the whole way through. I think a lot has to do with compliance. If you're going in there and you're trying to change everything or do it all your way, forget it. There are rules and there are certain things that you have to go with...and if you don't, you're going to have a hard time there. It's going to be hell. You know, if the nurses see that you're irresponsible, or that you're trouble they're going to treat you differently for sure...Some parents go there and think it's a hotel. And it's "Ping, ping - can you get me this", "Ping, ping - can you get me that?"...if you tried doing that, after a while they would cut off...you don't want to get on the bad side of nurse either, because you're always afraid if you

do have a bad reputation, well then, that maybe you're a problem parent, then you consider they may treat your child differently...You're always afraid if you rock the boat...your child may not get...the care that she should. Because they're angry at you...They don't want to go into the room because you're too bitchy, or something.

Neither of these parents experienced a realization of this fear. Nevertheless, the power of nurses to attend\not attend to the child's needs may have kept parents behaving "properly".

In summary, parents believed that nursing care could be influenced by characteristics of the hospital and its system as well as by their own presence and behaviour. This is diagrammed in Figure 5.

Figure 5: Diagram of Conditions Influencing Nursing Care



Parents and the Care They Give

This section discusses parents' perceptions of their own involvement in their child's care in the hospital. A description of the care parents gave to their children and an examination of the conditions that influenced that care are included here.

Parent Care: Making it Better

By providing care to their hospitalized child, parents were involved in a process called Making it Better. This process involved efforts to make the difficult experience of hospitalization more positive for their child. "The way we approached this whole treatment was to try to make things as positive as possible...Things were bad, but let's not focus on the negative..." Making it Better consists of four types of care: A. Just Being There; B. Providing Everyday Care; C. Providing Illness Care; and D. Providing Supportive Care. These types of care are outlined in Table 5 and are detailed below.

Table 5: Summary of Parent Care: Making it Better

A. JUST BEING THERE	B. PROVIDING EVERYDAY CARE
Parents' physical presence	<ol style="list-style-type: none"> 1. Attending to nutrition 2. Attending to hygiene 3. Attending to elimination
C. PROVIDING ILLNESS CARE	D. PROVIDING SUPPORTIVE CARE
<ol style="list-style-type: none"> 1. Medicating 2. Performing procedures 3. Keeping comfortable 4. Monitoring 	<ol style="list-style-type: none"> 1. Easing trying times 2. Interpreting 3. Being a voice 4. Making it fun

A. Just Being There. This type of care was defined as the support parents provided to their child simply by being physically present. Parents firmly believed that their hospitalized child needed to know that although his\her world had changed dramatically, his\her parents were still a part of that world. "It's just the expectation that you're there. I guess it's like a life raft. I know that individual, and I know they're going to help me through this situation". Parents stated that being there was different from doing things. "To D., I know it's important that I'm there. He's more relaxed so I know that's vitally important. Whether I do it or not, it doesn't matter who does it, as long as Mom's there".

Sometimes being there was the only comfort a parent could provide. "There's nothing much I could do. She was really miserable, she didn't want to play, she'd stay in bed, she'd complain of stomach aches. And she had

fevers...104 non-stop the whole ten days. So there was nothing much I could do. Just sit there." Parents believed that being there was in itself an important aspect of the care they provided.

B. Providing Everyday Care. This type of care was defined as behaviours related to maintaining the general well-being of the child. This care was not directly related to the illness. One mother referred to it as "the normal mother stuff". Three categories of behaviours for Providing Everyday Care were identified: 1. Attending to Nutrition; 2. Attending to Hygiene; and 3. Attending to Elimination.

1. Attending to Nutrition. Parents elaborated most about Attending to Nutrition. The child's illness and its treatment resulted in a loss of appetite at a time when nourishment was particularly important. Seeing their child not eating bothered parents immensely and they went to great lengths to entice the child to eat.

...he's a very picky eater on top of that, so you're reviewing the menu on a daily basis. And you'd go to the special lists of entrees and whatever, because, like most kids, they have their favourites. And food, nutrition is important, when you're battling cancer, and we wanted to make sure that whatever he wanted to eat, we got.

2. Attending to Hygiene. This included giving their child bed baths or tub baths (the latter with the help of the nurse if the child's condition warranted it) and did their mouth care. They expressed a belief that the child preferred that this care be provided by a parent. Parents

also dressed their child, preferring that the child wear his\her own clothes rather than those provided by the hospital. "I always take his own clothes, his own pyjamas and everything...Sometimes there's clothes on him so I take them off and give him his own clothes".

3. Attending to Elimination. Parents also reported Attending to Elimination, which included taking the child to the bathroom, giving bedpans or changing diapers. Taking the child to the bathroom was particularly important when the child was receiving chemotherapy that required large volumes of IV fluid and frequent voiding.

C. Providing Illness Care. This type of care was defined as parental behaviours necessitated by the child's illness and treatment. The four categories of behaviours identified were: 1. Medicating, 2. Performing Procedures, 3. Keeping Comfortable, and 4. Monitoring.

1. Medicating. This mainly involved giving oral and topical medications. This was particularly important when the child was reluctant to take medication. "N. had never swallowed pills before...usually my husband did that, he was the one who was able to relate and get him to do things, and to swallow". Some parents also learned to manipulate the IV pump.

2. Performing Procedures. This included doing central line care, inserting feeding tubes and helping nurses with whatever procedures they were doing.

3. Keeping Comfortable. The most frequently cited example of Keeping Comfortable was sponging a feverish child. "There were three or five solid days of these spiking fevers that got increasingly worse, and we'd have to keep him...sponged, in the middle of the night on many occasions to get this thing to come down". Parents also made sure their child received pain medication post-operatively.

4. Monitoring. This included observing the child's condition and ensuring his\her safety. Parents reported to the nurses when they saw that their child was in pain, feverish or showing a change in condition. "With a child with leukemia, a little thing that is missed, like a little bit of a raspy voice, green stuff, you have pneumonia...We would tell them she's starting to rasp a little bit, maybe you should check with a stethoscope..." Parents also maintained the safety of IV lines, oxygen tubing and the like. "He was on oxygen, the tubes in his nose, he kept pulling them out constantly...you had to stay up and watch him. You're watching him all the time, because the first opportunity he would get, he'd pull it out." Parents participated in many aspects of care that revolved around the child's illness and treatment.

D. Providing supportive care. Supportive care was defined as parental behaviours directed towards helping the child through specific aspects of the hospitalization

experience. This care included four categories of behaviours: 1. Easing Trying Times; 2. Interpreting; 3. Being a Voice; and 4. Making it Fun.

1. Easing Trying Times. This category involved supporting the child during difficult parts of the hospital experience, such as tests, treatments and painful procedures. It also included giving the child encouragement to get through a difficult period.

When he had his first surgery...we were trying to get him moving again...And he hadn't had a bike, so my husband had gone out and bought him a four wheeler...he got it the day before he went into surgery...he rode of course before surgery, and ...he was riding that bike on Sunday, and he had surgery on Friday. I just think it was an incentive to get him going.

For parents who could not be with their child at all times, Easing Trying Times included preparing the child for being alone.

...they've got to feel safe and they've got to feel that this is okay...So if this what the nurses are doing to me and mom says they have to do it, then okay, that's fine...I think if they were all by themselves and the nurses were doing this, I think the kid would panic. By being there, the kid learns to trust the nurses and then, like later on, I was able to leave because she trusted them totally. She knew they were there to help her and that they were nice and everything else. I think the important thing for them is to learn trust through you I guess. Trusting of the nurses...

2. Interpreting. The second category of Supportive Care behaviours was Interpreting. Most often, this included explaining to the child what was going on around him\her.

When the child's first language was not English, it also included translating for the child.

3. Being a Voice. This was the third category of Supportive Care behaviours. It involved speaking to the nurses and other hospital staff on the child's behalf, to ensure that his\her best interests were met. Parents approached nurses mainly with regard to the care that they provided, for example, timing of procedures and giving medications.

when he's really, really, really tired and he wants to go to sleep and he's waited for his bedtime medication for half and hour, forty five minutes, then an hour. You know? I usually go out and say, "Look, he'd really like to go to sleep. Could he have his medication soon so he's not woken up?".

Parents also approached doctors with respect to treatment decisions, and enlisted nurses' support in dealing with these matters.

4. Making it Fun. The final category of Supportive Care behaviours was Making it Fun, that is, entertaining the child and trying to add a little pleasure to the hospital experience. Parents played with their children, read to them, took them to the playroom or outside for a walk. Parents let the child's interests and preferences be the guide for these activities.

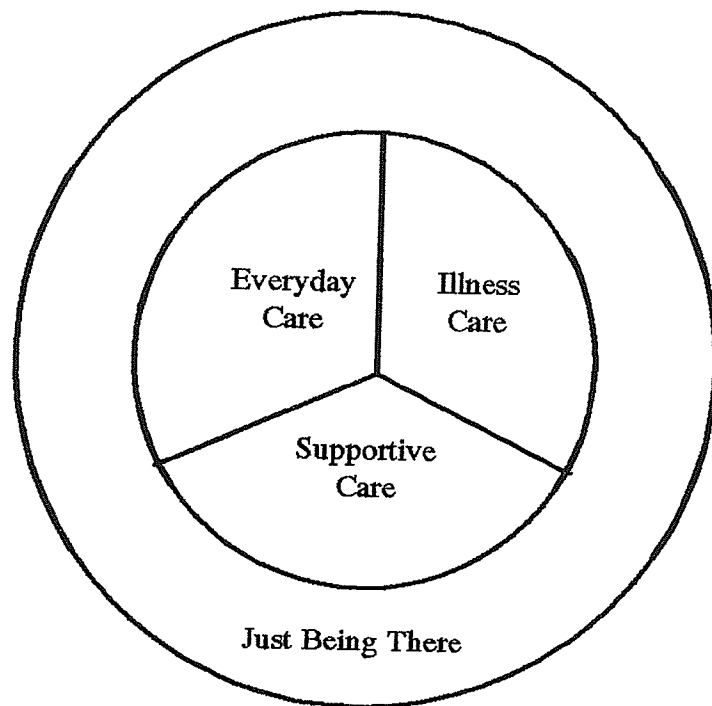
...N. loves to read books. We went to the library...And we used to take him up on the fifth floor where the elevators are. There's a big window there, and you look over the building top and you see the air-conditioning...He loved to sit there. Don't ask me why, but...so you find these

little nooks and crannies. They had this beautiful little bench in the library where you could look out on the corner and watch the cars go by, and people. No, he didn't want to sit there! And the last time we were in the hospital, they were doing some repair on the roof, bringing up pails of tar, and all these grubby men, and all this smoke coming up...and it was ugly, but he thought it was the greatest thing. So you find things like that...

Although initially the child's illness may have left the child feeling so bad that he\she didn't want to play, as he\she got better keeping the child busy became an important part of parents' care.

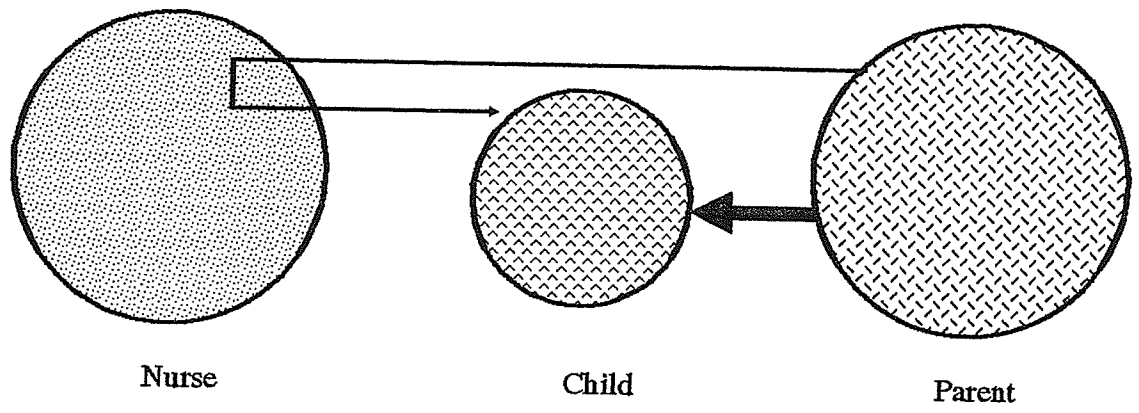
In summary, Making it Better consisted of four components: Just Being There, Providing Everyday Care, Providing Illness Care and Providing Supportive Care. Just Being There is unique among these four components in that it refers to only one parental activity, that is, spending time in the hospital with their child. Each of the remaining three components describes activities which parents may have chosen to undertake while they spent time with their hospitalized child. Parents could only provide Everyday, Illness and Supportive Care when they were with their child. In this way, the first of the four components, Just Being There, encompassed the remaining three. This is diagrammed in Figure 6.


Figure 6: Diagram of Parent Care: Making It Better

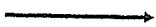


The care parents provided in Making it Better could be provided directly to the child (e.g., feeding, playing, holding a hand) or indirectly (e.g., tell nurse the best way to give child's medications, ask nurse to check on child while parent is away). This is diagrammed in Figure 7. This diagram illustrates how the parent cares for the child directly and indirectly through the nurse.

Figure 7: Parent Care: Direct and Indirect Care



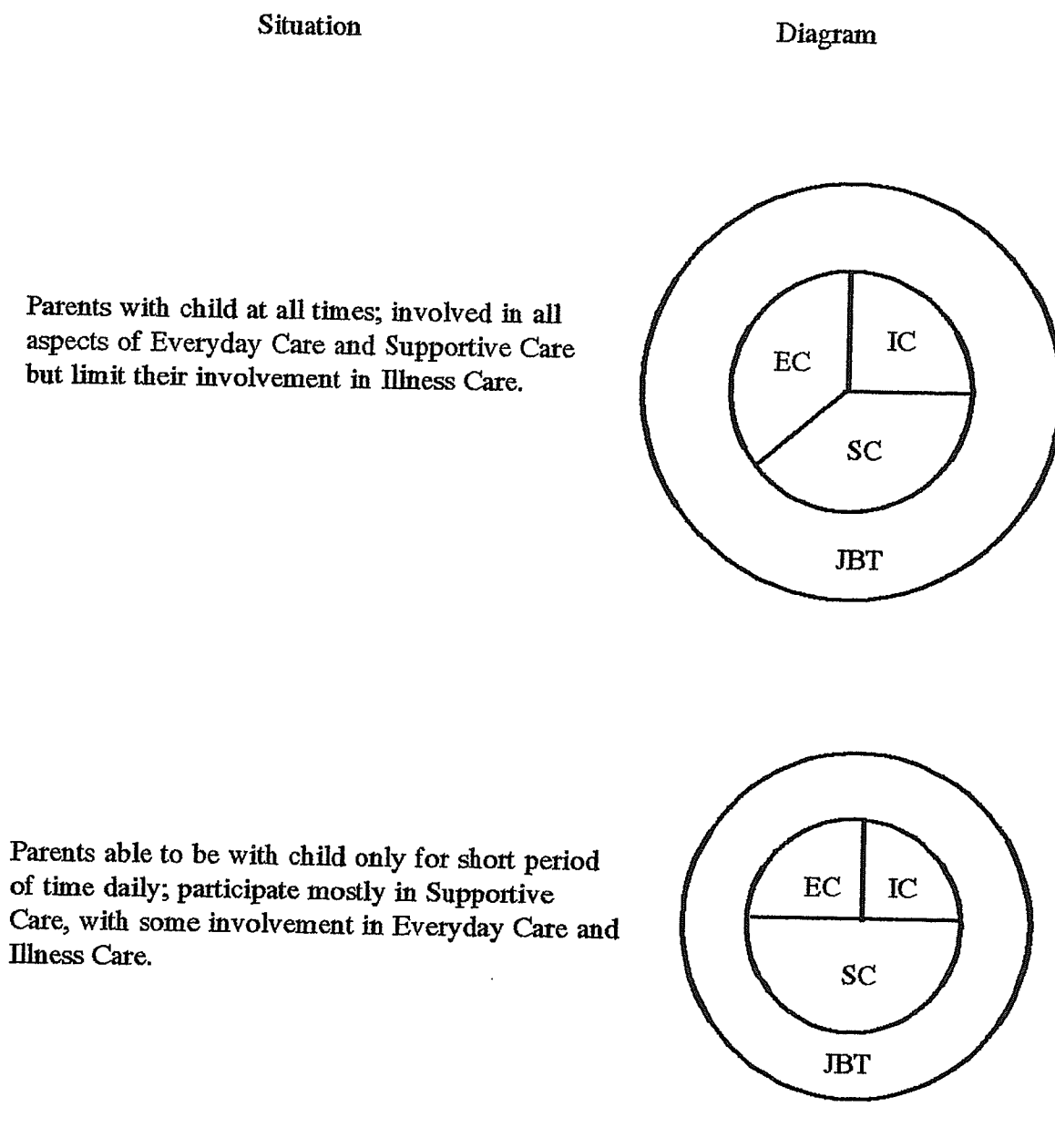
Direct Care = 

Indirect Care = 

Making it Better: Variations Among Parents

All parents agreed on the importance of Making it Better for their child, but each parent had their own way of doing so. Parents ways of Making it Better varied in terms of the amount of time the parent spent in hospital, the activities they participated in while there and their interactions with nurses and other hospital staff. These variations can be illustrated using the circular diagram entitled Making it Better. Two possible variations are diagrammed in Figure 8.

Figure 8: Example of Variations of Making It Better



Key:

JBT = Just Being There

IC = Illness Care

EC = Everyday Care

SC = Supportive Care

Parent Care Profiles

The care parents provided could be profiled according to three characteristics: A. Intensity of Involvement; B. Constancy versus Change; and C. Routine versus Unpredictability. These characteristics are described below.

A. Intensity of Involvement denotes the extent of parental participation in care. Some parents became involved in all aspects of care. In the words of one father:

Perhaps it's being overprotective, but given the nature of what he was going to embark upon, there was nothing we were going to let slip through the cracks. We wanted to make sure it was all taken care of from a to z...

Other parents were less involved in their child's care, such as one mother who "let the nurses do everything themselves when she was in the hospital because I figured that was their job". Each parent's Intensity of Involvement was unique to his\her situation.

B. Constancy versus Change describes variations in the amount of time a parent spent in hospital. Some parents spent the same amount of time with the child during each admission. For example, certain families ensured that at least one parent was with the child at all times during each admission. Other parents increased or decreased the amount of time they spent with the child in hospital:

...I had to use up all my sick time and my holidays from work ...I had no time left to take off to be with her anymore...that's why I ended up relying on the nurses as much as I did...

Constancy versus Change describes variations in the time a parent spends in hospital from one admission to the next.

C. Routine versus Unpredictability refers to the regularity of a parent's visits. Some parents established a set pattern of visiting, such as visiting daily on their lunch hour and after work. Other parents' visits were more random:

No [I didn't get into a routine], I was just there as much as I could be. And when I felt like I had enough, I just came home. Because sometimes I just couldn't handle being there, it was very stressful...

Routine versus Unpredictability pertains to how a parent's time spent in hospital varies within one admission.

Conditions Influencing Parent Care

During the interviews, parents revealed conditions that influenced their ways of Making it Better. These conditions were categorized into four groups: A. Life Outside the Hospital; B. Life Inside the Hospital; C. The Way I Am; and D. The Way My Child Is. These are outlined in Table 6. They are detailed below.

Table 6: Summary of Conditions Influencing Parent Care

A. LIFE OUTSIDE THE HOSPITAL	B. LIFE INSIDE THE HOSPITAL
1. Responsibilities 2. Supports	1. Surroundings 2. Nurses 3. What's Allowed 4. Familiarity
C. THE WAY I AM	D. THE WAY MY CHILD IS
	1. Development 2. Behaviour

A. Life Outside the Hospital. All of the parents reported that their life outside the hospital could influence the amount of time they had to spend with their child in hospital. This was determined by the balance between the parents' 1. Responsibilities and 2. Available Supports.

1. Responsibilities. The most frequently cited Responsibilities were caring for other children and going to work. Two families also had to deal with life-threatening illness in another family member.

2. Support. Available Supports varied among parents. In single-parent families with more than one child, mothers relied on family members or the child's father to provide support. When such support was unavailable, the single mother's time with the hospitalized child was restricted by the needs of her other children. In two-parent families, each parent could be a support to the other. The most commonly reported arrangement involved the mother staying

with the child in hospital while the father took care of things at home, visiting the hospital whenever he could.

Support also came from family and friends.

Well, we were really lucky...I come from a family of twelve...and we have five or six neighbours that were fighting over the kids...and my oldest was old enough to do babysitting...and my husband has his own business so he was able to be here after school if need be, or at noon,. And even that wasn't necessary....the neighbours would make them lunch, or at night there would always be food at the door, and I don't know where it came from, it simply was made and that went on for weeks and months...I could call anybody and they would help.

Supportive employers were also important. Parents reported that their employers were willing to be flexible. At times this flexibility rested on the availability of vacation time and leaves of absence, and if the hospitalizations were prolonged or frequent the parent would eventually have to return to work.

I had a leave of absence for three months and then...I would take [my other child] in the morning to the babysitter's and then I'd go to work and on my lunch hour I would go to the hospital and stay with S. for an hour and then I'd go back to work and then I'd go back to the hospital after work and stay a little while with her and then I'd come back [home].

Support could also decrease the time the parent spent in hospital, because someone could stay with the child while the parent tended to responsibilities or simply took a much-needed break. This support came in the form of close family and friends who were well-known and trusted by the child. The lack of this kind of support could make life extremely difficult for the parent who was constantly at the hospital.

"It's hard to have to be there all the time...my husband had already lost six weeks of work...so after that it was pretty well myself - me, myself and I!...there was no one else that could stay with her overnight." Balancing responsibilities with supports played an important role in determining how much time a parent could spend with the child in hospital.

A. Life Inside the Hospital. A parent's perception of their hospital experience could influence the amount of time he\she spent in hospital, as well as the parent's activities at the hospital and interactions with staff nurses. Four characteristics of the hospital experience were identified:

1. Surroundings; 2. Nurses; 3. What's Allowed; and
4. Familiarity.

1. Surroundings - Certain features of the physical environment were perceived negatively by parents. Firstly, it was difficult to get a good night's sleep at the hospital. Not only were the cots uncomfortable to sleep on, parents also reported being disturbed at night by nurses.

...as nurses they're all charged up at night and here you're there 24-hours. You don't appreciate the nurses coming in and putting the lights on and then taking off. I know they have to work, have to have some light. But they leave the room without shutting the light, and you're there at 2:30 in the morning, "I know I should get up and shut off the light, I know it's not going to help me sleep" but you're too tired to get out of your darned bed because you're up quite often during the night with your child...and also they're really very noisy....Oh come on girls, I don't go home after 12 hours and go to sleep, I'm here all the time!

These disturbances had the potential to decrease the amount of time a parent spent in hospital. "I was in a conflict. I

wanted to be with my son and sleep overnight at the hospital...but I would have such a rotten night's sleep that the next day is like torture." Secondly, parents reported a lack of privacy in the hospital: "...people are always walking in and out. There's always somebody else there, it's like you're never alone with your child...there are always people in the hallways and stuff". A parent for whom privacy was highly valued could feel uncomfortable in the hospital and so limit the amount of time spent there.

2. Nurses - Parents' perceptions of the nurses could influence parent care. The parents who saw nurses as supportive of their participation were more likely to be involved in care. These parents reported that nurses made them feel welcome and comfortable on the unit. "We were always accommodated when we were there...[they] encouraged us to be there. There was never a problem, like we were in the way or anything like that."

On the other hand, a parent who felt that the nurses were judgemental felt uncomfortable in the hospital, needed to spend time away from the hospital and limited interaction with the nurses. "Especially being a single parent, I felt very judged by certain nurses. I felt very much like they thought...maybe I'm not a good enough mother, that's why my son got cancer...I didn't want the nurses around, 'cause I felt judged by certain ones...I would only confide in the nurses I really felt were good listeners and good, caring

people who wouldn't judge me". When the nurses were seen as busy, the parent may have been more likely to stay with the child, to ensure that he\she got the care the parent wanted.

Knowing that the next morning he wouldn't have his breakfast if I wasn't there, bright and early. So I figure, "Oh, better sleep here". If they were really busy, I know that he wouldn't be changed in the middle of the night...For me, if his diaper is wet, he should be washed after with a warm cloth, not necessarily soap, but at least a warm, wet cloth...I knew that overnight he could stay in a wet diaper for a long time, and that bothered me. And sometimes I stayed overnight, just to know that...I would check him. And soon as he was wet, I would change him.

Parents' perceptions of nurses' actions and approach could influence the care they gave.

3. What's Allowed - Parents' perceptions of what they could or could not do regarding their child's care affected the extent of their involvement in care. Parents participation in care depended upon their beliefs about what was the nurses' job and what was their job. A mother who was involved in all aspects of her child's care stated:

I do her tubes, just because a lot of time I don't want them to, she's used to me. I do her tubes, I do her dressing, do her bathing, I will weigh her, I'll do all these things, and I don't mind. She's my child, that's my job, you know.

Another mother explained her involvement in care: "...not medication-wise because they would know exactly when she needed the medicine...No, I usually let the nurses do everything themselves because I figured that was their job."

For some parents, the distinction between their job and the nurses' job was less clear, leaving them unsure of what they could do.

Maybe I just think it's hands off up on the ward, that we don't have permission to do this, that it's not okay. I do feel that a little bit, I guess because nobody's said, "Yes you can. It's okay for you to do that". You feel kind of...like, going over to check the pump, and checking this...you kind of feel like you're intruding on someone else's territory.

Parents limited their involvement in technical care to what they were comfortable doing.

I would watch them all the time and then I would ask them. Sometimes, if she'd get a kink in the line or whatever, I'd just say, "If I straighten this out and everything, what do I do?" and they told me. So then I'd straighten it out and I'd do it. And if it stopped then everything was fine, and I'd leave it. But if I did whatever I'd seen them come to do, taking out bubbles and unkinking and it still didn't work, then I'd go get them. I figure I'm not going to play around with this. Like I'll do what's basic, which I know they're just going to come here and unkink it and push a button. I can do that. I don't need to call them every time. But if I couldn't get it to stop beeping after a minute or two, then I'd say "okay fine, I'll go and get the nurse".

One mother drew the line on her involvement in care according to her son's needs:

And sometimes I will step back because if it's going to make or break the moment of being a nurturing mother or the nursemaid, it's more important to nurture than to be the...to be a helper or a nurse. D. needs a Mom, needs me there as mom more than he needs me there as nurse.

Parents differed in their beliefs about the control they had over their child's care. One father described taking control of his child's care to the extent of

determining in what way a nurse could be involved in care. Nurses with whom he and his wife were uncomfortable were limited to "just the basics that we would allow them to do, things that we were not entitled to do". Nurses with whom they were more comfortable were allowed to do more nurturant care. For other parents, the nurse was in charge. They went along with his\her way of doing things and appreciated being allowed to help. "They let me do, basically, his mouth care, and his bed bath, and let me dress him. And sometimes I would make the bed. Sometimes I'd do it without asking them, they wouldn't mind, you know...And they let me feed him. And I appreciated that". Parents who were comfortable testing the limits of what was allowed assumed a wider range of care activities.

4. Familiarity - Parents perceived that the number and length of their child's admissions influenced their involvement in care and their relationship with the nurses. Parents whose children had frequent and\or lengthy admissions found that with time, they became more comfortable with procedures and ward routine and took a more active role in care.

[At first] we were wallflowers. I think we were also in shock, but...after we knew what we were dealing with and after the surgery and after we knew we had Wilm's, and finding out the treatment. I guess you know its there, you got to cope with it, you start participating more. And in the last time we were in the hospital, well, by then we'd been through how many weeks of treatment and everything else so that we were a lot of different that third time in the hospital. The second in

June, that was a lot different because we'd been through so much, and probably as parents, had a lot more knowledge of the hospital system and knew what to expect and knew what to ask and so we participated immediately. Whereas the first time we were in shock. Which I think is normal.

With time, parents' relationship with the nurses changed as well, as they got to know each other better.

When I first started taking him...I had so much anger and resentment that...I just didn't look at them, didn't talk to them or anything because I just couldn't stand the thought of my son being there...Why he was there...I was walking around with a big chip on my shoulder...but it's gotten to be pretty good just going to the hospital and visiting and that. The nurses joke and talk...so it's gotten easier going.

When a child was admitted less frequently and for shorter durations, parents reported that they did feel more comfortable with procedures and routines over time, but that their relationship with the nurses changed very little.

...there were a lot of different shifts that we went through, some of the girls we got to know a little bit from one admission to another. But in general...the relationship was pretty much consistent. I guess we got used to the routine in later admissions, but I think the approach was the same...probably the only difference was...our understanding of what was going on and what had to be done.

Thus, the cumulative number of days a child spent in hospital could influence the parents' relationship with the nurses.

Familiarity with the hospital also had the potential to decrease the amount of time the parent spent in hospital. As they and their child got to know the nurses, parents felt

more comfortable leaving their child in the care of the nurses while they took a break.

In summary, parents perceptions of Surroundings, Nurses, What's Allowed and Familiarity influenced their activities in the hospital.

C. The Way I Am. This was defined as the parents' personal response to their child's illness and hospitalization, which influenced the amount of time they spent in hospital, their involvement in care and their interactions with the nurses. Of the sixteen parents interviewed there were more differences than similarities in their experiences. However, one response was common in all of the parents; this will be discussed first. Following that, the responses of two parents will be profiled, as examples of the range of differences found.

All parents stated that they needed to have complete information about their child's illness and treatment in order to deal with it. "The more educated I am about something, the more I relax. So they gave me material to read, so I read everything and I asked a lot of questions. the more I understand something, the more I can cope with it." Parents needed to know what to expect over the course of their child's illness and expected honest updates about their child's condition.

I prefer to be told everything and to know what can happen, and what would be the symptoms if this were to happen. I prefer to be told everything...if something is happening, to be told

right away. If there's a problem, saying 'Is it serious?' and if it is, that they say 'Yes'. If it isn't, 'No, but it can become serious'. I prefer to be told...in a very direct way like that...If I felt like something was being hidden from me, then I felt very, very uncomfortable.

This led them to take a questioning approach to the situation. They questioned the nurses (and other staff) about the child's condition and greatly appreciated the information provided. Some parents kept a written record of the child's progress, including things such as daily blood counts, medications the child received, how the child was doing and questions they wanted to ask the doctor. Many saw participating in care as a way of learning about the child's illness and treatment. The desire for information could increase parents' involvement in care and their interactions with nurses.

Aside from the common need for information, parents ways of dealing with the situation varied. These approaches influenced parents' interaction with nurses, and the nature of their involvement in care. For example: a parent who needed to find humour in the situation would laugh and joke with the nurses; a parent who enjoyed being active would look for ways to be involved in the child's care. To further illustrate different ways of dealing with the situation, two parents will be profiled.

The first parent to be profiled is the father of a young boy. He and his wife provided almost constant company

for their son. This father was determined that all his son's needs would be met with as little delay as possible. He became extremely active in all aspects of his son's care. This father also became very vigilant of the nurses' activities. For example, he closely monitored the frequency of analgesic administration ensuring that his child experienced a minimum of pain. When asked to talk about his need to be so vigilant, he responded:

I don't know...lack of an understanding. There were so many things happening at one time that you wanted to be damn sure of what was going on, have a complete knowledge and understanding of what was taking place. So I was quite cautious, you know, as I said earlier, policing, watching them closely, find out what was happening. And I don't have an explanation of why...it's just the way it was. The situation at the time, in my mind, required the type of approach that we took. You were waiting for answers, you were waiting perhaps...why are we doing this, why are we doing that?...Just staying on top of the situation from the word go. I think a lot of it has to do with the type of people we are too, we're pretty much more hands on.

This father was confident that he had done all he could to
Make it Better for his child.

The second parent to be profiled is the single mother of a young boy. She was unable to provide constant company for her child in hospital partly because she found the situation so stressful.

At first he was very much out of it...and it was really scary...I wasn't always there...the stress

was too much for me, it was very hard to see him that way...

...It's hard to deal with it. I'm not the kind of person that can just deal with it right away, it takes time. To be there was being forced to deal with it when I wasn't ready to. That was the hardest. I was really worried about him.

This mother's difficulty in dealing with the situation decreased the amount of time she was able to spend with her child. When this mother was with her son, she did participate in his care (primarily physical care). Her interactions with nurses were also limited, because of her need to keep herself distanced.

I really kept myself distanced as much as possible because...I didn't really feel comfortable in the hospital because it was a very uncomfortable situation. And I didn't want to talk about it, I didn't really want to deal with it right there and then, it was too hard. So I was there as much as I could be for my son, and if I didn't have to be at the hospital, I didn't want to be there.

This mother felt she did the best she could for her son, but wished she could have done more.

These two examples indicate the disparity between different parents' responses to the situation. They demonstrate that although all parents want to do as much as they can for their hospitalized children, what they can do is dependant upon their personal resources for dealing with the situation.

D. The Way My Child Is. Parents' involvement in care and the amount of time they spent in hospital were partly

determined by their perceptions of their child. Parents considered both 1. Development and 2. Behaviour.

1. Development involved the parents perceptions of their child's abilities. Parents stated that because their child was young, it was better that they stay with him\her and do as much care as they could.

I guess maybe it was our attitude... our son just being a little guy, I just felt my husband and I should do it. I guess also, he was scared and these were people he didn't know. I mean, eventually he did get to know them and he did build a relationship. But I guess we were trying to minimize the fear that he had, and so that way if we did it, it was o.k., but if they did it...You know, he was nervous in things that they had to do that we couldn't do. He just wanted to hold our hands. So some of the times that we could do it, I just think it was better for him. If he were, you know, sixteen years old or something, it would be different then, they'd have a better understanding and you could reason things out. But...he had just turned three. You know, the communication skills aren't very good at that age.

Parents reported leaving their child alone for longer periods as he\she got older. Doing so gave the child the opportunity to develop new skills.

I knew she would use her buzzer when she had to and if she used that, [the nurses] would come. Other than that I wasn't really worried if they came in at all because she was old enough to understand, to get them when she needed help. I'd always tell her 'Don't get out of bed to pee on your own with a central line. Call.' And she did...I'd come back and she's all proud of herself, 'And I did this, and I did that'.

2. Behaviour. Parents also considered their child's Behaviour when deciding how much time to spend with their child. If the child was obviously upset by the parents'

absence, they would choose to stay with their child. Parents who feared that the child might hurt him\herself also stayed with their child: "...at some points I wouldn't leave her alone cause...if I walked out the door, she'd take her I.V. and rip it out, whether it was central line or not. Rip it right out! What can you do?..." Parents recognized that as the child got to know the unit staff better, they protested less about the parents' absence, and the parents were able to leave for progressively longer periods of time.

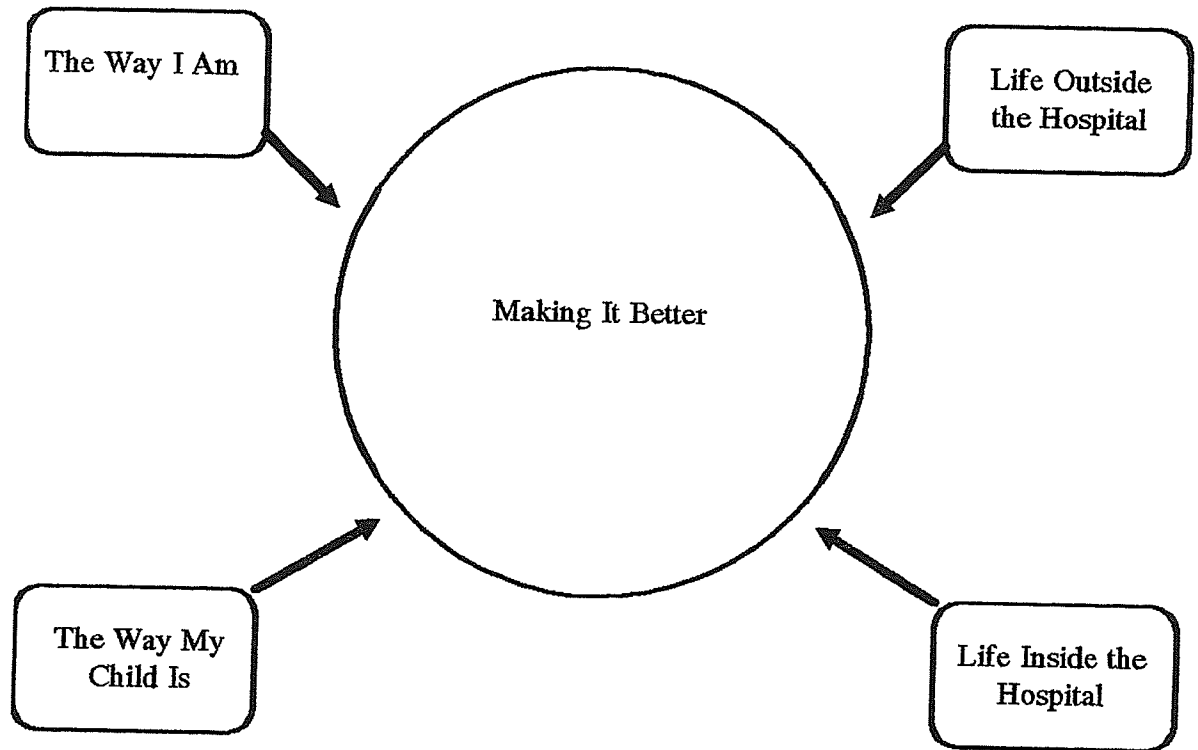
Not more than an hour, at the very beginning. I wouldn't take any chances. If I said I would be gone as long as three commercials...I'd be back because then I'd ruin everything I'd just gained. But if she knew I was in the hospital, everything was fine. So when it came to the point where I'm going home to get some clothes and that was OK, well, that was wonderful. Then it would be about an hour or something...I knew that the movie was at least an hour.

Parents considered both the child's actions and their perception of the child's abilities when determining the amount of time spent in hospital.

In summary, parents involvement in care, their interaction with nurses and the amount of time they spent in hospital were influenced by four conditions: Life Outside the Hospital, Life Inside the Hospital, The Way I Am and The Way My Child Is. The influence of these conditions on parents' actions varied from parent to parent. For example, the single mother with children at home might have to leave her child alone despite his\her protestations; parents who spend all day with the child may limit activity to

Supportive Care only, because they believe the nurse is responsible for all other care. These four conditions' influence on Making it Better is diagrammed in Figure 9.

Figure 9: Diagram of Conditions Influencing Parent Care



Parents and Nurses: Working Together

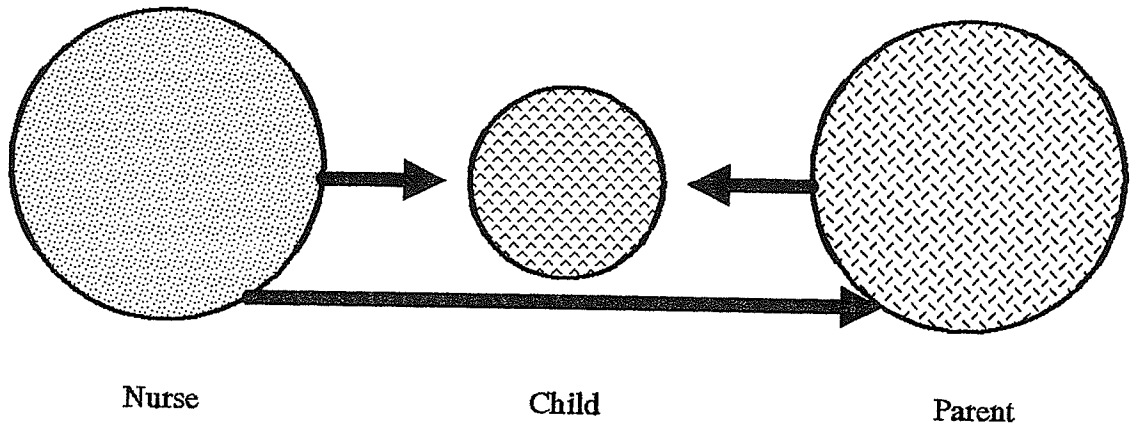
Working Together was the theme that emerged to describe the relationship that developed between parent and nurse as they cared for the child. Working Together varied with the care provided by the nurse. Three variations were identified: A. Territorial Caring; B. Sharing Care; and C. Making Friends. They are detailed below.


A. Territorial Caring. A relationship of Territorial Caring developed when the nurse was Going Through the Motions. Both parent and nurse assumed responsibilities in providing the best possible care for the child, but worked side-by-side rather than as a team.

...they pretty much handled [basic] areas and we handled...the human aspect of things. Which they did too, to a degree, depending on the nurse...you would look at the situation and determine how comfortable you felt with this person...some of them did a lot, some didn't do as much...just the basics that we would allow them to do...

Parent and nurse each provided direct care to the child, but did not provide indirect care. See Figure 10(a).

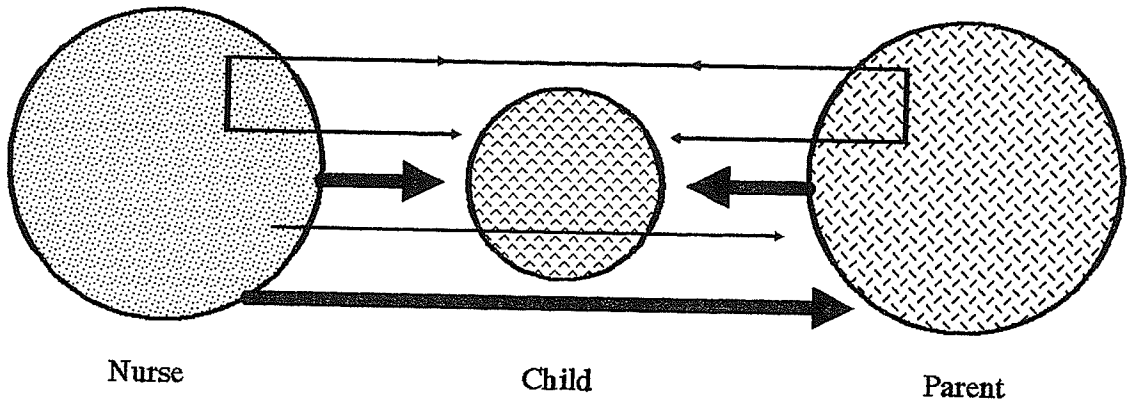
Figure 10(a): Working Together: Territorial Caring




Direct Care= 

B. Sharing Care. When the nurse was Caring Completely, the relationship was one of Sharing Care. In Sharing Care, both parent and nurse worked together to provide the best possible care for the child: "...it's almost like a team...it's almost unspoken. Parents do so much, we all do so much, and nurses do the rest..." Parents and nurses both cared directly and indirectly for the child. This is diagrammed in Figure 10(b).

Figure 10(b): Working Together: Sharing Care



Direct Care = 

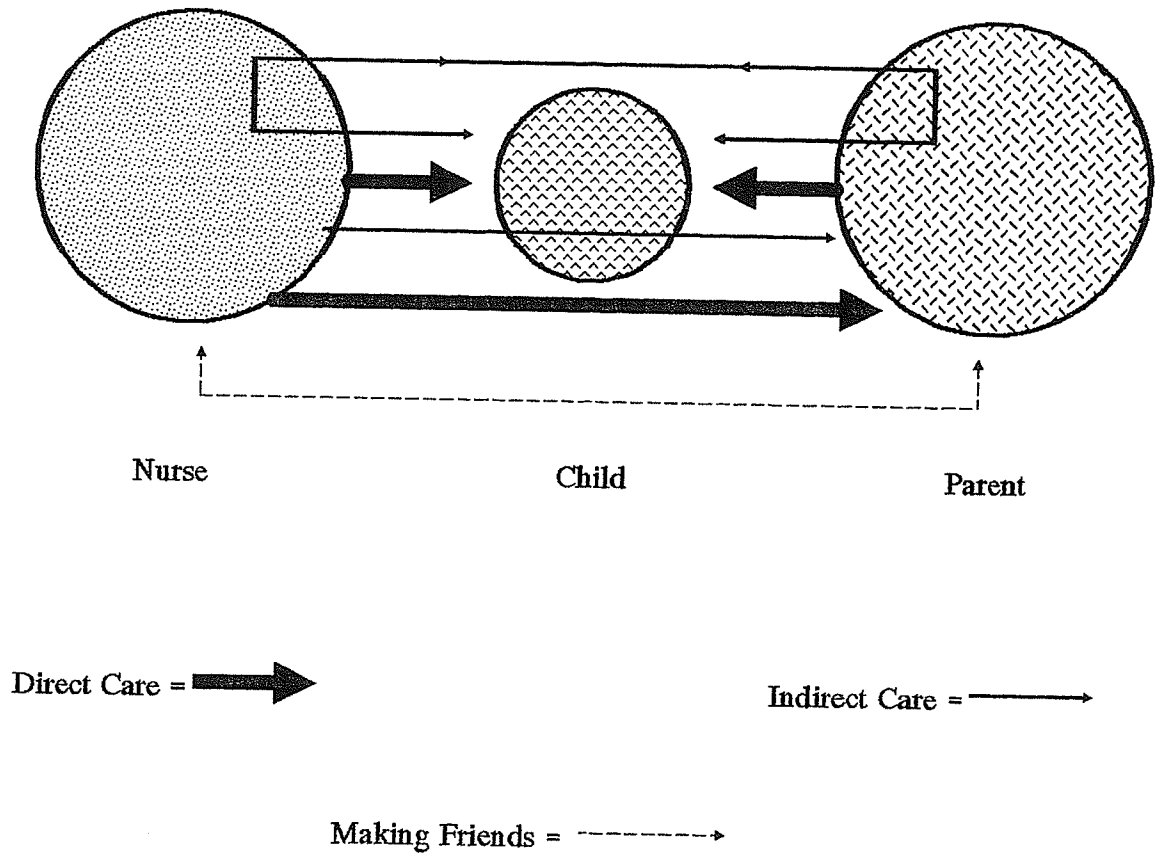
Indirect Care = 

C. Making Friends. Sharing Care could take on the added dimension of Making Friends. This occurred when parents and nurse found they had things in common and developed a relationship that extended beyond providing care for the child.

...over time, over a few days you'd see the same nurse in there...And you always had some type of conversation that always led to something slightly personal. But if you talked you realized that you and somebody else, that you have something in common...you'd get to know them. Not all of them were that way, but there's a number of special ones...It's not something you plan on happening, it's just like you work with somebody, and you probably wouldn't have become friends or acquaintances if you didn't work with each other, because there is no other way of crossing paths. So our paths crossed in the hospital.

Parents who described Making Friends saw it as an "extra" that helped to make the experience of spending time in the hospital a little more pleasant. Making Friends is diagrammed in Figure 10(c).

Figure 10(c): Working Together: Making Friends

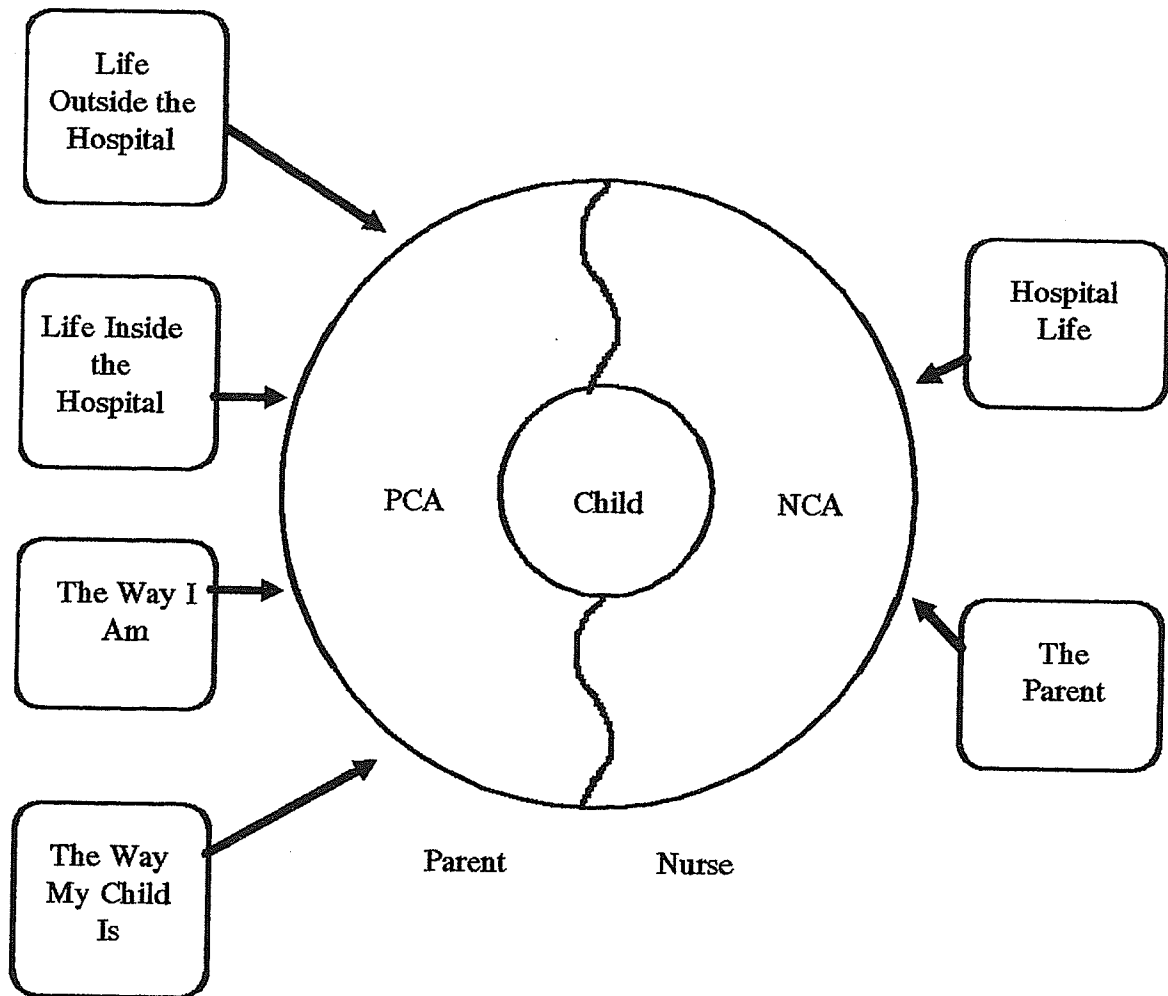


In summary, the relationship between parent and nurse, Working Together, had three possible variations: Territorial Caring, Sharing Care or Making Friends. The form of care provided by the nurse influenced the development of the relationship.

Summary of the Conceptual Framework

The conceptual framework developed from this research depicts two individuals, the parent and the nurse, participating in activities required for the care of the child. Parents' and nurses' performance of these care activities may be hindered or enhanced by a variety of conditions. The nature of the parent-nurse relationship depends upon the nurse's and parent's ability to work together in performing these activities. Thus, the aforementioned conditions can affect the parent-nurse relationship. This is depicted in Figure 11. In this diagram, the circle, made up of two interlocking parts (parent care and nursing care activities), represents the parent-nurse relationship. The arrows represent the conditions influencing parents and nurses as they perform their activities, thus influencing the parent-nurse relationship.

Figure 11: The Parent-Nurse Relationship in Family-Centered Care of the Hospitalized Child with Cancer



Key:
PCA = Parent Care Activities
NCA = Nursing Care Activities

Conclusion

This chapter described the conceptual framework of the parent-nurse relationship that arose from the analysis of sixteen interviews with parents. It described the care provided by both parents and nurses as well as the conditions influencing their care. Nurses' care was made up of two components, The Basics and The Human Touch. The outcome of this care depended on the nurse's ability to combine these two components. Parents' care was directed towards Making it Better, and consisted of four components: Just Being There, Providing Everyday Care, Providing Illness Care and Providing Supportive Care. Each parent had their own unique way of Making it Better. Together, parents and nurses were Working Together to provide the best possible care for the hospitalized child with cancer.

CHAPTER FIVE

DISCUSSION

Introduction

This chapter presents a discussion of the research findings. Methodological, theoretical and clinical issues will be examined. The final section of the chapter offers recommendations for nursing research, practice, education and administration.

Methodological issues

The limited amount of time available for conducting this research imposed restrictions on the study sample and data collection procedures. Possible effects of each of these limitations will be examined. Issues regarding the use of a purposive, theoretical quota sampling method will also be addressed.

Given the relatively small sample and the use of only one care setting, the results of this study must be considered preliminary. The use of a single care setting limits the variation in the sample, and thus limits the generalizability of the resulting conceptual framework (Chenitz & Swanson, 1986). Whenever possible, parents' experiences with other care settings were analyzed; however, such accounts were few in number. The small sample size may have affected the results in two respects. First, the small number of parents and the disparities among them made it difficult to develop parent profiles such as those developed

to describe nurses. Interviews with a larger group of parents may have allowed commonalities and differences among them to emerge. Second, the small sample inhibited the planned comparison between mothers and fathers. Small differences between them did emerge, but it is not possible to determine whether these were differences between mothers and fathers or simply differences between individuals. A larger sample may help to identify these differences. Further qualitative research may provide the basis for development of a questionnaire to systematically measure parents' perceptions. This questionnaire could be administered to a large sample recruited from a variety of settings. Such quantitative analysis may be helpful in determining differences between fathers and mothers.

Data collection was limited to interviews and did not include other qualitative data collection methods. Ideally, supplementing these interviews with participant observation would have provided a more complete picture of the parent care and nurse profiles and the parent-nurse relationship. Participant observation may also have been helpful in developing parent profiles.

The purposive, theoretical quota sampling method attempted in this study was to have provided two categories of parents for comparison. However, only one of the two categories was represented in the study sample. There are two possible explanations for this: 1. the definitions of

"complicated" and "uncomplicated" were inappropriate for the study population; and 2. the parents categorized as "uncomplicated" chose not to participate (characteristics of parents who chose not to take part in the study are unknown to the researcher). Although comparison of parents in the two previously-established categories was not possible, study results indicate that the cumulative time spent in hospital could influence the parent-nurse relationship. Further research examining the parent-nurse relationship when the child with cancer is hospitalized could benefit from a purposive, theoretical quota sampling method that would categorize parents according to the amount of time spent in hospital.

In summary, the small sample size and the collection of data solely through interviews place limitations on the interpretation of the results of this study. Further work to replicate and validate these findings in other samples, using both interviews and participant observation is needed. As well, theoretical sampling of parents according to the amount of time their child spent in hospital should be considered for future studies.

Theoretical Issues

The following discussion considers three theoretical issues: the use of the term "roles"; the child's position in the conceptual framework; and the linear design of the conceptual framework developed from the findings.

The theoretical framework for this study proposed an examination of parent and nurse roles. However, as data analysis progressed, it became evident that parents were describing a process of performing selected activities comprising care, rather than a series of specific roles in care. For this reason, the term "roles" was not used to describe the results.

Analysis of the data indicated that the hospitalized child must be considered in any discussion of the relationship between parents and nurses. The relationship exists because of the child, and the interaction between parents and nurses is based on the needs of the child. For this reason, the diagrams of the parent-nurse relationship developed from the study findings include the child. This was overlooked in the diagram of the theoretical framework proposed at the beginning of this study.

The conceptual framework arising from this study depicts the parent-nurse relationship in a linear form. Such representation, however, cannot fully describe the interaction that occurs between parent and nurse, as it does not illustrate the feedback process that occurs within the parent-nurse dyad. This feedback process allows the parent and nurse to adjust their actions according to the responses they receive (Friedman, 1981). The study findings indicate, to a limited extent, how parents adjust their responses according to their perceptions of their environment. This,

however, is only half of the picture: the study did not include nurses and so cannot illustrate how nurses respond to parents and environment. Future research can fill in this gap in two ways: first, by interviewing nurses about their relationships with parents, and second, by including participant observation of parent-nurse interactions.

The first theme of the conceptual framework describes parents' perceptions of both the nurses they encountered and the care these nurses gave. After careful consideration, the term "Outcomes" was selected to represent the end result of a specific form of nursing care, as described in the second component of this theme. However, the appropriateness of this term is debatable. Continued thought and discussion about this component of the conceptual framework and the terminology that would provide the best title for it may lead to changes in the future.

Clinical Issues

This research indicates that parents of hospitalized children with cancer value a good relationship with pediatric staff nurses. Taking this into consideration, the following discussion examines two issues relevant to the development of good parent-nurse relationships: 1. Fostering Parental Participation; and 2. Promoting Family-Centred Nursing Care.

Fostering Parental Participation

Fostering parents' participation in the care of their hospitalized child with cancer involves encouragement and acceptance. Nurses need to encourage parents to be involved in their child's care, while accepting each parent's choice about the extent of that involvement. Nursing staff on a given unit must foster an atmosphere that gives parents every opportunity to take part in their child's care. Having been given the option, parents can then make a choice regarding the extent of their own involvement. This research provides helpful insight into parents' care activities and the conditions that influence them.

The present study supports previous research examining parental participation in care of hospitalized children (Alcock & Mahoney, 1990; Algren, 1985; Beck, 1973; Caldwell & Lockhart, 1981; Hill, 1978; Jackson, Bradham & Burwell, 1978; MacDonald, 1969; Merrow & Johnson, 1968; Sainsbury et al (1986); Snowdon & Gottlieb, 1989). These findings indicate that parents want to participate in their hospitalized child's care, and that this participation includes general care, medically-related care, and provision of emotional support. Three of the four components of Making it Better (Providing Everyday care, Providing Illness care, and Providing Supportive Care) are evident in the existing literature. The remaining component of Making it Better, Just Being There, had not been recognized in

previous research. This study adds to previous research by identifying parents' presence with their child in hospital as a care activity in itself.

This research also identifies differences among parents regarding their participation in their child's care and identified conditions that parents believe affect their involvement in care. Previous research indicates that nurses have set expectations for parents' participation in care, and that parent-nurse conflict may result if parents do not meet nurses' expectations (Brown & Ritchie, 1990). Nurses who are aware of the differences among parents' approaches to care and can identify the conditions influencing parents' involvement in care may have fewer pre-set expectations of parents. They may be better prepared to adapt their care according to the unique needs of each family and thus be more successful in providing family-centred care.

Examination of the conditions influencing parent care identified in this study indicates that three of the four conditions (Life Outside the Hospital, The Way I Am, and The Way My Child Is) are not readily amenable to change by nurses. However, an understanding of how these conditions can affect parents' involvement in care may help the nurse to identify appropriate resources which may be able to ameliorate them. For example, the nurse who recognizes parents' responsibilities at home and their lack of support

in meeting those responsibilities can initiate a referral to a social worker. Although nurses are not in a position to mitigate such difficulties independently, identification of difficulties and referral to other health care professionals are certainly within the realm of nursing.

The fourth condition, Life Inside the Hospital, is more amenable to change by nurses. Three characteristics of this condition (Surroundings; Nurses; and What's Allowed) are particularly relevant and will be addressed here.

Hospital Surroundings can be detrimental to parental participation. This is largely related to the fixed aspects of the ward, such as its physical design. However, nurses can make the Surroundings more conducive to parent participation through careful management of the environment. For example, nurses can help by avoiding excessive disturbance of the family, particularly at night. Ultimately, the effect of Surroundings on parental participation in care needs to be taken into consideration in the designing of children's hospitals.

Parents' perceptions of Nurses can influence their involvement in care. Research indicates that nurses' awareness of their influence on parents is limited (Brown & Ritchie, 1989). As the nurse's approach can either hinder or promote parents' participation in care, it is imperative that nurses be able to recognize their own attitudes' and behaviours' potential effect on parent care activities and

develop a nursing approach that promotes parent participation in care. For example, nurses can develop a non-judgemental approach towards parents, and demonstrate their support of parents' endeavours to be involved in their child's care.

Finally, parents may be reluctant to participate in their child's care because of uncertainty regarding What's Allowed. Existing research suggests that communication between parents and nurses regarding activities parents can participate in is minimal (Algren, 1985; Hayes & Knox, 1983). Nurses can promote parent participation by establishing clear guidelines for parent care activities and helping parents choose the degree of participation they are comfortable with.

Promoting Family-Centred Nursing Care

The provision of family-centred nursing care requires that nurses have the desire and the ability to provide such care, and that they receive support in their efforts. This research indicates that parents value the work of nurses in caring for their hospitalized child. It also provides a description of what parents believe nursing care involves and the factors they believe influence nursing care.

The present study adds to existing literature by providing a description of nursing care from the parents' perspective. Only one previous study addressed parents' perceptions of nursing activities. Knafl, Cavalleri and

Dixon (1988) examined parents' perspectives of the nurse's role as part of a larger study of parents' perceptions of their child's hospitalization. The resulting description of the nurse's role was used primarily to illustrate the differences between levels of parental participation. The present study provides a more expansive picture of nursing care. These results illustrate the components of nursing care as seen by parents, and demonstrate how certain variations of nursing care can influence parents' perceptions of the care received. The description of nursing care provided by this research may enhance future studies of parents' expectations of nursing care and their satisfaction with nursing care received.

The description of nursing care provided by this study reflects the needs of parents admitted to a pediatric intensive care unit, as identified by Kasper and Nyamethi (1988). These needs included a need for information, a need to participate in their child's care, and being able to tend to physical needs (e.g., sleep, food). In the present study, the description of nursing care included strategies to meet these needs, suggesting that parents look to nurses to help them deal with hospitalization. Although parents did not report going to nurses specifically for emotional support, this study suggests that nursing actions that ameliorate the day-to-day difficulties of a child's

hospitalization are important to parents, providing them with an important form of support.

This study also supports findings from research examining patient satisfaction with care. Previous studies indicate that adult patients and parents of children with cancer rank sound clinical nursing skills as more important than psychosocial support skills (Calderwood & Koenen, 1988; Gardner & Wheeler, 1981; Larson, 1984, 1986, 1987; Mayer, 1987). Participants in the present study also voiced a preference for the nurse with good technical skills. At the same time, they emphasized the need for strong interpersonal skills. This study demonstrates that despite the importance placed on clinical nursing skills, it is the combination of clinical skills with supportive psychosocial care that results in the style of care most highly valued by parents of children with cancer.

Parents participating in this study recognized conditions external to the nurse that influence the nursing care they and their child receive. Three characteristics of Hospital Life will be discussed here: Nurses are Busy; Hospital Hierarchy; and Secret information.

Parents identified the fact that Nurses are Busy as an important influence on the care nurses gave. This has also been recognized by previous researchers (Elfert & Anderson, 1987; Flint & Walsh, 1989; Knafl, Cavalleri & Dixon, 1988). The parents interviewed recognized that nurses were trying

to do as much as they could for each child assigned to them, given the volume of work they had to complete. However, they also recognized that the large number of demands placed on the nurse could have a detrimental effect on their child's physical and psychosocial care. Some parents stayed with their child to ensure that no aspect of their child's care was overlooked because the nurse was too busy. Parents who had to leave their child alone reported feeling uneasy about doing so. The issue of the nurse's busy day has been addressed by provincial and national nursing organizations in studies of nursing worklife concerns (CNA, 1990; MONA, 1989). These studies identified factors contributing to the nurse's "busy-ness", including inadequate staffing of units, increased patient acuity levels and the expectation that nurses will perform non-nursing functions. Research suggests that inadequate staffing levels contribute to less-than-optimum nursing care (Flood & Diers, 1988). The pediatric staff nurse alone cannot evoke the changes needed to ensure a more manageable workload. This issue must continue to be pursued at the levels of hospital administrations and provincial ministries of health.

Parents recognized that nurses' position in the Hospital Hierarchy can affect the care they give. Of particular note is the nurse-doctor relationship. Parents recognized that poor communication between medical and nursing staff could result in gaps in care. The nurse-

doctor relationship has been fraught with difficulties (Campbell-Heider & Pollock, 1987; Devereux, 1981; Tellis-Nayak & Tellis-Nayak, 1984). Research indicates that such difficulties can have a negative impact on nurse-patient relationships (Nievaard, 1987). Concerted efforts to improve the relationship between nurses and doctors are warranted. Such efforts must be aimed at both nurses and doctors, emphasizing one common goal for both professionals: optimum family-centred care for the child with cancer and his\her family.

Parents identified *Bending the Rules* as a strategy nurses could use to individualize their care, recognizing that nurses' place in the Hospital Hierarchy may limit the extent to which nurses are able to do that. Research indicates that rule-bending is common among nurses. Hutchinson (1990) called such rule-bending responsible subversion, and found that it was necessary because nurses work within a set of rules determined by others. These rules may not coincide with the nurse's beliefs about patient care, and the nurse may judge it necessary to bend the rules to provide care that he\she believes to be in the patient's best interests. The fact that both parents and nurses believe that some rules need to be bent suggests that a review of hospital rules is called for. Such a review should include both nurses and parents, to ensure that rules meet the needs of not just the hospital

administration, but of the people giving and receiving care as well.

The final characteristic to be addressed is Secret Information, that is, the tendency to keep information from parents. This research indicates that although parents want to have complete and honest information about their child's illness, this does not always occur. An attempt to hide information from parents not only makes parents feel uncomfortable, it has a negative effect on nursing care. Nurses may avoid the patient and parents for fear of being asked a question they cannot answer, or letting "forbidden" information slip. Putting nurses in this situation is unfair to both nurses and parents. Maintenance of honest and open communication among nurses, doctors and parents may serve to enhance the family-centred care received by hospitalized children with cancer.

In summary, the development of a good parent-nurse relationship requires that the needs of both parents and nurses be met. The conditions identified here as influencing parent care and nursing care in turn influence the parent-nurse relationship. Taking steps to mitigate these conditions may enhance the parent-nurse relationship and facilitate the provision of family-centred care to children with cancer.

Recommendations

Based on the findings presented from this research, the following recommendations are offered for research, education, administration and practice.

Research

Three recommendations are made for future nursing research. First, a similar study combining interviews with pediatric staff nurses and use of participant observation of pediatric units is in order. Such research would extend and strengthen the parent care profiles identified in this study (e.g., routine versus unpredictable parent visits). Second, from the results of the present study it can be hypothesized that the parent care profiles and the variations in parents' ways of Making It Better may influence the parent-nurse relationship. Further investigations could examine this hypothesis. Finally, nursing research in the area of family-centred care to date is limited by small sample sizes and use of single settings. Collaborative research among settings may ease these limitations and increase the generalizability of research in the area.

Education

Research in nursing education to the present time has provided little knowledge regarding the efficacy of nursing education programs in preparing nurses to provide pediatric nursing care (Alexander & Johnson, 1989). Future studies should be directed towards determining how nurses learn to

provide family-centred pediatric care and how to facilitate this learning.

Nursing educators should consider the extent to which principles of family-centred care are included in basic nursing education programs. Development of communication and conflict management skills is particularly relevant to pediatric nursing education. Students need to be given opportunities to work with parents in the clinical setting, with learning activities that emphasize the parent-nurse relationship when caring for children.

Practising nurses can benefit from continuing education programs in family-centred care that would help nurses develop and strengthen the skills and knowledge base necessary to provide family-centred care. Program content could include: helping nurses to identify their own attitudes towards parents' participation in care and the influence they have on parents; and examination of the conditions influencing parents' involvement in care.

Practice

The results of this study provide information that can be applied by nurses in their daily clinical practice. Many of the strategies identified by parents can be easily incorporated into everyday nursing practice. For example, nurses can make efforts to provide parents with information in anticipation of their needs. Nurses can also be more attuned to the conditions influencing the care they and

parents provide, and do what they can to mitigate these conditions. Qualitative research such as this can sensitize nurses to the needs of parents and nursing actions useful for meeting these needs.

Administration

The results of this study point to an important role for hospital administration in facilitating a positive parent-nurse relationship. Pediatric hospitals and nursing units need to establish an atmosphere conducive to family-centred care by promoting caregiver continuity, easing nurses' workloads and giving nurses more freedom to make decisions about their nursing care. Hospital administrations should also direct efforts towards enhancing the nurse-doctor relationship. Nurses' best intentions will have little effect without the support of hospital administration.

Conclusion

The purpose of this study was to describe parents' perceptions of their relationship with pediatric staff nurses when their child with cancer was hospitalized. Analysis of data collected through interviews with parents led to the development of a conceptual framework describing parent care, nursing care and the parent-nurse relationship. Conditions influencing parents' and nurses' care were also identified. These results were discussed in terms of methodological, theoretical and clinical issues. Recommendations for nursing research, education, practice and administration were presented.

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APPENDICES

APPENDIX A

Recruitment letter, to be sent to potential participants

Date

Dear Parents,

My name is Daria Romaniuk. I am a Master's of Nursing student at the University of Manitoba, and am beginning the research study needed to finish my degree. The doctors and nurses caring for your child at the Manitoba Cancer Treatment and Research Foundation have approved this study and are assisting me with it. However, they will not know the names of parents who choose to participate in this study. A secretary at the Foundation has addressed and mailed these letters; no personal information about you has been released to me.

My area of interest and experience in nursing is in working with children who have cancer and their families. For my research, I have chosen to study parents' point of view of what it is like when both they and nurses are looking after their child with cancer when he\she is admitted to hospital. My research is being conducted under the supervision of three professors at the University of Manitoba. My research advisor is Dr. Linda Kristjanson; she can be reached at 474-8937.

I will be interviewing parents (both fathers and mothers) about their experiences. Each interview will take between one and two hours to complete. I would like to interview mothers and fathers separately, because I am interested in finding out what differences there are, if any, between mothers' and fathers' points of view. However, after both interviews are completed, arrangements can be made to meet afterwards to discuss and compare your views if you would like. All information I obtain will be kept confidential.

A secretary from the Cancer Foundation will be calling you to ask your permission to release your name and phone number to me to contact you for a possible interview. In the meantime, if you have any questions or are interested in participating, please call me at 589-0696. Thank-you for taking the time to consider this request.

Sincerely,

Daria Romaniuk, R.N.

APPENDIX B

Sample (paraphrased) of phone invitation to participate

Hello, this is Daria Romaniuk calling. You recently received a letter from me asking you to think about taking part in my research project. If you are interested, I would like to tell you more about the study, answer any questions you may have and find out if you would like to take part.

(Pause - find out if they are interested in learning more)

As my letter explained, this project is part of my studies at the University of Manitoba Faculty of Nursing. I have chosen to study parents' point of view of what it is like when both they and nurses are looking after their child with cancer when he\she is admitted to hospital. My research is being supervised by three professors at the University.

I would like to explain to you how the study will be done and what your participation in the study will involve. Please feel free to stop me to ask questions.

I will be interviewing fathers and mothers. I would like to interview fathers and mothers apart from each other, to see if mothers' and fathers' ideas differ. The interview will be between one and two hours long. It can be at a time and place that is good for you. The interviews will be tape-recorded, to help me remember what you say. I will also ask you questions to provide me with background information about you and your family (such as your age and how many children are in your family). I may contact you a second time after the interview to ask questions I may have; this can be done through a second interview or over the phone.

Whether or not you take part in this study is entirely up to you, and you may withdraw from it at any time. You may refuse to answer a question, ask to stop the interview or request that the tape-recorder be switched off at any time during the interview. All that you say will be kept confidential. If you would like, a report of the final results of this study can be sent to you.

Do you have any questions about the study?

All parents taking part in the study should be alike in certain ways. For this reason, I need to ask you a few questions.

1. How old is your child with cancer? (Your child must be younger than 12 years old)
2. How often has your child been in the hospital since he\she was diagnosed with cancer? When was the last time

- he\she was in the hospital? (Your child must have been hospitalized at least twice since diagnosis, with one admission within the last year);
3. Do both you and your husband (wife) speak English? (Fluency in English is important for a successful interview).

If you would like to be a part of this study, I would like to set a time and place to meet with you.

If you need to take time to think about my request, please do so. I can be reached at 589-0696 should you choose to participate or have further questions.

Thank-you for your time. If you have any further questions, please feel free to call me at 589-0696. I'm looking forward to talking with you.

APPENDIX C

Interview Guides

Interview Guide A

As you know, my study is looking at parents' points of view of their relationship with hospital nurses when their child with cancer is in the hospital. I'd like to get an idea of what it is like for you, as a parent of a child with cancer, to care for your child in the hospital, where nurses are also caring for him\her. To begin with.....

1. Can you tell me what life has been like since you found out that your son/daughter has cancer?
2. Would you think back and talk about the time when you found out that your child had cancer?
3. What do you remember about the nurses who looked after your child at that time? (What did they do for your child? For you? Were they helpful? How? Did they make things difficult? How?)
4. Could you tell me what it is like to be looking after your child when he\she is in the hospital.
 - (a) When it comes to looking after your child in the hospital, what kinds of things do you do?

probes: feeding, bathing, dressing, giving medicine, doing central venous line (CVL) care (if the child has a CVL); cuddling, helping your child through a painful procedure, helping your child through a hard time (e.g., bad news, side effects of treatment); telling your child about what is happening or going to happen; trying to keep a routine, disciplining your child, helping your child with school work, playing with child, taking him\her to the playroom

Is this what you would like to do? What other things would you like to do? Is there anything you would rather not do?

- (b) When it comes to looking after your child in the hospital, what kinds of things do the nurses do?

probe: (as above)

Is this what you think they should do? Are there other things they should do as well?

- (c) Are there any jobs that you share with the nurse? Can you tell me about what it is like to share these jobs? Are there jobs you would like to share or

think could be shared? Are there jobs that you think should not be shared?

5. Do you ever feel any conflict or bad feelings between yourself and the nurse about who should do what? If you do, how do you work that conflict out?
6. (a) How do you feel about leaving your child alone in the hospital? Can you tell me about the first time you left your child alone in the hospital?
(b) What do you think that the nurse should do when you are not with your child?
7. How can hospital nurses be helpful to you? Your wife\husband?
8. Has your relationship with the nurses changed since your child first started coming into the hospital? If so, how?
9. (a) How much time are you able to spend with your child in the hospital? Would you like to spend more or less time?
(b) What kinds of things affect the amount of time you spend in the hospital with your child? **probe:** work, other children, other family responsibilities (e.g., caring for an elderly or ill parent).

As our interview comes to a close, your point of view seems to be (summarize). Does that sound right? Is there anything else you would like to add?

Thank-you for taking the time to do this interview. It's been very helpful and interesting to hear what you have to say.

Interview Guide B

As you know, my study is looking at parents' points of view of their relationship with hospital nurses when their child with cancer is in the hospital. I'd like to get an idea of what it is like for you, as a parent of a child with cancer, to care for your child in the hospital, where nurses are also caring for him\her. To begin with.....

1. Would you think back and tell me about the time when you found out that your child had cancer?
2. What do you remember about the nurses who looked after your child at that time? (What did they do for your child? For you? Were they helpful? How? Did they make things difficult? How?)
3. Could you tell me about the times your child has been admitted since that first admission?
4. Could you tell me what it is like to be looking after your child when he\she is in the hospital.
 - (a) When it comes to looking after your child in the hospital, what kinds of things do you do?

probes: feeding, bathing, dressing, giving medicine, doing central venous line (CVL) care (if the child has a CVL); cuddling, helping your child through a painful procedure, helping your child through a hard time (e.g., bad news, side effects of treatment); telling your child about what is happening or going to happen; trying to keep a routine, disciplining your child, helping your child with school work, playing with child, taking him\her to the playroom

Has your involvement in your child's care changed since the first time he\she was in the hospital? How has it changed?

Is this what you would like to do? What other things would you like to do? Is there anything you would rather not do?

- (b) When it comes to looking after your child in the hospital, what kinds of things do the nurses do?

probe: (as above)

Is this what you think they should do? Are there other things they should do as well?

- (c) Are there any jobs that you share with the nurse?
Can you tell me about what it is like to share these jobs? Are there jobs you would like to share or think could be shared? Are there jobs that you think should not be shared?
5. What is the most important thing you, as a parent, can do for your child in the hospital?
- What is the most important thing a nurse can do for your child?
6. Do you have any favourite nurses? What can you tell me about them?
7. Do you ever feel any conflict or bad feelings between yourself and the nurse about who should do what? If you do, how do you work that conflict out?
8. How did your child react to being in the hospital? Had he\she ever been away from you before?
9. (a) How do you feel about leaving your child alone in the hospital? Can you tell me about the first time you left your child alone in the hospital?
(b) What do you think that the nurse should do when you are not with your child?
10. How can hospital nurses be helpful to you? Your wife\husband?
11. Has your relationship with the nurses changed since your child first started coming into the hospital? If so, how?
12. (a) How much time are you able to spend with your child in the hospital? Would you like to spend more or less time?
(b) What kinds of things affect the amount of time you spend in the hospital with your child? probe: work, other children, other family responsibilities (e.g., caring for an elderly or ill parent).

As our interview comes to a close, your point of view seems to be (summarize). Does that sound right? Is there anything else you would like to add?

Thank-you for taking the time to do this interview. It's been very helpful and interesting to hear what you have to say.

APPENDIX D

Demographic Questionnaire

DEMOGRAPHIC QUESTIONNAIRE

1. How old is your son\daughter with cancer?

2. Does (name of ill child) have any brothers or sisters?
How old are they?

3. When was your child diagnosed with cancer?

4. What kind of cancer does your child have?

5. (a) How often has your child been admitted to the
hospital?

(b) What were the reasons for admission? How long was
he/she in the hospital? _____

6. What is your age? husband _____ wife _____

7. Do you work outside the home? What do you do?

Husband _____

Full time _____ Part time _____

Wife _____

Full time _____ Part time _____

8. Could you tell me what is the highest schooling you have:

Husband: Less than high school diploma _____

High school diploma _____

Community college/technical/vocational diploma _____

University undergraduate degree _____

graduate degree _____

Other _____

Wife: Less than high school diploma _____

High school diploma _____

Community college/technical/vocational diploma _____

University undergraduate degree _____

graduate degree _____

Other _____

APPENDIX E

Ethical Review Approval Form

The University of Manitoba

FACULTY OF NURSING
ETHICAL REVIEW COMMITTEE

APPROVAL FORM

Proposal Number N#92/29

Proposal Title: "THE PARENT-NURSE RELATIONSHIP IN FAMILY-CENTRED CARE OF THE
HOSPITALIZED CHILD WITH CANCER: THE PARENTS' PERSPECTIVE"

Name and Title of
Researcher(s):

DARIA ROMANIUK, R.N., B.N.

MASTER OF NURSING GRADUATE STUDENT

FACULTY OF NURSING UNIVERSITY OF MANITOBA

Date of Review: OCTOBER 05, 1992

APPROVED BY THE COMMITTEE: OCTOBER 05, 1992.

Comments:

Date: OCTOBER 08, 1992.

Lorna Guse, (R.N.) Ph.D. Chairperson
Associate Professor
Member, Ethical Review Committee
University of Manitoba Faculty of Nursing
Position

NOTE:

Any significant changes in the proposal should be reported to the Chairperson for the Ethical Review Committee's consideration, in advance of implementation of such changes.

Revised: 92/04/22/se

APPENDIX F

Disclaimer

Disclaimer

You are being invited to take part in an interview for the research project titled "THE PARENT-NURSE RELATIONSHIP IN FAMILY-CENTRED CARE OF THE HOSPITALIZED CHILD WITH CANCER: THE PARENTS' PERSPECTIVE". The purpose of this project is to study parents' point of view of what it is like when both they and nurses are looking after their child with cancer when he\she is admitted to hospital. Whether or not you participate in the study is up to you. By answering the questions, you will be agreeing to take part in the study.

The interview will be between one and two hours long, and will be tape-recorded. You may be contacted a second time to answer a few more questions; this can be done through a second interview or over the phone. The tape-recorded interviews will be typed by me or by a clerical assistant. All that you say will be kept confidential. No names will be recorded on the typed interview, only a code number. Typed interviews will be locked separately from the list of names and code numbers. The professors I am working with may see the typed interviews, but your name will not be known to them. These interviews may be used in future studies to learn more about what families experience when a child has cancer. When the research is done, the information will be kept locked in a safe place for seven to ten years and then destroyed. All reports of this study and any other studies using these interviews will be written in such a way that you cannot be identified (no names will be used, details will be changed).

There is no risk to you or your child. Any questions you may have will be answered. You may refuse to answer any questions and are free to withdraw from the study at any time. The care you and your child receive will not be affected.

Date _____

Initials _____

APPENDIX G

Request form for report of study

I would like to receive a summary of the research report:

Please send to: Name _____
Address _____

