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UNIVERSITY OF ALBERTA

PARENTING THE HOSPITALIZED CHILD

by

CAROLINE LOUISE PARK

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH

IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE DEGREE

of

DOCTOR OF PHILOSOPHY

DEPARTMENT OF EDUCATIONAL ADMINISTRATION

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DEDICATION

IN MEMORY OF

my colleagues, classmates and friends

Barbara Zier

&

Marlene Mercer-Glatz

ABSTRACT

The purpose of conducting this study was to explain the experience of parents during the hospitalization of their children. The experience is one of symbolic interaction. The research design was grounded theory, based upon the work of Glaser and Strauss. The main or core category was found to be a Basic Social Process, the relinquishment and regaining of responsibility for parenting the hospitalized child. The categories were connected and became a stage theory.

The first stage occurs prior to the actual hospitalization, when the parent notices a change in his or her child's behaviour. If the parents' attempts to understand the changes are unsuccessful then they become alarmed and seek outside confirmation that something, beyond their capacity is wrong with the children. This stage was labelled losing control because attending the physician begins the transfer of power.

Relinquishment of responsibility is the second stage. Parents let the hospital staff assume the care of the child deeming them to be the experts. The parents stay with their children if they see a need to be there. For some parents the need is continual.

While being there with their children parents become aware of the inadequacies of the care in relation to their child's individual needs. They notice that nurses are very busy. All parents mentioned anger at being ignored as a source of information and assistance. Some parents become frustrated and liberate themselves by recognizing their own potential to become more powerful and to resume responsibility. Other parents repress their frustrations, being resigned to the situation.

The parents who feel liberated increase their resources by getting information, developing trusting relationships and assuming responsibility for care. The parents who repress their frustrations, resume responsibility when their children are discharged. They express anger at themselves for not having taken more control during the hospitalization.

The theory is a framework for further research which encompasses existing knowledge about parents of hospitalized children and indicates the large gaps. It is also a useful model for planning care which includes parents.

ACKNOWLEDGMENTS

Many individuals have assisted in the completion of this research. My supervisor, Dr. Al MacKay has been supportive with encouragement and also with thoughtful advise about both the contents and its organization. His knowledge about sailing has also been an enormous support to me. Dr. Jan Morse has been invaluable in her methodological advise and her expertise in the content area of the illness experience. Special acknowledgement is also deserved by committee members Dr. Linda LaRocoque, Dr. Margaret Haughey and Dr. Frank Peters. Dr. Edna McHutchion, external examiner, provided excellent comments and advise.

The participants in the study are greatly appreciated. They are committed to improving care for all hospitalized children and their experiences are important to health care professionals.

I would like to thank the Alberta Association of Registered Nurses Educational Trust for awarding me the Helen Sabin Scholarship, and my colleagues on the Faculty of Nursing who helped me many times.

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CHAPTER 1

THE NATURE OF THE STUDY

This research is a grounded theory study which focused on the question: what is the experience of parents when their children are hospitalized? Commonalities of experience were theoretically linked to provide an explanation of the experience, so that those professionals working with families in the hospital setting, might begin to better understand both the experience and the implications it holds for health care, child welfare and family development.

This chapter provides the foundation for the study. The statement of the problem will introduce the reader to the significant issues in health care philosophy that relate to parents of hospitalized children. The significance of the research is explained next, followed by the research question. The chapter concludes with an overview of the organization of this thesis.

Statement of the Problem

Children's hospitals and paediatric wards within larger hospitals are the environment in which physicians, nurses and other health care workers care for ill and injured children. These institutions are a part of a large health care system and reflect the philosophy and practices of the larger system. Within the paediatric settings a move toward increased involvement of parents in the care of their hospitalized children is evident in philosophies labelled "family centred care" and in the establishment of care-by-parent units. An examination of the changing philosophy of the overall system indicates that this is a reflection of systematic changes in approach to health care. The changes in philosophy in the Canadian Ministry of Health and Welfare have been very progressive. They will be reviewed here so that their reflection in paediatric hospital care can be illuminated.

> The times in which we live are characterized by rapid and irreversible social change. Shifting family structures, an aging population and wider participation by women in the paid workforce are exacerbating certain health problems and creating pressure for new kinds of social support. (Epp, 1986, p. 2)

To meet these emerging health challenges the Minister of National Health and Welfare for Canada in 1986, the Honourable Jake Epp called for "health promotion" and proposed strategies in Achieving Health for All: A Framework for Health Promotion as a realistic course of action to improve the health of Canadians.

Epp's framework builds upon the 1974 Lalonde Report, A New Perspective on the Health of Canadians. Lalonde's report was significant because it broadened health care from the cure of illness perspective to encompass: lifestyle, the organization of health care and social and physical environments. The inclusion of aspects of everyday life in health care legitimized quality of life issues as health care issues. Quality of life in this context implies "the opportunity to make choices and to gain satisfaction from living" (Epp, 1986, p. 3).

The nature of health challenges facing Canadians are outlined in Epp's report as: reducing inequities in the health of different socioeconomic groups; increasing prevention of injuries, illnesses and chronic conditions; and enhancing people's capacity to cope with chronic conditions, disabilities and mental health problems. The best way to address these challenges is to encourage health promotion. "Health promotion is the process of enabling people to increase control over and to improve their health" (Epp, 1986, p. 6). Health promotion strategies are actions which increase self-care, mutual aid and provide a healthy environment.

Self-care in Epp's view is "decisions taken and practices adopted by an individual specifically for the preservation of his or her health" (p. 7). Mutual aid is "people's efforts to deal with their health concerns by working together" and healthy environments are achieved by "altering or adopting our social, economic or physical surroundings in ways that will help not only to preserve but also to enhance our health". (p. 7) These three strategies will be implemented by : fostering public participation, strengthening community services and coordinating healthy public policy.

This framework is seen to be timely by Epp (1986) because "people everywhere are demonstrating a willingness to act on matters of health" (p. 12) and it is an approach that can become part of the existing health care system.

Nursing, as part of the health care system, has been cognizant of the advantages of health promotion and has incorporated Epp's ideas into the theory base of both hospital and community care by nurses. Self-care as a nursing concept, was publicized by Dorothea Orem's work beginning in 1959. "Individual self-care as a framework for nursing is defined as a specific approach to clinical practice that places primary emphasis on the individual's ability to promote and protect health" (Bomar, 1988, p. 68). In the 1970s family nursing research evolved and family self-care as a framework for nursing was developed. The uniqueness and strength of the family constellation was recognized in this approach to clinical practice, which emphasizes the family's ability to promote and protect health (Bomar, 1988, p. 69). The overall goal of self and family-care is personal control over one's own health or that of one's dependents. Within the sub-specialty of paediatric nursing "family-centred care" has become the focus of research projects and curriculum design in schools of nursing but the interpretation of "self" within family-centred-care has been problematic because children are seen as dependent and not able to care for themselves and parents are seen as incapable of caring for their child in the hospital. Orem describes parental decision-making and care for the child as "dependent self-care". Family self-care and family-centred-care can have two different meanings. The definition of family-centred-care often includes mutually negotiated division of care-giving by nurses and parents. This can be interpreted as family-self-care.

Mutual aid and promoting healthy environments are issues discussed in the nursing literature, particularily where health promotion is the focus, but they have not been used as curriculum frameworks or nursing theories as has self-care.

In actuality, within hospitals, family-care can be placed upon a continuum from being non-existent to being total. In most paediatric settings parents are encouraged to stay with their child as much as they want, but care will be provided in their absence or their presence. In settings where family care is non-existent children are cared for as individuals, apart from and not interlinked with their family system. Physical care can be excellent but emotional care may be ignored. The total care perspective is seen in care-by-parent units which are popular in many medical centres. Parents, who find out about the opportunity, and who meet the entrance requirements of such units, are admitted to hospital with their children and care for their children under the direction of nurses, while their children undergo testing and treatment for certain medical conditions. The units are usually not staffed on nights and weekends even though the parents and children are still there. Investigation into the efficacy of these units suggests that there are great advantages to the child, the family and the institution. Unfortunately, very few children and families can take advantage of such situations when they are segregated into small, specifically defined units, with selection criteria.

Increasingly sophisticated technology has encouraged increasingly technological care in high-tech, high-cost institutions. Large financial and personnel resources are devoted to health care. Torrence (1981) stated that ten percent of the total labour force and eight percent of the gross national product of Canada was devoted to health care. That was 10 years ago. The recognition of this high cost, is seen by some as a factor which triggered the consideration of health care in the broader scope of the meaning of health, and as a motivator for the encouragement of health promotion. As well, the cost of institutional care has encouraged the search for other cost effective ways of caring for patients. Shorter hospital stay and increasing home care or care by non-professional care givers are more common than in the past.

In the paediatric field, the situation is that of increasing ratios of hospitalized children per nurse, shorter hospital stay per child, care-by-parent units and a discussion in the literature of the advantages of increasing parental involvement in the care of their children in traditional ward settings. It does appear logical to deduce that, given the same physiological outcome, that shorter hospital stay and more involvement by parents would be beneficial to the child, the family and society collectively because of improved psychological value to the child and family but caution must be taken in implementing cost reduction strategies without understanding the existing situation. The literature review, which follows this chapter, shows that there is no policy development research in relation to parental involvement in the care of their hospitalized children and there is little in the way of evaluation of the involvement that does occur. Bomar (1988) states that family-self-care is influenced by the individual characteristics of the family, such as age, education developmental state, and by the processes of the suprasystem, the health care system. There is no research to substantiate this.

The problem identified here is that nurses and other health care providers are being encouraged by federal policy and economic constraints to increase self-care. In paediatrics this must be translated to mean parent-care. Many ideas about the abilities and desires of parents to care for their ill or injured children both in and outside of hospitals, are available, but the basis for decision making in parent care, the experience of being the parents of a hospitalized child, is unknown.

Significance of the Research

Physicians decide when a child needs hospitalization, not parents. Traditionally, when this decision is made, professionals within the health care system assume responsibility for twenty-four hour a day care of the child, as well as the implementation of all "doctor's orders" for medical care. Nurses make the decisions about how these orders will be carried out and about what happens to the child between times of active medical treatment. Boman (1988) and Epp (1986) state that there is a populist movement towards self-care. Such a movement is not apparent in most paediatric settings but care-by-parent units are being established nonetheless. These units are encouraged because of proposed benefits to the child and family and because of their economic benefits to the health care system.

The self-care, health promotion movement is seen as a way to redistribute economic benefits. Constraints to self-care imposed by health care and nursing systems are described by Muller (in Bomar, 1988) as: the illness focus, not an individual or family focus; the task focus, not mutually identified needs; the identification of care by type of task; the conflicts between meeting the needs of the system and meeting the needs of the family and misconceptions about autonomy and accountability of nurses and families (p. 75). Are parents affected by these constraints?

If one accepts the tenets of the health promotion movement then hospitalized children and their parents would benefit from being admitted to a care-by-parent unit rather than a traditional paediatric ward. Surely any movement towards increased parent-care in the traditional setting would then be beneficial, as well. Unfortunately, very little is known about the experience of parents when their children are hospitalized. Is increased parent-care a realistic objective? An understanding of the parents' experience would be valuable base line data in the development of systemic changes to move the situation of hospitalized children and families toward the shared advantages of parent-care and shorter hospital stay, in the situations where parents are able and willing to be involved. An understanding of the experience would also be of benefit to those planning care for children who cannot have the advantage of care by their own parent, for whatever reason.

The findings of this study will be significant to those parties involved in the planning and implementation of programs intended to increase the involvement of parents in the care of their hospitalized children regardless of the expected advantage. This includes: provincial governments, who control hospital funding; hospital board members, who make policy regarding operation of the hospital; hospital administrators, who carry out the directives of the board and who want to keep their employees and consumers (children and their parents) happy; doctors, who use the physical and technical services of the hospital to treat children; nurses, who care for the children and their families; other hospital staff, who have an interest in the care of the child; and last but not least parents, who want the best possible care for their children.

Changes to current practice and the design and implementation of new programs must be based upon the reality of the parents' experience, what it actually is and how it occurs. The parents, children, hospital, government and in the entire scheme of things, society, will benefit from programming evolving from a real data base.

The results will also be of interest to other professional groups concerned with increasing or improving the involvement of parents in the activities which they sponsor for children, regardless of the health status of the child. As well, lay and professional members of other "helping professions" may find the relationship of the "third party" care-giver (as the parent is in the hospital setting) with the health care team relevant for them. regardless of the age, or familial connections of the care givers and care receivers.

The findings will contribute to the nursing literature on parent involvement and participation, introducing an element, that of the process of parenting a hospitalized child, which is currently absent. Theory development on parenting in the hospital is at a beginning stage.

The Research Question

The question answered by this research is: what is the parents' experience when their children are hospitalized in traditional ward settings?

Organization of the Research

This research report has been organized into six chapters. Chapter one introduced the reader to the research question and its significance. Chapter Two provides an overview of the literature on the history of parental involvement in hospitalization while their children were admitted, the advantages of parental involvement with their children when hospitalized, and the existing research on parental involvement. This allows the reader to know where the researcher was in their understanding of the concept at the beginning of the data collection stage.

Chapter Three describes the philosophical framework of the study design. The design is presented, along with ethical considerations and information about the subjects.

The findings are presented as a composite story, or theoretical perspective in Chapter Four.

Chapter Five is a discussion of the theory which emerged from the data in relation to the literature review presented in Chapter Two and in relation to a secondary literature review, based upon the concepts developed during the research process.

The final chapter, Chapter Six, is a presentation of concluding statements, validation, and implications relating to the theory.

CHAPTER 2

LITERATURE REVIEW

The literature review for this study begins with an historical review of visitation by parents in children's wards from the time when they first opened to the present. The proposed advantages of increasing parental involvement in the care of their hospitalized children is next, preceding a report of research relating to the involvement of parents in the care of their hospitalized children. The research studies are presented under the subheadings of quality of care, type of participation desired by parents, economics, and parent satisfaction with increased involvement. The reasons why increased involvement by parents has not developed as a common practice in children's wards is presented next. Parental involvement in other arenas follows, finishing up with conclusions about the literature review.

Historic Review of Parental Involvement in Hospital

In the early years of hospitals, physicians were reluctant to admit children, especially babies, to these institutions because of the high rate of cross-infection between patients. Ill children were cared for at home by their mothers. This practice began to change when Charles West founded The Great Ormond Street Children's Hospital in London, England, in 1851. West's original motivation in establishing a children's hospital was to set up a research laboratory and classroom for his students (Spence, 1947). This hospital and other children's wards and hospitals that followed were modelled after adult wards, with many patients in the same room and with severely restricted visiting. As Sir James Spence(1947) stated, "They suffered from an overdose of Shaftsbury and Dickens" (p. 125). As a result, the areas designated paediatric wards were still high risk areas for children.

The Matron at the Great Ormond Street Children's Hospital started a hospital-based school for the training of children's nurses. Nurses became better qualified to care for children at the time, but the limited knowledge about asepsis continued to contribute to as many deaths as before.

In 1925, Sir James began admitting mothers with their children to The Babies Hospital in Newcastle upon Tyne, which he founded in an attempt to decrease mortality rates (Sainsbury, 1986). As he was later to state in his 1947 article, Spence felt that a major problem with hospitals was the change of caregiver at the change of shift, sometimes three in twenty-four hours, while at the same time, mothers were "suspended in anxiety." Spence felt that the admission of the mother to hospital and her total care of the child would have multiple benefits. Unfortunately, the existing hospitals continued to prevent mothers from looking after their ill children because of the physical structure of institutions.

From 1928 to 1942, Dr. and Mrs. Pickerill admitted mothers to care for their young patients, who were undergoing plastic surgery in Wellington, New Zealand. Their goal was to eliminate this transfer of infection from one child to another by the nurse. Dr. Pickerill found that he could complete delicate repairs (e.g., cleft lips) at a much younger age and with less scarring and other complications because with their mothers caring for them the children were more relaxed, cried less, slept more, ate better, and were less restless (Pickerill, 1954).

The pattern in North America was similar. A Department of Paediatrics was established at Harvard Medical School in 1888. Johns Hopkins established a chair in Paediatrics in 1913, and many other medical schools followed suit. Unfortunately, hospital construction was the same as in England, with large open wards and no accommodation for mothers. As well, concerns about infection, sanitation, and the abilities of the parents of the ill children (most of whom were poor) to care for their children under any circumstances were the rationale behind continued highly restricted or non-existent visiting policies, and most hospitals continued to have only total care by nurses.

In their review of paediatric hospital practices, MacCarthy, Lindsay, and Morris (1962) state,

> It seems that the example of these pioneers could not be followed until a change of understanding and attitude had come about. This took a long time, twenty-five or thirty years. Voicing the conscience of hospital paediatrics, Spence made us feel disturbed about the child in hospital, and psychiatrists gave us theoretical reasons for change. It had to be admitted that keeping parents away from fretting children was wrong, and a battle for daily visiting had to be fought. (p. 7230)

Studies on the the effects of separation from the parent on young children were reported in the 1940's by James Robertson and in the 1950's by John Bowlby (Robinson & Clarke, 1980). The importance of the parent-child bond was finally being recognized, and changes in visitation practices were made. Parents could visit more frequently and for longer periods of time.

In 1962, MacCarthy et al. stated that daily visiting was not completely accepted but that unrestricted visiting was occurring in some progressive institutions. They noted that these hospitals recognized the value of the mother's presence to the welfare of the child and the fact that she actually might help rather than hinder in the care, but they understood that her living in the hospital was not acceptable to most professionals (MacCarthy et al., 1962, p. 7230).

By that time, though, a few British paediatric institutions had established paediatric wards where mothers were encouraged to stay and look after their children. In 1953, units for mothers and babies were opened at the Royal Hospital for Sick Children in Aberdeen and the Huntington Medical Centre, New Jersey, and Amersham General Hospital, Buckinghamshire (MacCarthy et al., 1962).

This recognition of the importance of the parent-child bond, combined with a shortage of nursing personnel and budget cutbacks, encouraged hospital administrators to institute programs which required the parent to be responsible for their child's care in the hospital. These programs are called Care-by-Parent Units. For example, the Kentucky Medical Centre Care-by-Parent Unit opened in 1966 (James & Wheeler, 1968; Lerner et al., 1972), and the Riley Children's Hospital Centre in Indianapolis opened in 1971 (Green & Segar, 1961). Other American centres mentioned in the literature as having parents admitted to the institution to look after their children are The Child Health

Centre at the University of Texas (est. 1977) (Caldwell & Lockhart, 1981) and a unit at the North Carolina Memorial Hospital (Jackson et al., 1978). Canada's first unit was established in 1974, the year of publication of the Lalonde Report, at the Children's Hospital in Vancouver, and it is still the only one mentioned in the literature (Evans & Robinson, 1984). Units exist at the Isaak Walter Killam Hospital in Halifax and as smaller parts of paediatric wards in many other institutions. Nursing shortages have not been a problem in Canada as they have been in the United States and Great Britain, but increasing medical costs have. Budget cuts, at the hospital level have decreased the numbers of nurses being hired.

The Association for the Care of Children's Health (ACCH) recently published a document entitled Elements of Family Centred Care (Johnson, 1990). These elements include recognition of the family as the constant in the child's life, facilitating parent/professional collaboration, honouring diversity in families, respecting different methods of coping, sharing complete and unbiased information with parents, encouraging family-to-family support and networking, and designing health care systems which are flexible, culturally competent, and responsive to families' needs. These elements are difficult to incorporate into traditional settings and difficult to evaluate. When they use the title, family-centred, nurses on paediatric units believe that these elements are included in their settings.

Most paediatric staff provide what they call "family-centred care." Parents are allowed to visit whenever they wish and are encouraged to participate in the emotional care and support of their child. The philosophy of family-centred care can encompass the concepts of care-by-parent, but it can also mean little more than open visiting for parents.

Care-by-Parent Units

Care-by-Parent Units are seen as an "extreme example of parent participation...in which staff are only minimally involved and parents provide all physical and emotional care for the dying child, the non-acutely ill child or the child having minor surgery" (Knafl, Cavallari, & Dixon, 1988, p. 99). In studies involving participants on care-by-parent units, the actual units are described to some extent. As well, several descriptive articles have been published (Green & Segar, 1961: VassFore & Holmes, 1983; Vermilion et al. 1979). In all reported examples of Care-by-Parent Units, parents or their designate are required to be present with their child at all times. Nurses may or may not be on the ward, but a ward manager is present during the day. Teaching and supervision are provided by nurses on a negotiated basis, and arrangements are made for obtaining assistance during the night or on weekends should it be required. Families are admitted to Care-by-Parent Units on the basis of admission criteria and bed availability.

Advantages of Parental Invclvement in the Care of their Hospitalized Child

There are many advantages to involvement of parents in the care of their child presented in the literature. Basically, parental involvement benefits the child, the parent, and the institution. Many of these benefits are supported by the authors' experiences or studies.

Having a parent present to look after their hospitalized child is believed by many to free nurses to spend more time with children needing more complex care. The advantage was first postulated forty-four years ago (Spence, 1947). Parents who have had the experience of caring for their child in hospital are perceived to have an increased confidence level as a parent (Spence, 1947; Pickerill, 1954). Having a child cared for by his or her own parent instead of several nurses, who also are caring for other children simultaneously, decreases the incidence of cross infection between children (Pickerill, 1954). Having children cared for by their parent decreases the number of nurses necessary on a ward and therefore decreases hospital costs. Hospital costs will also be decreased because fewer tests are ordered for children cared for by their parent, and hospital stays are shorter (Evans & Robinson, 1983; Green & Segar, 1961; James & Wheeler, 1967; Lerner et al., 1972; Monahan & Schkade, 1985; Pickerill,1954;). The parent's presence while their child is hospitalized is thought to decrease emotional stresses on both the child and the family (James, 1972; James & Wheeler, 1967; McClure & Ryburn, 1969; Pickerill, 1954). Children cared for by a parent are happier, eat better and sleep better (Pickerill, 1954; Sainsbury, 1986).

Parents who are able to remain with their child in hospital are able to maintain and sometimes improve their parenting skills (Pickerill, 1954). Children, who have their parents present adjust better to the hospital setting (Brain & MacClay, 1968; MacCarthy, 1962). When children are cared for by their parents during hospitalization, they have fewer post-operative complications (Brain & MacClay, 1968; MacCarthy, 1962). The caring for the child by his or her parents during hospitalization allows an opportunity for hospital personnel to observe parent-child interaction (Wheeler, 1967).

Wheeler (1967) also postulates opportunities for clinical research and opportunities for medical students and staff to improve their skill in handling parents and children as advantages of having parents care for their hospitalized children. The opportunity for personnel to provide better health education to parents when they are present and caring for their child was stated by James and Wheeler (1967) and James (1972). Brain and MacClay's controlled study, reported in 1968, provides evidence that the participation by parents in the care of their hospitalized child also decreased emotional disturbance following discharge.

As well, some researchers speculate several advantages of parental involvement without providing any evidence. They include the following: the advantage to both the parent and the staff of having the parent role clarified by the rules of care-by-parent and the idea that parental involvement actually speeds up the healing process (Sainsbury, 1986); the idea that communication between parents and staff would be increased because of the parent's involvement in their child's care, which presumably is good (Vander Schyff, 1979); and the idea that parental involvement provides for the maintenance of the child's home routines and continues the contact with home, this being seen as advantageous (Hardgrove & Routledge, 1975).

Although many of these advantages are not supported by research findings, this is a factor of the small amount of nursing research in the area, not that they might not indeed be true. Advantages are cited repeatedly in articles about care-by-parent units. There do not appear to be any disadvantages to the practice, if it occurs. There are some inconveniences to nurses and parents which might be associated with care-by-parent implementation but they are not disadvantages stemming from parental involvement.

Existing Research on Parent Involvement

Quality of Care

Two studies are reports of attempts to measure care outcomes using parent involvement as the independent variable. Of a British study Brain & MacClay (1968) report differences in outcome of paediatric patients, the parents, and the staff through an experimental design, with manipulation of the amount of involvement by the parents in the care of their hospitalized child in the control and study groups. Twenty percent of 1000 mothers bringing their children into hospital for tonsillectomy or adenoidectomy consented to come into the hospital with the child. This twenty percent was randomly divided into two groups, one with regular visiting privileges and the other with constant parent presence. The finding was that "there was significant reduction in the incidence of emotional and infective complications when the child was accompanied by its mother" (Brain & MacClay, 1968, p. 279).

In a study reported in 1985, Monahan and Schkade compare care-by-parent with traditional hospital care. The parents of children having recently undergone leg muscle release surgery were randomly assigned to a control and sample group. In measures of weight loss, skin condition, and parental anxiety, there were no significant differences for the two groups. Nurses did collect slightly fewer contaminated urine samples than parents, although the number of samples was small. The researchers conclude that care-by-parent "does not lower the quality of care and has numerous advantages to parents and children" (Monahan & Schade, 1985, p. 468).

These studies indicate that quality of care, when provided by parents is at least as good as in traditional nurse care models. Given the psychological advantages, and potential cost savings, there is no reason not to encourage the practice.

Type of Participation Desired by Parents

Other studies examine the parents' desire to be involved in the care of their hospitalized child. In 1973, Beck surveyed 96 parents of children hospitalized for heart disorders and found them to be agreeable to providing emotional support but uncertain about their abilities to undertake specific duties such as taking pulses, measuring urine, changing dressings, and so forth. Algren's (1985) questionnaire survey of 20 parents who were staying with their children on a medical/surgical paediatric ward in the United States found that 80% of parents surveyed wanted to participate in their child's care, but each of them had different desires in relation to that participation.

Jackson, Bradham, and Burwell (1978) surveyed 31 parents about their desired level of participation using an eleven category questionnaire. The parents responded that they wanted to participate in all nurturing activities, all medically related activities (with assistance), and some housekeeping activities, depending upon time required for other care activities.

In a similar study, with lists of activities in which parents could indicate their preference for participation, Hill (1978) determined that 78% of the 18 mothers surveyed wanted to participate in activities of daily living, and 61% wanted to participate in the listed therapeutic measures, without assistance.

Webb (1986) reports on a questionnaire completed by parents and paediatric staff. Eighty parents responded to inquiries about a list of nursing procedures. The parents were asked if they had ever performed them or is they believed that they could do so. The same list of procedures was given to all paediatric staff and senior house officers (54 of 67 replied). They were asked it they thought that the "average" parent could perform them. The conclusion states that: "In most instances the paediatric staff thought that the parents could do more than they did, but parents thought that they could do even more than the staff thought" (p. 177).

Finally, Stull and Deatrick (1986) surveyed 24 American parents and determined the activities in which they, the parents, felt that they would like to be involved while their child was hospitalized. They identified four areas of care not previously mentioned in the literature: participation in play, assistance with the child's school work, relating to other patients and parents, and having conferences with the staff.

These studies indicate that those parents who were on the wards at the time of the data collection for these studies and who consented to participate in the studies, wanted to participate more than they currently did. The parents indicate some anxiety about their abilities in unknown procedures. Parents who were not present, for whatever reason, would not have been in the studies, so it is difficult to know how widespread this desire to participate is.

Economics

The economic questions were addressed by Evans and Robinson in 1984. Their Canadian figures argue that care-by-parent units, in which parents stay on the ward, can reduce costs by 13.5% to 33% depending upon the child's diagnosis. Average cost of an episode of care was calculated using five different categories to "yield representative service profiles by setting of care and diagnosis" (p. 772) The cost for children in the care-by-parent unit was compared with the cost for children in other in-patient wards in the same institution. Cost savings were achieved because: the children admitted to the care-by-parent unit were in the hospital for a shorter period of time; the overhead cost of the care-by-parent unit was lower because of decreased nursing salaries, even though the cost of feeding and housing the parents was included; and the children in the care-by-parent unit had fewer diagnostic tests.

Care-by-parent practice became standard practice on a unit at the Welsh hospital reported in a study by Sainsbury (1986) but it is not being fully utilized because "by the time busy nursing staff have spoken to the parents specifically about care-by-parents, then it is time for the child to be discharged" (p. 615). Sainsbury says that parents are not told about care-by-parent at the time of admission "because of all the demands on the nurses" (p. 615). One might question Sainsbury's claim of no additional cost being required as obviously more nurses are needed on this ward. Regardless of the difficulties of implementation, Sainsbury stresses the advantages to the child of this mode of care delivery.

Evans' and Robinson's (1984) study, and reports by Caldwell and Lockhart (1981) demonstrate a reduced cost on specific care-by-parent units. Sainsbury (1986) reports that attempts to implement care-by-parent practices on a traditional ward were hampered by the fact that the nurses were too busy to tell the parents about it. Increased cost might be incurred by partial implementation, if nurses are still doing most of the care and trying to include parents more, at the same time.

Parent Satisfaction

Parent satisfaction has been sought specifically as a comparison between traditional and care-by-parent experiences in two cases and in a third study as satisfaction with communication between parents and physicians on a care-by-parent unit.

Three reports have come from one study in Kentucky. The first is a description of the care-by-parent unit there and the proposal of study questions (James, 1969). In 1972, James published a report of the study based upon the earlier questions. The questions were:" 1) To what extent and in what ways do the families feel that their lives have been disrupted by such a hospital experience?; 2) How effective is parent-physician communication?; and 3) How do students feel retrospectively about their experience on such a unit?" Parents, physicians and medical students were interviewed.

In relation to question one, James concludes that the parents presence on such a unit caused minimal strain on the family. He did note at that point that "these results were found with families who were screened, and/or self selected partly on the basis of their ability to cope with the parent's absence and partly on the basis that one of the parents *could* stay with the child" (p. 73).

In relation to parent-physician communication James (1972) states that parents felt that communication had been satisfactory" and that they had a high degree of trust and confidence in their physicians" (p. 73). The doctors replied that communication had been "at least average" (p. 73). James continues by commenting on "important discrepancies in communication" without giving any further detail or saying if these discrepancies might have any effect on the results.

The last question led to medical student responses, indicating that they liked the care-by-parent unit because they had a greater variety of patients' conditions, greater responsibility, more involvement in decision-making and they became more involved with the patients and parents. James gives no reasons for this. It may be that because this particular unit's nursing staff consisted of one consultant nurse "on-call" in a clinic in another location, that medical students were doing some of the traditional nursing duties.

Lerner et al. (1972) report on the same study as James, although neither mention each other. This second report includes much more detail on study design and sample. The sample consisted of the parents and physicians of 54 patients and 60 medical students. The communication discrepancies commented on by James are explained. Apparently parents lacked understanding about their child's diagnosis. As well, they state that: "most surprising was the finding that even after receiving the extensive attention and training on this unit, a majority of parents had less that complete understanding about whether special procedures were required after hospitalization" (p. 54). No attempt is made to identify the source of the communication breakdown or to explain the satisfaction in communication cited by the parents who apparently also disclosed a low level of understanding of the communication being offered them. The other findings are stated in a similar fashion to James' report. The conclusion section of the Lerner et al. (1972) publication is devoted to the issue of credibility of interview data.

Another care-by-parent unit, this time in Texas, is the site of a study by Caldwell and Lockhart (1981). The numbers presented in this study are incomplete, but the result appears to be that of 155 questionnaire respondents, 60% had had a previous hospital experience. Of this 60%, 82 parents preferred the care-by-parent unit to the traditional ward. Twelve preferred the traditional ward and five had no preference. Caldwell and Lockhart comment on the fact that some members of the care-by-parent unit committee felt that a halo effect was in operation during the collection of this data and then conclude that "the high level of patient and parent satisfaction, the acceptance by the medical staff, and the lower cost of operating the unit when compared with a regular unit all lead to the conclusion that a care-by-parent unit is desirable, effective and efficient" (p. 7). Cost reduction is presented in the article, as is the information that patient complaints had decreased, indicating increased satisfaction of patients. Medical staff satisfaction was not addressed.

Sainsbury et al. (1986) report on a study of 32 families of children admitted to a general paediatric ward in Wales. The families, who indicated a desire to be "resident", were provided with a bed and locker, and access to communal living area, bathroom and kitchen. A nurse decided if the family could be in the study group basing the decision on the child's condition and a judgement about the parents' capability to provide care for the child. The parents in the study group received literature, general information about the hospital, an explanation of what they could do if they wanted and what help they could receive. The parents also received instruction relating to their child's care and "support by a specially designated nurse" (p. 612). "Parents were encouraged to undertake all nursing procedures, but they were only allowed to proceed by themselves if their nurse considered them to be competent". (p. 612)

Information about the child's condition, the medical management and the family structure were compared with questionnaire responses from both the parents and the nurses. The parents were asked what they had done, difficulties they had encountered and how they felt . Nurses were asked about the parents' abilities, difficulties encountered and how they felt about their role. Presumably the care received by the children was at least adequate. The results reported are that the parents approved of the system of care and nurses felt that their relationships with the parents were better than in the traditional method and that it was not difficult teaching the parents the required skills. From this Sainsbury concludes that he has shown "for the first time" that care-by-parent can be possible on a traditional paediatric unit with no additional cost and no change to facilities. As mentioned in the section on economics, the Welsh hospital hoped to implement care-by-parent concepts on the traditional ward as a consequence of the pilot study but found that it was not happening because the nurses were too busy.

It can be concluded here that parents, who have experienced both traditional care and care-by-parent prefer care-by-parent.

The Implementation of Parental Involvement in Hospital

If, as the studies indicate more involvement by parents in the care of their hospitalized child is advantageous to the child, to the parent, and to the hospital and it is desired by parents and is cheaper, why has it not flourished?

Fagin and Nusbaum (1978) found that 95% of the head nurses and supervisors in their study favoured parents having a caring role for their hospitalized children, and Jackson's (1978) study supports this finding. Other authors however, discuss the general lack of support by nurses for this concept.

In their 1968 study, Brain and MacClay comment that even with the demonstration of positive outcomes of parent care for both parent and child the nurses preferred having the child admitted to the ward alone. Ayer (1978) identifies four areas that nurses perceive as problematic in relation to parents caring for their children: geographic considerations (living facilities for parents are not present), therapeutic considerations (parents might make mistakes in care-giving), staffing considerations (nursing positions might be eliminated), and personal considerations (less personal contact with the child, more contact with the mother).

The first published report of nurses satisfaction with parent participation was Seidl's 1969 study. Seidl developed a Likert-like attitude scale called the Parent Participation Attitude Scale of PPAS which he tested on 231 nurses. The hypotheses supported by the data were that increased support for parent participation would be found amongst nurses with higher education, nurses with administrative positions and nurses who had children of their own. Seidl also concluded that if the charge nurse on a ward was accepting of parent participation then the nurses in her charge would have a higher than expected acceptance level. This study is important because this data collection tool has been used by others. In 1979 Dunn published similar results, indicating decreased support in nurses under 25 and over 38 years of age, nurses with less than a bachelors degree, nurses spending less than 25% and more that 75% of their time in direct patient care and nurses with no formal course in growth and development. Two studies using the same tool have been conducted by Gill (1987). She reports support for Seidl's findings. In her studies, nurses with masters degrees had the highest mean scores. It would be interesting to know what percentage of paediatric nurses possess the characteristics of the nurses with higher appreciation of parent involvement.

Goodell (1979) did not feel that Seidl's scale met her needs in comparing the perception toward parent participation of nurses on an oncology care-by-parent unit with the perceptions of nurses on other types of oncology units. She developed her own Likert-like scale and added 5 open ended questions at the end. Validity of the scale is not addressed in her publication. From a 71% return Goodell concludes that "nurses on the care-by-parent unit scored higher on both desirability and feasibility items, showing a stronger agreement with the concept of parent participation in care (p. 44).

According to Evans and Robinson (1984), the practice of parent care has not become popular because staff have not been given time to become aware of and consider the implications, because the hospital organizational structure resists the introduction of new measures, and because there are no financial incentives for the individual to induce change.

It appears that increased parent involvement in the care of their children has not flourished because staff, particularly nurses do not support the concept. Nurses demonstrate increased appreciation of the advantages of parental participation under certain circumstances, one being after achieving more education and another being the demonstration that their immediate superiors support the idea.

Some factors which might encourage or hinder the increased participation by parents are not as yet addressed. Are parents demanding increased participation? Are parents aware of the advantages to their children and themselves ? What are the characteristics of those parents who do participate in the care of their hospitalized child? Are some parents really more able to participate than others because of education, age etc. as speculated in reports that subjective judgements are made to decide who can participate in care-by-parent? There was nothing found in the literature on these topics. James (1972) and Lerner et al.(1972) did question the disruption of families if one parent was absent to look after the hospitalized child, but with their select sample found it not to be a problem. There is an indication that any hospitalization of a child disrupts family life (Knafl, Cavallari & Dixon, 1988; Knafl, Deatrick & Kodadek, 1982) but nothing to indicate that increasing parental involvement in the child's care changes this disruption in any way.

Parental Involvement in Other Arenas

The interest in parental involvement in hospital might be similar to the interest in parental involvement in schools and other institutions that provide services to children. The care of the hospitalized child by the parent might be equivalent to parent teaching in the classroom or parental assistance with homework or parental involvement in social services or church programs. The parent-child relationship is vitally important to administrators in these fields.

An example is parent involvement at a group level in the school system (PTA or Parent-Teacher Association). This type of group involvement is not usually seen in the hospital setting. Parent interest groups revolving around a specific cause are common in both areas (E.G., Parents for French Immersion or Parents of Cystic Fibrosis Children). There are national and international parent education groups concerned with the school system, and there is a parent section of the ACCH (Association for the Care of Children's Health), an international multi-disciplinary group concerned with the paediatric hospital system.

The literature of parental involvement in schools describes the same advantages to the child, the parent, and the school as parent involvement in the hospitals:

-increased parental satisfaction with schools
-solution to lack of professional help in schools
-transference of educational principles to the home
-decreased cost of education
-provision of insight into child behaviour
-more rewarding relationships between parents and teachers
-more rewarding relationships with children
-improved parent behaviour
-increased cognitive development of the child
-prevention of and compensation for problems in education
(Williams, 1985)

Williams (1985) says that "parental involvement in the volunteer, advocacy or policy-making process for children can help to create a society in which having children is valuable, honourable and enjoyable" (p. 103).

There are several important differences between these two populations. For one, parents are often alarmed when their child is hospitalized. For another, the experience of hospitalization is not desired, as education is, and it has many unpleasant connotations. Finally, hospital experiences are unplanned, episodic,and do not involve all of the childhood population.

Aside from the similarities and differences in hospital and school, interest in parental involvement and the corresponding interest by both groups in the findings of this study are the aspects of education and administration which are historically part of the hospital setting and the nurse's role. The nurse is seen to be an educator as well as a care-giver. The nurse has a major role to play in the education of both the child and the child's parents in relation to normal and specific health care. To ensure a successful outcome of nursing intervention within our institutions, hospital administrations have adopted philosophies similar to other bureaucratic and publicly funded institutions. The theories of educational administration apply as well. In the words of Guba and Lincoln (1981), "it is up to each audience to determine what if anything, the information means and to determine for itself the information's applicability" (p. 117). For this reason, it is important that the research report contain adequate descriptions of the circumstances under which it was conducted.

Summary

It is evident from this review that at the onset of the practice of admitting children to hospital for medical treatment parents were discouraged from visiting and, in some cases, denied visiting rights. Several physicians were aware of the fact that care of the child by the mother decreased cross infection and decreased mortality. If the physical structure of the institution allowed, these physicians admitted mothers with their children. Increased visitation occurred following the publications of Bowlby and Robertson in the 1940's and 1950's, indicating that separation from the parent was harmful to the child. Many institutions went to unrestricted visiting by parents. In most cases, though, the physical structure of the institution still interfered with continued contact between parent and child. This situation improved for a few children with the advent of care-by-parent units. In these settings, screened parents who met specific criteria assumed total responsibility for the care of their hospitalized child.

The following assumptions can be drawn from this literature review:

1. Increased involvement by parents in the care of their hospitalized child is believed to be advantageous to the child, the parent and the institution.
2. Quality of care received by the child does not suffer, and might indeed be improved, when provided by the parent.
3. Parents want to be more involved in the care of their hospitalized children but are unsure about their abilities.

4. Structured care-by-parent units are cheaper than traditional wards.
5. Parents who have experienced both traditional wards and wards incorporating care-by-parent concepts prefer the latter.
6. Care-by-parent concepts have apparently not been embraced by nurses.
7. Parents have more confidence in their own abilities to care for their hospitalized children than staff have.
8. Nurses with advanced education, supervisory positions, children of their own and/or experience on a care-by-parent unit are most favourably disposed to the concepts of increased parent involvement.
9. There is no indication that parents are aware of the advantages to their children and to themselves, of increased participation by them, in their childrens' care.
10. There is no information about parents who want and do not want more involvement.
11. There are no studies comparing disruption to family life of families with children hospitalized on traditional wards and those admitted to care-by-parent wards.
12. There is no information about the parents' experience when their children are hospitalized.

CHAPTER 3

RESEARCH METHODS

A parent's experience when his or her child is hospitalized is a social phenomenon influenced by the interactions which occur between the parent and others within and relating to the hospitalization. Such interactions can be analyzed using symbolic inteaction theory. Parents of hospitalized children were interviewed, using an unstructured interview format, to obtain their stories about the hospitalization experience. These stories became the data for analysis in this study. The methodology used for interpretation of the data was grounded theory.

Symbolic Interaction

Symbolic interaction theory is a view of the social world as an experience that is dependent upon the interactions that occur between an individual and the environment and the individual's interpretation of the meaning of the interactions. It is a theory about human action. Rock (1982) defines the view as a model of man that describes the organized workings of people's symbolic capacity, and that produces some reconstruction of the sense people make of the world. This view "challenge[s] the possibility of furnishing a rationally organized, competent, and definable account of human activity" (Rock, 1982, p. 33). Instead, common sense, conscious behaviour, and self-reflection are emphasized, stressing the notion that people do not merely respond to stimuli but actually create their actions through continuous interpretation of the situation.

Blumer (1972), one of the early proponents of interactionism, believes that "human beings interpret or 'define' each others actions instead of merely reacting to each other's actions. . . . Thus, human interaction is mediated by the use of symbols, by interpretation, or by ascertaining the meaning of one another's actions" (p. 145).

There are several assumptions inherent in this view. The most basic is that people express themselves through the use of symbols and interactions. As well, it is assumed that society consists of "multiple symbolic universes." People are rarely members of only one universe. They move back and forth from one to another. Rock (1982) identified three features of collective life, which are also assumptions: (a) people can make reflexive use of the symbols they employ, (b) people are symbolic objects to themselves, and (c) perspectives and plans emerge out of the interplay between a socially constituted self and a socially constituted environment.

The concept of "self" is also central to symbolic interaction theory. This symbolic behaviour is self-directed, a concept that Blumer believes is unique to humans. Behaviour is viewed as the result of a process, which is directed by the individual.

A situation such as experiencing the hospitalization of one's child is changed by the parent's interpretation of the events which are ocurring and therefore, it can never be exactly the same thing more than once. The other roles or universes in which the parents live affect the dynamics of the interpretation which they make. A nurse/parent would interpret the situation differently than an accountant/parent. The situation is not only an interface between the parent's individual universes and the hospital, but also between the hospital and the society. Both of these interfaces change and affect each other.

With such a fluid view of the social world, it would be impossible to have a static and precise definition of any social phenomenon. Interactionists focus on activity and process, creating descriptions of the understandable evolution of small parts of the social world.

"The symbolic interactionist studies behaviour at two levels: the behaviour or the interactional level and the symbolic level" (Chenitz & Swanson, 1986, p. 6). Intellectual devices used include "the sensitizing concept, the rejection of grand theory, an emphasis on restrained induction and the use of logic that is particularly suited to symbolic transactions" (Rock, 1982, p. 42). Emphasis is placed on the emergent and the unique. A conception of society is built upon "modest analysis of a host of minor occurrences" (Rock, 1982, p. 41). This emphasis is possible because formal similarity can be found in seemingly distinct occurrences. These forms provide a set of categories to be deciphered by the interactionist.

Symbolic interaction theory is a type of sociology. It is used frequently in fields of study where researchers are interested in human behaviour. Categories of behaviour or situations or phenomena can be viewed from the perspective of the participants, without the restriction of preconceived assumptions. The researcher wants to know what the participant is experiencing, what the participant decides is significant to note, how the participant interprets the situation, and what the participant decides to do.

The process of parenting the hospitalized child is a small portion of the social world. This identification required an interpretation of the symbols used in interaction in the hospital setting, the reflexive use parents make of these symbols, and an interpretation of how they structure the environment in relation to their interpretation of the meaning.

How do parents interpret the hospital setting? What does it mean to them? What interactions do they have in the setting? How do their interpretations and their interactions change as the experience continues?

Grounded Theory

Symbolic interaction study "requires the student to catch the process of interpretation through which they [the subjects being studied] construct their actions" (Blumer, 1972, p. 145). Grounded theory is a method for doing this: "Grounded theory is based on the systematic generating of theory from data, that itself, is systematically obtained from social research" (Glaser, 1979, p. 2). Researchers develop their own theories by applying their creative intelligence to the data. Grounded theory requires the researcher to think and discover.

Grounded theory is undertaken to discover abstract concepts within individual experience, to categorize these concepts and to propose relationships amongst the categories. To do this concepts must be carefully defined and validated. The method of analysis is constant comparison.

Situations are observed by the researcher, and theoretical accounts and explanations are postulated as concepts and categories in an attempt to explain the situation under study in a way that is easily understood and makes sense, even to the participants in the situation. The explanations must be defensible, with examples from the observations of the situation, the data. The most useful data are the "qualitative data generated from participant observation, from the observation of face-to-face interaction, from semi-structured or unstructured interviews, from case study material and from certain kinds of documentary sources" (Turner, 1981, p. 227). Quality work develops through an understanding of the data by the researcher, who learns to recognize the properties of the situation under study. The researcher must identify the properties which relate to the research question under study and must learn enough about the properties to hypothesize their relationships to each other. The process of symbolic interaction occurs not only between participants and setting, but is also simultaneously occurring between the researcher and the data: "The understanding which emerges from such research must thus be considered the product of an interaction between the researcher and the phenomenon under study" (Turner, 1981, p. 228).

Researchers using grounded theory to study symbolic interaction have a great deal of knowledge about existing theory, cognitive processes, and substantive detail relevant to the situation being studied. The ability to analyze qualitative data requires skill in identifying the properties of the situation and in continual movement from datum to datum. Conceptual ideas generated by the data lead back to other data. This must be done without imposing one's own hypotheses upon the data. The process is systematic and inductive and begins with constant comparisons within the data itself.

At the outset researchers are encouraged to attempt to identify and record their preconceived assumptions about the situation under study and to continue to do this through the development of the theory in an attempt to reduce their influence on the developing theory. Once the researcher has created a theory, existing theories are evaluated and those that "fit" are integrated with it (Rennie, Phillips & Quartaro, 1988).

In grounded theory, it is not assumed that any two researchers would develop the same theory independently from the same data. Each would develop his or her own view which might emphasize different aspects of the situation, both credible but different in scope. Theories generated in this manner must not be overlooked because the theories are found to be interesting by those who read them, are remembered by those with an interest in the situation, and are used in the field by those aware of them. Complex interactional phenomena are not subject to strict quantitative measures and are, therefore, left unexamined without qualitative measures.

The end results of a grounded theory might be the description of a category, a process or multiple processes (Chenitz & Swanson, 1986). The process outlined above will generate substantive theory, "theory developed for a substantive or empirical area of sociological inquiry -- such as patient care, race relations, professional education" (Glaser, 1979, p. 144). This must be differentiated from formal theory, "theory developed for a formal or conceptual area of sociological inquiry - such as status passage, stigma, deviant behaviour" (Glaser, 1979, p. 144). Formal theory requires analysis amongs different kinds of substantive cases or theories. In this case, studying parents experience when a child is hospitalized, might become part of a formal theory of parents experience whenever aspects of parenting are delegated, be that educational, religious instruction, jail, summer camp and so forth.

Glaser (1979) identifies the steps of grounded theorizing as entering the field, collecting the data, coding the data, integrating the categories, generating memos, and constructing theory, all of which are influenced by the emerging theory.

Research Design

The process of parenting one's hospitalized child is a social phenomenon which develops through symbolic interaction between parents and others in their social world. It is appropriate to study the process using the grounded theory method because grounded theory is a method of interpreting symbolic interaction.

The research design is presented here using the topic headings of researcher sensitivity, entering the field, collecting the data and transcribing it, coding and developing categories, memoing, theoretical sampling, identifying the core category, creating connections and conditions, validating, searching for negative cases, and making connections to existing theory.

Researcher Sensitivity

Glaser (1979) speaks of "this sensitizing concept" and its importance at the beginning of the research to "uncover data that otherwise might be overlooked" (p. 39). This sensitizing concept also provides the researcher with "the tools within himself to consciously conceptualize and formulate a theory as it emerges from the data" (p. 44). "Values cannot be kept out of inquiry simply by making most of the procedural decisions before rather than during the inquiry" (Guba & Lincoln, 1981, p. 27).

This researcher is sensitized to the paediatric ward, through interaction as a paediatric nurse for six years and the instructor of nursing students in paediatric settings for fifteen years. As well, the researcher is a parent who experienced a brief hospitalization of one of her own children. This is viewed as a positive feature to the research as the researcher was able to focus on the experience of the parents in this study, without the distraction of an attempting to interpret and unknown field. The researcher's past experiences can be viewed as the repeated and continuous observation referred to by Guba and Lincoln (1981, p. 109) that is necessary for researcher credibility.

Past experience has also been recognised as a potential for researcher bias. Personal experiences of the researcher as a hospitalized child herself and as a mother of a hospitalized child were recorded, in a log, to increase researcher sensitivity and decrease bias. As well, the researcher documented her assumptions about parental involvement in their child's care during hospitalization. These initial assumptions and the memoing of their changes during this research program become an interesting part of the research process.

When referring to the researcher as instrument, Guba and Lincoln (1981) write that: "the best cure for biases is to try to become increasingly aware of our own biases and how they slant and shape what we hear, how they interfere with our reproduction of the speaker's reality and how they transfer truth into falsity" (p. 148). Guba and Lincoln (1981) also note that "what one individual experiences is not necessarily unreliable, biased or a matter of opinion, just as what a number of individuals experience is not necessarily reliable, factual and confirmable" (p. 127). The researcher, in this case is just another individual.

Denzin (1972) speaks of sensitizing a concept in his writings. He says that a concept under study is left "non-operationalized until I enter the field and learn the processes representing it and the specific meanings attached to it by the persons observed" (p. 86). The meaning is similar in that until he is sensitized to the field he does not attempt to define a concept. This researcher's sensitivity to the general field assists in sensitization to the concepts of the parents' experience which had not been operationalized.

Entering the Field

Once the proposal for this study had received ethical clearance from the department of Education Administration, it was submitted to approval processes at three local hospitals, all of which had paediatric wards. Two hospitals approved the proposal quickly, allowing the researcher access to parents of patients admitted to their paediatric wards. The proposal was stalled on the desk of the chief of paediatric medicine at the third institution. Following a verbal presentation of the proposal, the physician signed the necessary form and approved the forwarding of the proposal to the institution's research review committee. Unfortunately, that review committee met only once every three months. As data collection was under way at this point in time and as there appeared to be an abundance of potential subjects, the proposal was not resubmitted to the third institution.

The nurse managers on the two approved paediatric wards were very helpful in orienting the researcher to the environment and introducing her to the staff. Both nurse managers offered their own offices for interviewing purposes. This did not cause any problems as interviews were conducted in the evenings and on weekends when more parents were on the wards and when the nurse managers were off duty.

Initially, both institutions were visited in search of participants. Because one institution was closer to the researcher's residence, it was approached first, and it always provided a participant. The nurse manager at the second institution was kept informed of the progress of the research. On two occasions no parent was available for interviewing at the second institution. In the end, all participants, both primary and secondary informants, whose children were hospitalized at the time of the interview were obtained from the first institution.

The researcher's initial concern about difficultly in obtaining participants led to obtaining formal access to more institutions than was necessary. In fact, only four of the primary informants were obtained in this way. Once the study was begun and paediatric nurses and other nurse researchers became aware of the research question they supplied the names of potential participants whom they thought would be good informants. When informants were sought on a paediatric ward, the researcher always spoke with the nurse-in-charge to make certain that it was appropriate to approach a particular parent.

Collecting and Transcribing the Data

Parents visiting their hospitalized child were approached and briefly introduced to both the researcher and the nature of the research. If the parent expressed interest in being involved and was able to take their attention away from the child long enough to be interviewed, then a detailed explanation was provided. The formal consent form contains a description of the expected involvement of the informants as well. All informants were provided with a copy of the consent form to keep for future reference (Appendix 1, p. 159).

The interviews often took place at the time that the consent was obtained. Occasionally another time was arranged. All but one of the hospital interviews took place in the nurse manager's office. The nurses on duty at the time of the interview were informed of the researcher's presence and the location of the parent being interviewed. It was important that the nurses felt free to interrupt the interview at any time if the parent was needed by the child. No interview was interrupted.

One interview took place in the child's room. There were no other patients in the room. The door was closed and the recording was found to be audible. As a result, the parent was able to attend to the child during the interview.

The tape recorder was tested for audibility before the start of each interview. Parents were asked a few demographic details relating to age, education, marital status, previous experience with hospitalization of a child, their opinionabout their support system, and their involvement with community and school activities.

At the time that the research proposal was developed the researcher felt that both constraints upon the sample and demographic information would be necessary in some way to the development of the theory. In the long run, the demographic information was not used. No attempt was made to try and correlate any part of the developing theory to demographic variables as they did not emerge as categories from the data. The collection of these data was useful only as a warm-up exercise for both the parents and the researcher.

At the same time, participants were asked if they would like to receive a summary of the research findings once the study was completed. All of the participants expressed a desire for a summary. Small index cards were provided to the participants, on which they wrote their name and mailing address. These cards were kept with the consent forms, separate from data.

The interviews all progressed well. One mother who had informed me at the start that she did not have much to say talked for over an hour and then said, "I think that was therapeutic for me." The only uncomfortable moment during the interviews was when a parent realized that although she spoke of the child's tumour as benign she did not know how the doctor had arrived at that diagnosis. The parent became upset and said, "I should have asked more questions." The parent's discourse was not interrupted as she continued right on with the story. By the end of the interview the parent was relaxed and not upset about her child's condition. As a researcher, I felt badly because my research interview had caused the parent distress. After some soul searching, I accepted the fact that the parent might have made that realization at any time, and indeed, more questions might have been asked of the doctor. The parent was now free to ask more questions of the doctor, if she so wished.

One participant was obtained by written request. A mother was interviewed in the local newspaper following the death of her daughter. The child had experienced multiple surgeries and hospitalizations during her short life. The mother was obviously able to talk about her experiences. An address was included in the paper because the family had established a foundation in the child's name. The mother responded quickly and positively to the request for an interview. As a mother with a great deal of experience with hospitalization, she was an articulate, expressive, good informant.

Another researcher supplied the name of a family with whom she had contact. The researcher felt that the mother was a good informant but that she was having difficulty negotiating the system, even after many hospitalizations. I was keen to interview this mother because she did not seem to "fit" the emerging picture. Perhaps she was a negative case. I interviewed the mother in her home. The child was at home sleeping. The parents had been up most of the night with the child, who had a chronic illness. The interview went well. The mother spoke of her inability to give anything back to those who have helped her because her child was so ill that she required all of the mother's time. She was pleased to talk to me because it was a way to "give something back."

All of the tapes were transcribed by the researcher. The actual mundane task of typing was valuable analysis time. It was not necessary to check the typed interviews for transcriber accuracy. Some parts of the tapes were difficult to decipher, but having actually participated in the interview helped the researcher/transcriber figure out what had been said.

Four published accounts of parents' experiences while their children were hospitalized were considered primary data. These four parents had written their experiences as an article, to be read by health care providers. Two were in nursing journals and two were in Phenomenology and Pedagogy, a multidisciplinary source. Because these parents, had they been available for interview, would have been expressive informants for this study, their written experience was seen to be additional data.

Coding and Developing Categories

Glazer (1979) differentiates between substantive and theoretical coding. Within substantive coding, there is a further subdivision of open and selective coding. "Substantive codes conceptualize the empirical substance of the area of research. Theoretical codes conceptualize how the substantive codes may relate to each other as hypotheses to be integrated into the thoery." (p. 55) Substantive coding will be discussed here. Theoretical coding is discussed in the section on creating connections and conditions.

Initial data, from transcribed parent interviews, were subjected to open coding. The data were coded in every way that ther researcher could imagine, and sampling proceeded in all directions, based upon the initial codes generated. Coding and analysis were begun with the first data. Glaser (1979) provides six rules of open coding, which are summarized here: (a) Ask a set of questions of the data (i.e., What category does the incident indicate? What is actually happening in the data?); (b) Analyze the data line by line; (c) Analyst must do own coding; (d) Always interrupt coding to memo an idea; (e) Stay within the confines of the substantive area and the field of study; and (f) Do not assume analytical relevance of any face sheet variables (i.e., age, race, sex, and so forth) until it emerges as relevant.

The transcribed interviews were printed on approximately two-thirds of the width of the page so that codes could be written in the wide margin. Initially, the question was what is this comment? Comments or phrases were descriptions of what happened to the child or the parent, how the child reacted or how the parent reacted, and what the child or parent did. As well, accounts of medical and nursing actions, environmental stimuli, and family responses were given. The next question was what is actually happening in this case? For example, all descriptions of the parents perception of what happened when they first realized that something was wrong with their children were compared for variations. The categories of "getting information" and "being with" the child emerged first because hospitalization itself was being examined at this stage and not the preceding events. None of the demographic variables emerged as important. Every parent expressed anger at not being in control of some aspect of their child's care. The question became when did they lose control?

As the categories appeared, a file was prepared for them, and all parents' experiences relating to that category were filed together.

When an interview had been coded, theoretical notes were written about the meaning of the codes and categories in this particular situation. As the data collection progressed, selective coding was used with the interviews coded by existing categories; anything different started a new file. As notes and memos on the conceptual categories increased, theoretical notes on the individual interviews decreased.

Files containing examples of a category were studied as a whole. For example, in "getting information", the descriptions of all parents attempts to get information were compared. A large chart was constructed which listed all ways of getting information, from whom the information was received, how the parent felt when receiving the information, and so forth. This led to the definitions within the category and the conditions about getting information.

When data collection generated nothing new about a concept, the concept was considered saturated: "The researcher feels confident that he or she is fully aware of what is meant when any new phenomena encountered are classified into the categories in question" (Turner, 1982, p. 235).

Memoing

From the beginning of the proposal writing process, the researcher wrote memos about all the ideas that materialized. Any interesting new ideas from current literature searching were included. Memos lead to abstraction and ideation and become part of the data. The researcher developed a fund of ideas about categories emerging from the data. The memo ideas connected the data and the final analysis. These memos also recorded many of the decisions made by the researcher, providing audit documents (Guba [illegible] 1981). Memos were written on coloured paper and interspersed [illegible] data and theoretical notes.

Identifying the Core Category and Basic Social Psychological Process

At this stage of the research process, Glaser (1979) recommends limiting coding to only those categories (indicators) that relate to the core variable. Once all of the existing interviews had been coded, the search began for the core category.

Criteria for a core category are centrality to other categories, frequent reoccurrence, a long period of time needed for its saturation, easy connections to other categories, and clear and "grabbing" implications for formal theory (Glaser, 1979).

One category of experience mentioned by every parent was anger at the hospital staff for disregarding the parents' opinions or ignoring or even denigrating their concerns. What made them angry? It was more than disrespect; loss of control over their own child's welfare was the issue. In examining loss of control, it became apparent that parental involvement in the care of the child revolved around the relinquishment of control. It was a downhill slide until the parent recognized the cause of their anger, and then an uphill battle began to regain control.

Once this category, "relinquishment of control", was identified as the core category, it became more obvious, and connections could be made between it and the process developed by parents to resolve it.

If the core category is procedural, changes over time, or has stages, it is also a basic social process. Not all core categories are BSP, but this one is. The relinquishment of responsibility takes place over time in a series of stages, with critical junctures between them and therefore qualifies as a BSP.

Theoretical Sampling

Theoretical sampling means the selection of new data sources on the basis of the emerging theory, or what is called theory-based data collection.

Any category or concept identified in the ongoing data collection can be used as the important factor in selecting the next participant. In the proposal for this study, limitations of age of child and number of hospitalizations were imposed upon the sample. It was found that these inclusion criteria excluded good informants from the sample. Good informants are informants who have gone through the entire experience under study and are able to look back and reflect on the situation. They are also willing to share their experience with much detail.

Parents of children with repeated hospitalizations were available as subjects. They knew more about the situation of being a parent in the hospital setting and wanted to talk about their hospitalization experiences.

An additional example of theoretical sampling was finding parents who were not involved with their children's care or who visited infrequently as this appeared to be an important category in the theory, but it was one more difficult to saturate because these parents were at the hospital less.

Definitions of the categories were used to stimulate theoretical reflection. Relationships and hypotheses were postulated about the links between the categories as well as the conditions under which the links hold (Turner, 1980).

Creating Connections and Conditions

"Theoretical codes conceptualize how the substantive codes may relate to each other as hypotheses to be integrated into a theory" (Glaser, 1979, p. 72). Theoretical codes also emerge from the data, but it is necessary for the researcher to know many theoretical codes from a variety of disciplines in order to be sensitive to the possibilities.

Theoretical codes were created to connect the categories in relation to relinquishment and regaining of control, the core category. Different theoretical samples, provided by Glaser (1979), were considered. As a process involving change in the parents' perceptions and actions was anticipated, a longitudinal theory looked like the best "fit." The common experiences, diagnosis, hospitalization, uncertainty, treatments, and discharge, were chronologically experienced. Using a linear model, it was possible to link all of the categories which related to the core category. Although, it is not suggested here that all possible combinations have been exhausted, this is one combination which makes sense.

Validating, Saturating, and Searching for the Negative Case

Secondary data is the term used for data collected after theoretical coding has been established. In this case, three key primary informants were re-interviewed, two of them twice, to encourage verbalization of their perspective on the emerging theory. In discussing the theory, they introduced additional examples from their experience as a parent of a hospitalized child which reinforced the theory and more fully saturated the categories.

Additional parents, those who had not been primary informants, were interviewed about particular aspects of the theory. Specific questions were asked of them in order to assist in explaining connections and conditions. Some of the additional parents were obtained on the hospital ward, and some became known to the researcher in other ways. Every time the researcher spoke of the emerging theory to a group of individuals, parents within the group would present their experiences as well.

During all of the data collection, coding, and theorizing, the researcher was watching for a negative case. Some situations, viewed initially as negative cases, became variations within categories. There was an instance of behaviour which is not explained by the theory, in a published account by a parent.

Making Connections to Existing Theory

At this point, the researcher also made comparisons between the newly developed categories and the literature. These comparisons built bridges to existing work. A secondary literature review was ongoing as categories emerged and led the researcher to new areas. Sampling outside of the substantive area was not undertaken as Glaser (1979) says that it is permissable only after a "focus on a Basic Social Psychological Problem and the process by which it is resolved BOTH have been discovered and stabilized in an emerging theoretical framework" (Glaser, 1979, p. 50). Sampling outside of the substantive area leads to formal theory.

The Participants

Parents are not a sociologically homogenous group. Those who experience the hospitalization of a child are drawn unwillingly by fate from a broad and varied population. They do not self-select to become the parent of a hospitalized child, and they are not chosen from a pool of applicants. Indeed, they would rather not be in the situation at all.

There are, therefore, no common demographic characteristics that one would use to describe the sample of this study other than that each parent has a child who required hospitalization, that all spoke English, and that all lived in Western Canada.

Twelve parents, ten mothers and two fathers, of hospitalized children were interviewed as the primary informants. The marital status, hospital experience, educational level, age, sex, and employment particulars were obtained from the participants. Parents were asked if they had personal support during the hospitalization and if they were involved in the school or community were requested (Table 1, Appendix 2, p. 160). Four of the parents were interviewed during the first hospitalization of their child. Four of the children had one time, short-term conditions (two burns, abdominal surgery, foot surgery). Two of them had long-term correctable conditions (repeatedly blocked tear ducts, spondilythiasis). Five of the children had chronic, potentially fatal conditions (asthma, cystic fibrosis, lupus [an autoimmune disorder], congenital bowel disorder, esophageal atresia [the baby's throat is not connected to the stomach at birth]). One child had died eight months prior to the interview, and one child died shortly after the interview. A predominance of parents had experienced more than one hospitalization, making them good informants. They have been through the experience and were thus "experts" able to reflect on this experience and talk about it. They differed in many respects but all shared a common circumstance and a specific problem.

Data were also collected from published accounts by parents of hospitalized children and by conversations with twenty additional parents about specific aspects of the emerging theory.

Reliability and Validity

The reliability and validity of research utilizing a qualitative methodology such as grounded theory is usually inherent in both the data and the methodology. Morse (1986) suggests that the test should be both adequacy and appropriateness of the sample and the developed theory. Theoretical sampling and saturation of the categories are strategies which are used to meet this test. In discussing qualitative research Brink (1989) states that "validity and reliability are provided for by the use of the constant comparative method and the search for alternative hypotheses or negative cases" (p. 151). These strategies are inherent in the process of carrying out grounded theory.

In addition to the strategies mentioned as part of the process, insecurity of a beginning researcher led to additional checks. The first interviews were read and assessed for interviewer style by a faculty member who was not on the thesis committee and by three PhD candidates who composed a peer review group attended weekly by the researcher. Initial open coding was also discussed with these individuals. As well, the researcher presented data, categories, and theoretical connections at two research seminars led by a member of the thesis committee. Feedback from these presentations and two additional presentations of the findings, one a research conference and one a graduate level research methods class, resulted in a modifications to the emerging theory. In general, responses from both the informants and other audiences have been very supportive of the theory.

To be used, though, the theory must be useful. Glaser (1979) identifies four criteria, which if met, will lead to a useful theory:

1. IT MUST FIT. The categories generated by the researcher must fit the data and vica versa. This is relevant in relation to fitting the data to previously generated categories as well (i.e., those found in the literature).

2. IT MUST BE RELEVANT. Relevance is achieved by allowing core problems and processes to emerge.

3. IT MUST WORK. The theory will work if it explains what happened, predicts what will happen, and interprets what is happening in the area of interest.

4. IT MUST BE MODIFIABLE. Social processes are constantly changing in variety and relevance. The theory must be re-castable in the light of new data. These criteria will be discussed in relation to the theory after the theory itself has been presented. Introspection by the researcher was also used as a credibility check. An "audit trail" was kept through the memoing process.

Ethical Considerations

This research fell under the definition of human research. Interviews and observations were carried out with human participants for the purposes of contributing to knowledge. Although interviews for research purposes in medical settings often are seen to have therapeutic potential (Munhall, 1988), this is distinct from "therapeutic procedures whose purpose is solely to benefit the persons on whom they are performed" (Dept of Educational Administration Ethical Review Policy, Jan. 1988).

"Since interviewing is essentially a process of human interaction, all of the potential risks of interaction, such as embarrassment, anger, violation of privacy, misunderstandings and conflicts in opinions and values, are likely to arise as some point in a research project" (May, 1989, p. 165). May (1989) suggests ways to decrease potential trauma, i.e., debriefing sessions, provision of additional emotional support, and careful termination and closure. Previously researchers have been also advised to have referral agencies available for specific types of counselling should a participant in the study demonstrate the need for follow-up. Within this study, there were instances where informants said that describing their situation had been helpful to them. One participant used the term therapeutic, and another said that she felt this was her way to give back something to the health care system. No informant appeared to be distressed by the researcher's presence. In one case, a mother came to realize how little she knew about her child's diagnosis during the interview and said, "I should have asked more questions." The researcher's discomfort at that moment led to introspection about the right and need to know.

There is reason to believe that this research has generated knowledge about an important process, parenting the hospitalized child, and that this knowledge will be useful in planning to increase and support the level of involvement by parents in the care of their hospitalized children as this has been shown to be beneficial to the child, the parents, and the institution. The benefits of parental involvement are many.

Once in the field, participants were chosen by the researcher on the basis of probability that they would have information to share. Stress relating to the illness of the child was taken into consideration. The researcher did not approach parents who appeared to be in the midst of stressful situations. As well, the nurse in charge of the ward was approached before any parent was approached to ensure suitability of researcher contact. Participants were receptive to the research and the researcher (Morse, 1986).

Consent

Participants were fully informed about the research and consented voluntarily to participation. They were informed that they could refuse to answer any particular question or could withdraw completely at any time without penalty. The fact that there were no risks was also included. Anonymity and confidentiality were guaranteed in the informed consent. Participants were informed that although their names will not be used, direct quotation of parts of their interviews might appear in the printed/published report.

In case of complaints, concerns, or consequences, my advisor's name and phone number was available to the participants. Participants received a copy of the consent that they signed. Institutional consent was obtained before any interviewing occurred in an institutional setting.

Anonymity

Consent forms and coding criteria for identifying data are kept in a locked file. Participants were asked if they would like to receive a copy of a summary of the study. In requesting a summary, the participant provides their name and address to the researcher. This information was recorded on an index card and kept separate from any data.

The consent form asked the participants for permission to use their interview in future studies, provided appropriate ethical clearance was obtained for the future study.

Summary

The research methodology employed in this study was grounded theory, an inductive process of interpreting qualitative data in a symbolic interactionist perspective. The Glaser and Strauss (1967) interpretation of methods for grounded theory was followed closely. Twelve primary informants, four published reports by parents and twenty secondary informants provided data for this study. Data were analyzed in an ongoing process from the time of obtaining the first interview. Data were compared and contrasted within and between interviews and written reports. While analyzing, the researcher saught information about the emerging concepts and categories from the literature as well. Secondary informants were questioned about all or parts of the theory, after categories had emerged and connections had been made.

The researcher developed in an interactional way, as did the parents in their interactions in the hospital setting. Nothing in the literature prepared the researcher for the trial and error nature of this type of research. The expression of assumptions and personal experiences, prior to the study was undertaken because the experts in this methodology suggest such a practice. It was not until the very end of the process, when these documents were reviewed that the researcher truly realized their value. As well, many conceptual labels were used with the common descriptions in the data. Increasing depth of the data led to better descriptions of the concepts and the labels "fit" much better. The selection of theoretical codes is also a trail and error process, with the researcher always looking for the best explanation of the relationships between the categories.

CHAPTER FOUR

FINDINGS

In this chapter the researcher's interpretation of the data is presented. The purpose of the research was to explore and describe the experiences of parents, when their children were hospitalized and identify commonalities or patterns of behaviour within the experiences. The interviews with the parents provided descriptions of the parents behaviours, all interactions based upon their interpretation of the situation. The behaviours were analyzed and coded into categories of behaviour. The behaviour categories were analyzed and coded theoretically, to describe the relationships between the categories. The theory emerged. The experiences of twelve individual parents became a theory of behaviour which depicts the commonalities found in all of the experiences. The experience is theorized by this researcher to be a process of parenting, a stage theory. The stages and their relationships are depicted as a schematic diagram in Fig. 1 (p. 63). A brief overview of the theory is presented here followed by a detailed description of each stage, the phases within it and the relationships between the stages.

This process, parenting one's hospitalized child develops in a series of stages. The term parents, used in the description of these data, refers to the parents in this study. The common circumstance experienced by all of the parents in this study was the hospitalization of a child. The common problem was the feeling of frustration upon realizing that they had relinquished more responsibility for the care of

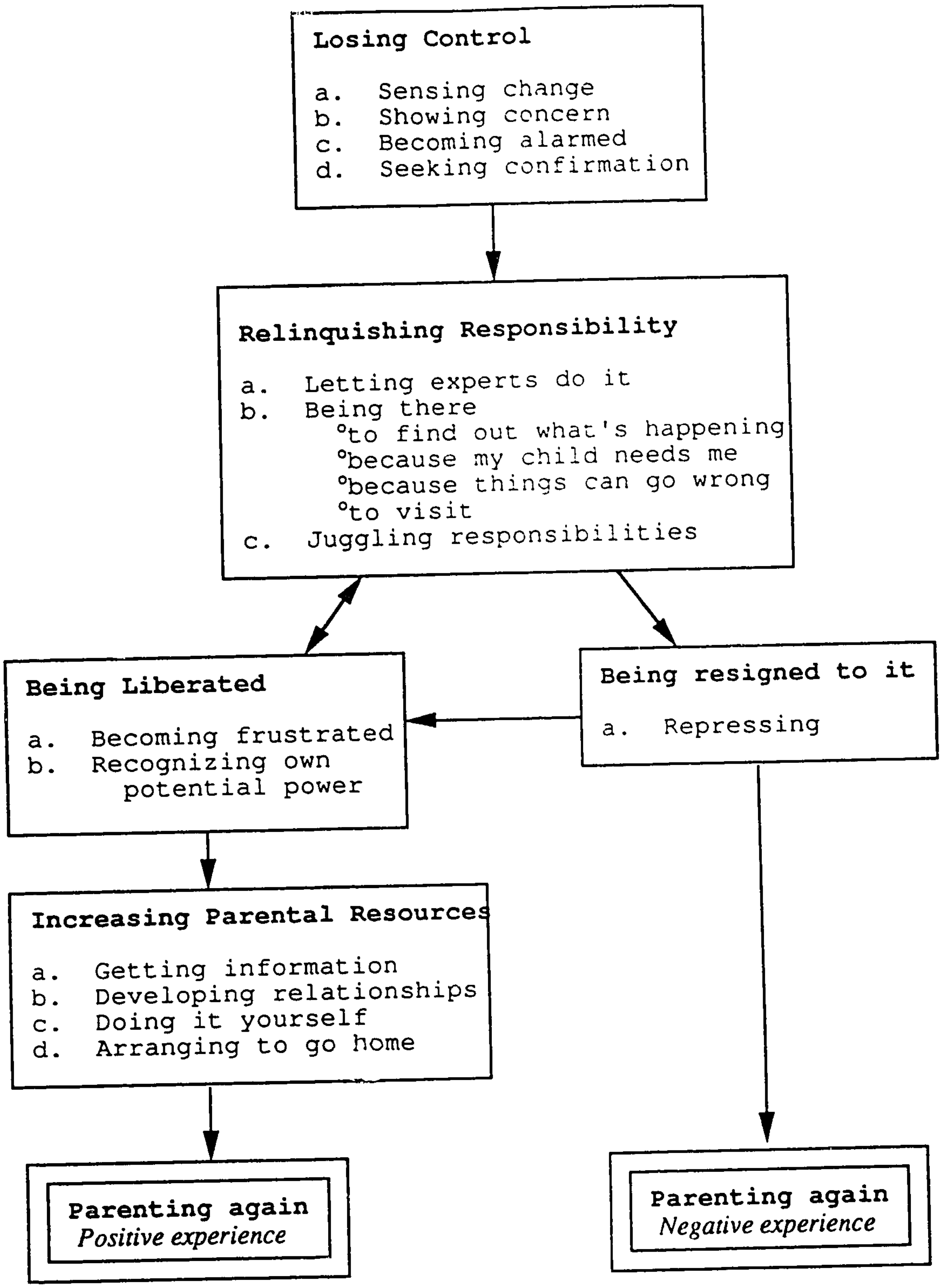

Fig. 1 The Process of Parenting the Hospitalized Child

the child to the system, than they had intended or than they wanted. These parents could not be totally responsible for parenting their children because the need for medical intervention required them to take their children from the home to a hospital, and in the hospital, the system is designed for professional responsibility for the children.

The experience of relinquishing responsibility for the care of their children began at the point in time when the parents decided to seek outside /professional help in dealing with an illness or injury related behaviour which they had noticed in thier children. Up until then, they had been in control of the care that their children would receive. The first stage is therefore called *losing control*. Losing control developes as four phases: sensing change, showing concern, becoming alarmed, and seeking confirmation. This is the pre-hospitalization phase.

Relinquishment of responsibility, a formal change of command, usually occurred at the time of hospitalization (a point Glaser [1979] would call a critical juncture). It contains phases called letting experts do it, being there, and juggling responsibilities. A splitting of the participants occurs at this point, another critical juncture, with some of the parents *being liberated* and others *being resigned* to the situation. Liberation flows from becoming frustrated and recognizing one's own potential, and being resigned to it occurs because the parents consciously or unconsciously repress their frustrations.

The liberated parents are able to *increase parental resources*: by getting information, developing relationships, doing things themselves, and arranging to go home. They feel that they regain most of the rsponsibility which they relibnquished, or as much as is feasible and feel in control within the confines of the specific situation. A new diagnosis or new staff on the unit might require them to relinquish responsibility temporarily again, but the knowledge that they can increase their resources again is a comfort. Liberated parents have a feeling of personal growth and accomplishment when they began *parenting again*, following the discharge of their child. The parents who repressed their frustrations always had the option to become liberated at a later time, and some did become liberated. Those who did not or who did not feel that they hadassumed enough control, left the situation at discharge to *parent again* feeling angry at themselves.

The theory explains the stages experienced by parents when their children ars hospitalized: the relinquishment and regaining of responsibility for their children.

Losing Control

When the children of the primary informants were at home, the parents made many different decisions every day which affected the entire family. These decisions related to daily habits such as bedtime or the family's nutritional status as well as to more abstract subjects such as who their child's playmates would be. Everyday decisions were based in part upon established routine and, in part, upon the child, the parent and other family members' situational needs.

Parents had the power to make these decisions, to change routines, and to use any means they considered available and appropriate to address these needs. For example, if a parent realized that it was a particularly cold day, he or she could elect to dress a child more warmly, to drive the child to school or to ask a friend to drive the child to school. Their consideration of this issue stemmed from the recognition of the cold weather, which exemplified the recognition of and mobilization of resources, and it demonstrated the control that parents exerted over the welfare of their children. Indeed, parents also had the option to choose not to mobilize any resources which might be available to them in any particular situation. Parents were in control of the day to day aspects of their children's lives. Certain aspects of the child's care were delegated to others, such as the delegation of education to the school system and the delegation of health care to the medical system. The delegation to the health care system only occurred when the parents' own resources were inadequate.

Parents who sensed that something was medically wrong with their children tried to figure out what the problem was and usually tried to remedy the problem themselves. If they could not solve the problem, they became alarmed and sought outside expert advise. Once advise was sought, the parent had little choice but to heed it. The control of one aspect of the child's care was now determined by the expert.

Sensing change

In the course of a family's daily activities, parents and children grew to know one another, and they learned to expect certain verbal and non-verbal behaviours. Because of their close proximity and prolonged exposure to their children, parents knew their children better than anyone else, and they were usually the first to sense that any behaviour was unusual. Such behaviour might have been a manifestation of a child's normal development, or it might have symptomized an illness or injury or a psychological problem. Certain unusual behaviour was indeed expected, for example, when an infant climbed the stairs for the first time or when a child who had been exposed to chicken pox developed spots, but some unusual behaviour was also unexpected. The parent sensed a change in the child's behaviour and then decided if the behaviour was indeed unusual. Not only did the parent have been able to sense changes in the child's behaviour, but he or she had to possess a norm, a model of the child's usual behaviour. One parent said, "Our son was born in June. By August, we had a sense that there was something not right with him."

Some parents did not recognize their children's subtle unusual behaviour because they, the parents, had not incorporated the usual behaviour of their children into their knowledge resource. This lack of recognition also occurred when parents were preoccupied with other concerns. Their limited physical, intellectual, or psychological resources rendered it impossible for them to be cognizant of their own children. Unfortunately, a parent occasionally noticed behaviour that was symptomatic of an illness or injury but discounted it as the child's usual behaviour. For instance, one parent in this study was able to ignore her daughter's complaints of pain because "she likes to complain." Another parent did not immediately respond when his son cried because "I thought he was being wimpy."

Once parents sensed a change in their child which was felt to be unusual, they showed their concern by trying to decide what the change was, why it is happening, and by doing something about it.

Showing Concern

When parents sensed a behavioural change and recognized it as unusual, they searched their past experiential base for logical, plausible explanations. Then they instituted remedies to relieve the situation. In fact, in the two previous examples of parents discounting an illness or injury behaviour because it was a behaviour that the child used in other circumstances, the process of deciding whether a behaviour was usual or unusual required a search of the parents' experience with that particular child. These parents also searched for understanding in their knowledge (a) of child behaviour generally, (b) of the behaviour of other children that they had known, (c) of their own experience as a child, and (d) of what they had learned about children through word of mouth or reading. Obviously, different parents have different resources, including different explanations and remedies.

The object of the search was to find information that would help parents to decide whether or not this unusual behaviour was to be expected and if it required any intervention on their part.

One mother, in searching her past experience with her child, mused about possible causes of the child's back pain.

> I was trying to think of maybe something that happened, and the year before that she had a pony ride, and the pony threw her off. . . . She was never dropped as a child, you know

> that I know of. Unless she was dropped by a sitter or something, but anyway, I don't know of any trauma that she could have experienced that could have caused it.

If the behaviour could be expected under the circumstances (for example, she had a trauma, so no wonder it hurts), then parents could decide to change their expectation so that the behaviour was no longer unusual: or they could initiate another search of their own experience for possible remedies to return the child to his or her usual behaviour, or they could do both.

Parents with more resources (such as a medical background) were prepared to accept more serious behavioural irregularities as being expected under the circumstances. One mother, a nurse, said;

> I thought that she was developing pleurisy, from this migrating virus, so in my head, everything was still fine. . . . I should have got her to a doctor then already, except it was really cold out that week. It was minus thirty stuff. And the thought of taking her out in the cold, I weighed that in my mind, too, and I thought, "I don't know if I want to do that either.' It was just kind of like the measures all worked, and I thought, "If I go to emergency, they will just say, 'This is a virus and we can do nothing for it.'" So, I just, um, decided to leave her.

If parents were able to accept the behaviour as expected under the circumstances and change their expectation of what is usual behaviour for the child in these conditions, they were able to then carry on with their lives in the usual fashion while instituting remedies to fit the situation.

Becoming Alarmed

Alarm is defined in the Oxford English Dictionary (1976) as "a state of surprise, with fear or terror, suddenly excited by apprehension of danger" (p. 52). Alarm was the factor that prompted parents to seek outside professional resources. Alarm was triggered both by a sudden onset of unusual behaviours, such as, a child screaming or after an injury, or by the slower realization that a remedy instituted by a parent was not having the expected results:

> I became very worried about her that day. I just didn't like her colour and the fact that she suddenly developed a fever and that her pain had worsened. In so many respects, she looked seriously ill to me. I had already been somewhat concerned that the paediatrician hadn't given us many suggestions in relation to the original complaint. And when she suddenly worsened, I felt quite alarmed and was very anxious to get her in.

The length of time between sensing a change in behaviour of a child and arousing alarm in the parent depended upon the parent's perception of the available resources that could be mobilized to deal with the situation. Two children experienced burns. Both of them screamed. One parent immediately became alarmed when a pan of grease spilled on her child's feet causing second and third degree burns:

> All I saw was the pan on the floor and that she was holding her feet screaming. I just tore off her socks and thought, "Do I put her in cold water? I don't know." So I thought, "I'll just get her to the closest place that I possibly could."

This parent took her child to a medi-centre because it was closer than the hospital, and she was alarmed. She was alarmed because she did not know how serious this injury was and because she did not know what the treatment should be.

The other burn occurred when a young boy trapped his leg between the exhaust and the wheel of a motorcycle. He experienced a second degree burn to his hand and a third degree burn to his calf. The parent, who had a medical background, looked at the burn, picked up the child, and carried him to a snow bank. There, the parent packed the burn with snow, wrapped it in a sweatshirt, and took the child home. This parent later telephoned a specialist for advice about grafting. The parent was concerned but not alarmed because he had knowledge about burns and their treatment. He knew the seriousness of this burn. He knew what the treatment would be, and he knew what to do in the meantime. For this parent, knowledge was a valuable resource.

The length of time between sensing a change in behaviour and arousing alarm in the parent also determined the length of time until expert advice was sought. The second parent in the example above would have become alarmed if the burn became infected or the child's pain did not recede as he had expected. Parents with more medical knowledge did not become alarmed until the symptoms were severe or unexpected. One family, in which the mother was a nurse kept a very ill child at home because the mother felt that she knew the diagnosis, but the husband became alarmed when the mother was not at home and took the child to the doctor. In fact, the mother's diagnosis was correct but incomplete. The child's symptoms were part of a serious chronic illness which was a total surprise to the mother. At the point of admission to hospital the child was in shock caused by pain, dehydration and inflammatory processes.

Slow onset symptoms were not noticed as quickly as sudden onset symptoms, so the alarm was not triggered as quickly. One child had injured his ankle many months before medical advice was sought. [illegible] condition was not any worse but alarm was raised by it not getting any better.

Seeking Confirmation

Once a parent's own resources became inadequate to explain or to remedy the child's unusual behaviour, the parent grew alarmed and sought expert advice. This action is yet another step in the mobilization of resources. The parent sought confirmation that something was wrong with the child, that required expert intervention: "We took him when he got progressively worse. He's a little guy who doesn't complain about anything. We were alarmed enough to take him to the emergency."

Parents expected the expert to confirm their fears and to do something to remedy the situation. Yet, often the professionals' explanations did not match the parents' expectations, or the treatment did not appear to be effective and did not change the child's unusual behaviour. In these instances, the parents would seek another professional's advice:

> There [in emergency] they dismissed the symptoms as simply flu and told us to take him home, that there wasn't a problem and that he would be fine. And then he slept through the night, and [he] seemed to be better in the morning, [but] by the afternoon, he was complaining again. So we took him back, this time not to the emergency clinic; this time my husband took him to the medi-centre before he left to go out of town, Sunday morning. The [doctor] at this medi-centre said there was no problem and also again it was just flu-like, and it was just a tummy ache....He still was complaining on Monday. I left to go to work, he went to school in the morning, but [my husband] was sensitive enough and wondering about this stomach ache that was still there that he called, the family paediatrician. The paediatrician [by this time], was concerned that [the problem] was something more than that. He then made a direct contact with a specialist that he called, and there was some very quick work.

All of the children in the study sample were hospitalized. Obviously, at an earlier stage, someone had noticed that something was wrong and had acted upon this observation. In certain cases, because the children were at school, camp, or engaged in extra-curricular activities, individuals other than parents often noticed that something was wrong with a child. For such activities, parents necessarily delegate responsibility for this vigilance to teachers or supervisors.

Relinquishing Responsibility

In the Canadian hospital system, only a medical doctor can admi a child to hospital. When parents seek professional advice about their child's alarming and/or unusual behaviour, they take their child to a doctor. When the doctor believes that the required tests or treatment required more services or equipment than can be provided in the home or in the outpatient settings, he advises admission to hospital.

When a child is admitted to hospital, the child lives in the institution. The child eats institutional food, sleeps in an institutional bed, and interacts with the institutional staff. The child is registered by number, labelled with an arm band, and assigned to a bed in a particular ward. The child's parent or guardian must sign an admission consent form which grants the institution responsibility for decisions affecting the child. Indeed, to remove the child from the institution on a temporary basis before discharge means that the parents must request a "day pass," which is issued only with the doctor's permission.

Only one parent in this study hesitated about having her child admitted to hospital. The parent argued with the "attending" physician about the need for institutionalization. The parent felt competent to care for the child at home. The child was eventually admitted because "the feeling I got from him [the attending physician] was that she was iller than he knew how to explain."

Parents did not even mention the actual admission procedures. They discussed their mode of transport to the hospital, the difficulties they encountered on the way, the time of day, the arrival on the ward, the blood work, and the tour of the ward, if one took place. No one mentioned signing the admission forms or the attachment of the identification band, two potential indications of the relinquishment of control. Secondary informants, when questioned specifically about the admission, stated that they were "in shock" themselves or just did not remember because the admission was not necessarily the "moment of surrender." They did, however, generalize about the environmental impact: "It's like you are warped into another planet," said one. Except in the one case already noted, parents did not question their children's need for hospitalization. One parent eloquently described the real surrender as the first time that you allow the staff to do something that you as a parent would not do, either because it was a medical technique or because you just would not do it. It was the realization that you allowed it to be done to the child. This may indeed be an admission procedure, such as blood work, or something as innocuous as dressing the child in pyjamas at two o'clock in the afternoon.

Letting Experts Do It

The time of admission was described as calm. Even when the child's admission was under emergency conditions, the admission formalities were left until after the child was treated.

Parents transported their children to different parts of the institution or around the wards for blood tests, examinations, and tours. They interacted with clerks, doctors, nurses, technicians, recreation therapists, other parents, and other children. The children were physically and mentally examined, and many people asked them questions, often repeating questions asked by others. Parents did everything that they were told to do.

Parents spoke of the environment, the strangers, and the intrusions upon the child as being stressful to the child, but they accepted this as normal for a hospital. They spoke of the doctors and nurses as the experts, the ones who knew everything. Even a parent who was a medical doctor did not question the attending physician's statement that he was to be here [in the hospital] as a parent and not as a physician. One parent even used the words omnipotent and omniscient to describe how parents view both doctors and nurses at the time of the admission.

In contrast, parents spoke of their own inadequacies in the situation: "It made no difference that I am well-educated and had worked with parents and children for years. I was just as terrified as the sixteen year old mother of the child in the next bed."

> [Parents] long to be involved with their child's care, but feel threatened and inadequate when confronted by high-tech

> complexities of their child's illness. (Neilson, 1990, p.18)

Smith (1989), speaking as the parent of a hospitalized child, states, "The child has been admitted to hospital and in so doing we have admitted our compliance to the rule of the hospital" (p. 149). In effect, Smith is saying that by allowing the child to be admitted to hospital one yields or relinquishes control to the all-powerful, all-knowing experts. The relinquishment is not done happily, but there is no other choice. When one's child is ill and the care is beyond the parent's resources, expert advice must be taken. It is not the time to try to change the system, even if the parent considers the system to be objectionable:

> The worst thing about having a child in the hospital is the lack of power. You know the complete feeling of having this child taken away from you and sucked into this big institution and everybody is going to tell you what's best for this child, whether you believe it, agree with it, understand it, or anything else.

Four of the original twelve parents used the expression "ignorance is bliss" in relation to the unpleasant information with which they eventually had to deal. They said that they had insisted upon learning more about the conditions affecting their children, but upon learning "bad" news, felt ambivalent about the new knowledge. This ambivalence however, did not prevent them from trying to learn more.

Being There

Although factors such as the gravity of the child's illness or parental responsibilities away from the hospital were mentioned as reasons to stay or to leave, all parents indicated, either directly or indirectly, their need to feel confident that the staff would be capable of looking after their children before they could leave them there alone. Most parents waited until they felt that they knew what was going on and they knew the staff or had seen the staff interact with their children and then they used this as a basis for decisions about when to stay. Two mothers stayed very little with their children because they felt that the staff were capable of managing, and their children did not need them. A third group of parents (5 of the 12) never left their children.

Because my child needs me Parents identified several reasons why their children needed them to be there. These included to act as an interpreter, to be the historian, to provide a home context, and simply to be there for the children.

Parents described acting as an interpreter or translator of their child's behaviour and his or her comments to the staff. Interestingly, age was not a big factor in relation to interpreting. One parent described giving the nurses "the clue" that her fourteen-year-old son was nervous. She said that she "knew his personality," and so she had to ask questions for him.

As well as using their knowledge of their children's usual behaviour to act as an interpreter, parents stayed at times to provide information about the child's history although this information was not always requested:

> All this sort of garbage that they could have avoided and looked for the real problem was if they had just stopped and said, "Okay, Mom, what's going on here?" They wouldn't have known by asking anybody else.

Parents also made comments which indicated that they believed that their child wanted or needed them to be there and that they, themselves, needed to be there. Parents never mentioned their child expressing a need for things from home, but all parents described activities that they undertook on their own initiative to maintain a bridge between home and the hospital. This included bringing the child's personal belongings to the hospital, bringing food from home, maintaining contact with the child's teacher and bringing homework to the child, and arranging visits from siblings.

One child's parents requested a "day pass," and even though the child was acutely ill and did not want to be moved from her hospital bed, they felt that the child needed "to touch base with home" and that they needed to "get a hold of that healing part of her."

One situation did not fit this pattern. Perhaps it is a negative case, or perhaps, in this situation, the child was behaving more like an adult and therefore should not be expected to fit the category. The girl had experienced many hospitalizations and is now twelve years old. When an intrusive procedure is to be performed on her, the child requests that her parents leave. The child has found that she can "draw upon her own resources" during the procedure if alone. When a parent is present, she feels that she regresses and acts babyish. The parent's removal of themselves in this instance does exemplify attendance in relation to the child's needs, but it is not what might have been expected.

Because things can go wrong

> I always stayed until either he was admitted or he was asleep or whatever happened, but um, I just felt better about it because things would happen.

Parents talked about IV's coming out, overdose of medication, and incorrect diet. They learned to be afraid of things going wrong. These types of things happened because the nurses were "too busy" and "nobody was watching."

Sometimes their fears were based upon personal experience, sometimes upon logical deduction. For example, many children in the playroom had intravenous antibiotics. One mother could read the medication labels and knew that antibiotics are used in infections. Her child had a lowered resistance and should not be close to infectious processes. Therefore, it was dangerous for the nurses to suggest that her child be in the playroom with these other children. Another mother knew that her child's dressing had not been changed since the surgery. She felt that the dressing smelled, and she knew that infected wounds smell. She decided that the dressing had to be changed as soon as possible to decrease the danger to her child.

As well, parents were generally scared that a treatment might not be necessary; therefore, the inherent dangers of that treatment would be unwarranted:

> I certainly felt that part of my role was to protect him from unnecessary hospital intervention. There was that. I didn't have to do it, but, there was, I mean, I was looking for things that were being requested that were unnecessary.

One parent refused a lumbar puncture for her child. Another refused a narcotic analgesic. But the converse, that a needed treatment might not be provided, was also a fear. One mother was outraged when medical staff made the decision not to find a new broviac catheter location for her child because the physician deemed the quality of the child's life to be not good enough to maintain.

After describing his feelings about admitting his child to hospital, Smith (1989) states, "And yet, I do not think this admission takes away our obligation to stand up for the child, especially when the logic of things done to him seems unclear" (p. 149).

Parents who stayed because their child needed them were in a position to observe what happened to their child and to other children during hospitalization. This supplied another reason to be there. Unfortunately, being there was no guarantee that things would happen as the parent wished: "You can tell them what to do, but they don't necessarily do it."

<u>To visit</u> Two parents did not spend much time with their hospitalized children. Both were mothers who were employed on a full-time basis outside of the home. Neither missed any work while their child was hospitalized, yet both were emergency, rather than expected, admissions. One had her mother, the child's grandmother, as a parent substitute so that the child was not alone. The other child had no one. He did have his mother's business telephone number, but he never called her. Incidents that occurred long after the boy's hospitalization revealed that the mother was experiencing extreme marital stress and did not seek support from others for her problems. In fact, she said in her interview that it was a mother's responsibility to "do everything." Both of these mothers stated that the nurses knew what to do and that they only had time to visit the children. They both felt that their children were better without them.

<u>To find out what's happening</u> The initial situation was one of a certain familiarity with hospitals, in general. All parents had delivered babies in a hospital, but they did not know what would be happening or when. They had to be there to find out.

> Since yesterday I was quite worried because you never know what is going on.

> There was always discussion of more tests but we never knew

> if they were going to be done or when. So, we were always sort of living from one moment to the next wondering is the doctor was going to come. Wondering if the test was going to be performed.

Constructing a Typology

Glaser (1979) indicates that when differentaiting criteria emerge from the data, which identify an *earned* distinction between subjects in the study, then a typology can be constructed to demonstrate the distinction. Parents certainly talked about level of confidence in the staff and also about coming to know more about the system. These are two differentiating criteria which emerged and are not collapsible into one category each because those with high confidence exhibited different behaviours than those with low confidence.

The differentiating criteria *confidence in the staff* and *knowing the system* can be depicted in a two-by-two typology and do identify the *being there* relationship between a particular parent and the system, at any point in time.

Parents were not always in the same quadrant of the typology. Confidence in the staff could change from shift to shift. Knowledge of the system could increase with exposure and could decrease with the introduction of new procedures or treatments.

		CONFIDENCE IN THE STAFF	
		HIGH	LOW
KNOWING THE SYSTEM	HIGH	come and go (as child needs me)	stay all the time (things can go wrong)
	LOW	don't stay much (to visit)	stay all the time (to find out)

Fig. 2 Being There Typology

Whether the parent(s) decided to stay all the time, for long periods or for short periods, time at the hospital was in addition to their regular responsibilities.

Juggling Responsibilities

If the parent was spending any time at the hospital, something else had to give: either work time, leisure time, or time usually devoted to home or other children. Parents decided what could be ignored or rearranged and then dealt with the required responsibilities, either by assigning the responsibilities to another or alternating their responsibilities and the time in the hospital.

In two parent families, alternating being with the child and undertaking other responsibilities was most common. The decisions about who would be with the child depended upon the nature of the other responsibilities (i.e., whose job could afford more time off, the strengths of the individuals involved, or the needs of the child). One family decided that the mother would stay with the twelve-year-old daughter at night because, at her stage of development, she would not want her father to bathe her during night fevers.

One single mother, who rearranged what she could and had her older child babysitting at home, did not call upon available family support and did not even tell her colleagues that her child was in hospital because "they are already too busy."

The potential helpers, on the other hand, were described by one parent as "scared," "wanting to help," and "not knowing how to help." She had established a network to help all parents of hospitalized children in her church congregation. The help is automatic, not requested, and includes such things as taking turns bringing in supper, babysitting, and doing laundry.

At this point, parents have a choice of two paths: the road to liberation or resignation.

Being Liberated

Becoming Frustrated

Every parent talked about their developing anger and frustration. Their faith in the system of hospitalization and medical care as being the best alternative for their child under the circumstances held strong, but many individuals within the system said and did things that caused parents to consider them as less than perfect. As the parents became more familiar with the diagnosis, the treatment, and the environment, they increased their internal resources and felt more in control. The balance of power began to change. All of the parents spoke of doctors' and nurses' lack of respect for the parents' opinions. Examples of this demonstrate that parents' opinions were accepted/respected if they concurred with the medical opinion and if they fostered compliant behaviour. Non-compliant behaviours appeared to be unacceptable to doctors. One parent went to court to obtain the right to refuse surgery for her child. Another sued the doctor for not listening to her opinion about the child's symptoms. This disillusionment could almost be viewed as a transition phase because the anger or realization that the professionals were not infallible motivated some of the parents to become more aggressive in their participation in their child's care.

Recognizing Own Potential

One mother, upon overhearing a physician refer to her as "a bitch," reviewed her actions since her child's admission and decided that perhaps he was right in his interpretation but that she would not in retrospect change anything that she had said or done. She noted that this understanding on her part was her "liberation."

Even a quiet mother from a traditional family structure who spoke English as a second language found the frustration of having staff disregard her opinion enough for her to change her normal behaviour and "demand" care for her son. She said, "I'm not a person who makes a problem," but in this instance she had to demand action.

Parents' initial reverence for doctors and nurses evolved to a belief that they were fallible or, in one case, to a total lack of respect for doctors: "It's like once you graduate as a physician it's like you turn into this brain-dead, air-head, egotistical twit."

At this point, the anger and frustration led to either a determination to become more involved by taking more control of the child's care, to decrease the chances of becoming frustrating again, or to a resignation that systems are naturally frustrating and that control would only be attained upon the child's discharge. The expected length of hospitalization and the prospect of future hospitalizations influenced this decision. Parents could endure the frustration if they knew that it would be short-lived.

Being Resigned To It

Parents in this group did not use the term resignation to describe their lack of activity when faced with situations in the hospital of which they did not approve. Their words did indicate that they had to accept it, that they had no alternatives, or that perhaps they did not know as much as they thought. Their descriptions did fit the definition of resignation: as "to make surrender of (one's will, reason etc.) in reliance upon another" (Oxford Dictionary, 1976, p. 2509).

Neilson (1990) describes her feelings about non-involvement thus:

> I wanted to be involved in my child's care and to be knowledgable about his condition. Unfortunately it was

> difficult to get and give and sort information. I had to cope with rules regulations and schedules day in and day out. A lack of access to my child during crises and procedures increased my anxiety. (p. 19)

<u>Repressing</u>

When they became frustrated, some parents were unable to vent their feelings appropriately. They expressed the concern that if they told the staff that they did not like a particular aspect of the system they might jeopardize their child's care. This fear caused them to repress their feelings. Repress means to "keep down one's feelings, to keep under control" (Oxford Dictionary, 1976, p. 2499).

One mother, who freely spoke of her strong religious faith, expressed the opinion that everyone is human and makes mistakes and that one should be forgiving. She said this after expressing rage to the interviewer about several incidents that had occurred in the hospital:

> I always, like I have to be careful what I do and how much I say because if you say something to a nurse and she doesn't like the way you say it or something, it's not you that is going to get it back. It's because it's your kid that she is working with.

This parent and the others who felt that they could not express their frustrations to the staff did not have the sense of power that was expressed by the parents who became liberated. They also did not become involved in the decision-making about their child in the hospital, and they did not actively seek to increase their personal resources.

One mother stated that her child's prognosis was stated by the doctor to be better than she had expected. She deliberately did not read about her child's condition for fear that she would find out otherwise. She did not try to increase her knowledge, and she did not form trusting relationships with anyone. She stated that the doctor had told her "not to interfere." Now, long after the discharge of her son from hospital she is very angry at herself for not taking more control in the situation.

Increasing Parental Resources

Parents who felt liberated by their realization that they were not powerless and that they should use some of their power to enhance their child's care began to consider how they might best deploy their resources. Their first step was to aggressively accumulate information. Then they sought to formulate a relationship with the health care professional whom they trusted the most, and finally, they began to do things themselves, thus accumulating skills along the way.

Getting Information

Parents needed information to "get them out of the dark." They could not significantly participate in decision-making because they were not aware of what was going on. Initially, they waited for information; they stayed at the child's bedside thinking that at any moment someone would come in and explain what was happening. When that did not happen, they began to ask and question persistently. They asked the doctors and residents. They asked the nurses. They asked the nurses to ask the doctors. They asked technicians. They asked librarians and they asked themselves.

When the answers to their questions did not give them enough details, the parents read. They were given some information in doctors' offices, but they generally found material themselves in libraries. One nurse told a mother not to read anything except what she was given by the doctor because it would be out of date. Another mother was refused admission to a medical library, but the librarian agreed to search and photocopy medical research articles about the specific diagnosis. Several parents stated that they felt much better when they had read about their child's diagnosis, not because it improved their child's condition, but because they felt they were more in control and were able to ask appropriate questions and secure adequate care. Two mothers spoke of knowing more than the staff about their child's condition. Indeed, the parents who had been to the library spoke in very sophisticated terms about surgery, lab tests, and so forth. Some parents read the child's chart.

Many parents were more comfortable with reading than with asking questions because much of the information given by specialists was "rushed," "brief," "tight lipped," or non-existent. Parents responded negatively to this approach. They "doctor shopped," demanded another opinion, grew angry, or remained anxious. However, parents who had accepted that they were powerful in their own right did not hesitate to call doctors at home to demand answers to their questions.

Procedural or policy information was often volunteered by nurses without prompting. This included ward policy and orientation. Parents were pleased to learn that they "could" stay over night and that in many cases a cot was provided. However, several parents spoke of policy inconsistencies when staff changed. One parent said that when the supervisor returned on Monday, the rules changed. Nurses did not provide information about the child's diagnosis, the child's prognosis, or the daily plans for care.

A mother who did not feel powerful in terms of her son's situation said that the doctors had told her that the boy's prognosis was "very good to excellent," so she deliberately did not read anything for fear that she would expose herself to the possibility of a less favourable prognosis.

Developing Relationships

From whom the parents sought information and how much of the information they believed depended upon their trust in the individuals caring for their child. Parents learned that certain doctors and nurses could be trusted. Their early experiences taught them that the unconditional trust they brought to the institution on their first admission helped neither their child nor themselves.

One mother explained how she had learned to not ask questions of anyone but her doctor because each person gave their "own opinion," and the inconsistencies made her anxious. Another explained that her decisions about whom to trust in the hospital were similar to her decisions in any other situation: "In your day-to-day life, you don't empower everybody around you with everything. Why would one do that in this situation?" Her conclusion was "trial and error."

The main criteria for trust were correct information and honesty. Parents discussed broken commitments, lack of respect, lack of concern, and being too rushed as characteristics which they associated with staff who were not worthy of their trust. They tended to trust friendly, courteous staff with whom they became familiar.

The issue of familiarity was a big one because the staffing structure within the wards did not seem to allow parents to become familiar with the nurses. Although nurses are in attendance for longer hours than any other health care worker, their shifts and assignments kept them from nursing the same patient more than once or twice:

> One nurse who took care of our child for just four hours of his 21 month stay stands out in my mind. When the doctor said the child would need a tracheostomy, this nurse burst into tears because she could imagine how she would feel if it were her child. Some might say she was unprofessional. We say she did more for us than all the technology in the world. (Neilson, 1990, p. 19)

An honest, emotional reaction by nurses was seen as caring by the parents, and they felt it was too bad that they could not have developed a caring nurse-patient relationship with the nurse over the long-term.

Parents spoke of "getting to know" a nurse on one shift and then never being assigned to her again, even if that nurse was on duty. They felt that it was important to the children and to themselves to "see a familiar face, who knows you and knows your child." One mother went so far as to say that she could have gone home at night if she had had the same night nurse twice because she would have developed some confidence in the nurse. One parent speculated that the staffing was done deliberately so that nurses would not develop a relationship with their patients.

Even with the handicap of a lack of continuing contact, some parents were able to develop a trusting relationship with a nurse. One marvellous account of a nurse who, in the parent's words, "transcended nursing" includes a description of how this nurse was able to discover the parent's goals for the day and then work her plans around them, without "deferring right away" like the others: "She was friendly, courteous, and still had her plan of care." This is significant because one comment about hospitalization generally was that the parent never knew what would happen next. Another description of a trusted nurse is a one who asked the parent's opinion about the child's need for sedation before she expressed her opinion.

If the child is hospitalized repeatedly in the same institution, there will be some familiarity. One mother said, "The nurse was a nurse that she had had ever since she was an infant. And it was total. I knew I trusted her totally." If the repeat hospitalization was in another institution or on another ward, then the parent would move back to the being there stage until resources were rebuilt:

On one ward parents came to know the staff and we were asked

> every morning to participate in the discussion regarding our child's care. On another ward, I felt like a three year old when I was automatically asked to leave during rounds and procedures due to "staff discomfort" and "confidentiality." (Neilson, 1990, p. 19)

Individual doctors were the professional that parents most often trusted because they were consistent. Doctors on some specialty services also rotate:

> I found the monthly change [of cardiologists] overwhelming. If one's hospital stay never exceeded a month, you would never run into this.

Doing It Yourself

Parents who had accumulated specific knowledge about their child's condition and about the hospital and who had formed a relationship with a health care professional began to learn specialized care for their child, which extended beyond the range of being there. Their skills developed in many areas: "If I want things done right, I do them myself. Then I know it's OK." Parents began to assume the responsibilities of many of the members of the health care team.

Their intensity of getting information became that of a researcher. The skilled parent ended up knowing more about their child's condition than most of the others within the institution. One parent flew to California to talk with a world renowned expert in the area of her child's illness and then reported back to the physicians. Other comments included:

> So my way was to go to the. . . . spent my life in the library. Research exactly what it was and decide what was the most intellectual decision at that point and go with it.

> I don't think I know it all, but I think I know now as much about her condition as they would know.

One parent described caring for her child at home following hospitalization, where she had monitored intravenous set-ups, administered IV antibiotics, suctioned, catheterized, and resuscitated, all of which required 24 hours of care. She then said: "Within two months it's the same as anything else, you become the expert on it. And it gives you a sense of confidence as a parent to do that." Another parent said,

> We were taught nasogastric and gastrostomy feeding and suctioning, physiotherapy and trachoestomy care, procedures we would have to continue after discharge. But to my disappointment staff continued to supervise me long after I had learned the procedures. (Neilson, 1990, p. 19)

Several parents planned the day for their hospitalized child, which is usually seen as a nursing role. They felt forced to do this by default: if they did not plan the day, then no one did.

One mother in the primary informants' group actually went into nursing after experiencing hospitalization with her child: "There were lots of good nurses that we met that inspired me and lots of crappy nurses that I thought that if I was doing that I would not do it that way."

When the necessity arose, parents were even willing to purchase lab equipment and learn to use it:

> I think if she does develop kidney disease I will definitely get a microscope. It will cost $600, and I don't know how to see a good cast from a bad cast, and all that kind of stuff, and do I, you know, I can learn all that. They have charts, and I think I can work it out. It's going to take some time.

When parents assumed responsibility for the emotional health of their child, they became psychologists:

> And I am really working on her um, emotions. Not to focus on her illness. I mean, we don't really talk about her illness at all. I mean, we had to with this pneumonia, but we are really focusing on her on her positive aspects and self-concept so that I don't um, make her a neurotic about her illness.

Parents with children with chronic or long-term conditions spoke of making their lives "normal." They spoke of "quality of life" and how to promote it within an institution.

Parents who learned about their child's condition had an advantage over the professionals in that they also knew their own child and the child's specific responses to certain conditions. In some senses, they became better diagnosticians than the specialists. Unfortunately, many specialists had not accepted such a possibility.

One mother "knew" from her child's behaviour that the child was growing candida. The growth of this organism would be cause to cancel pending surgery. The doctor would not accept the mother's diagnosis, and the lab report did not confirm the mother's opinion, so the surgery took place. The child's surgery was a failure, and the lab test reported candida growth soon after. The mother had the advantage of knowing her child's reactions to the growth of this organism. She had grown it many times before. The surgeon was seeing the child for the first time and relied on the lab result over the mother's opinion.

A second parent told the admitting physician that her child had pleurisy. The physician told her that she was wrong. There was no evidence of fluid on the Xray. The mother knew that the child had the symptoms: the pain resolved when heat was applied, and the child was sitting. The mother just laughed. The next xray, one and a half days later, showed "the whole thing was filled with fluid."

Parents also learned about specific treatments and requested them:

> And I would also recommend alterations in the regime, based on this, and I'd have immediate results. And I started a

> sign and symptom book and a lab value book that I record these things, along the way, just to keep control of the illness, so it's just not here, there, and everywhere, but you can see it's patterns.

One parent explained that she did not expect to be believed because she was only a parent; indeed, she did not want the responsibility inherent in making a diagnosis even though she thought that she had the ability to do so. She was concerned about accountability if she were mistaken. She did not expect the hospital staff to act upon her direction without verification from her family physician because they might expect her to sue them if they did something wrong even if she had told them to do it.

Along with responsibility, as with other new roles, comes accountability and the fear of making a mistake. Also, perhaps it is easier to relinquish decision-making and the accountability, initially.

The fear of being wrong is accompanied by the fear of the future. Parents who became experts in relation to their child's condition also learned of the possible courses of the condition and the complications. This can be unnerving:

> Sometimes you know too much, and you wish you didn't. Sometimes you wish you were just green and didn't know anything. (laugh) But....

> And all of a sudden things are clicking together for me, and

> I wish, part of me is saying "I wish these weren't clicking. I wish I didn't understand this. But I am."
>
> I give you a loading dose of prednisone, not liking to make medical type decisions, but knowing it is the only decision against the mad flutter of xanthines. (Clarke, 1990, p. 215)

But there was good news, too. The parents stated that they had increased confidence and were received much better by the staff when they assumed these new roles:

> Actually, it does change, because you are more confident, I think, in speaking to them and saying, "I know this isn't going to work, will you please try this instead. Because we've used this before, and we know it will work." And they really didn't hesitate in doing what we said if we appeared to know what we were talking about.

One of the published accounts appears to present a negative case in relation to *doing it yourself*. The parent was a medical resident on the paediatric service to which his child was admitted. In describing his activities at the time of hospitalization, he said,

> I kept busy. I read and doublechecked the medical record to make sure nothing was missed. I spoke personally with consultants. I prayed a lot. I switched responsibilities

> to avoid being put in the position of starting an IV line on my own son. (Schum, 1989, p. 370)

This is unusual in that some of the non-medically trained parents learned to start IV's on their own children. In addition, there is the example of U.S. Senator Edward Kennedy who, upon learning that his son had bone cancer, said that he would give the treatments. He learned how to start IV"s and administer chemotherapeutic agents to his own son. Without the ability to discuss this with the doctor involved, it is difficult to say why Dr. Schum wanted to be so closely involved in the decision-making process but not in the actual treatments. Perhaps he felt that the ethic of not treating your own family applied in some way to the hands-on care and not to the decisions.

Arranging to Go Home

The child's discharge from the hospital did not mean that the child was well or that life would return to "normal." Parents who had taken on new roles did feel that it would be easier for them to care for the child at home than to continue travelling back and forth to the hospital. In most cases, the parents recognized when discharge was appropriate for them and suggested it to the staff.

Many situations still required care, from dressing changes to IV therapy. Once the parents had learned the technique, they wanted the child at home.

Not all parents reached this stage. Some parents, after sensing a problem, seeking help, and relinquishing their child to the system, never went past the "being there" stage: either being there because their child needed them or being there to protect the child. Their children were treated and discharged without these parents assuming any additional responsibility for parenting the child in the institution. For them, regaining the child was an abrupt transfer of responsibility at the discharge, one for which they may not have been prepared.

One parent described a situation in which a family would not take their child home when the doctor discharged him because he was not back to "normal." They were apparently very angry that their child had been involved in a car accident and that they were involved in a law suit. They listed the requirements that they expected their child to achieve before discharge. This is an extreme case of relinquishment to discharge with no involvement during the hospitalization. Because of the parents' total lack of involvement in their child's care, they could then say that they no longer knew how to care for him.

Parenting Again

Whether a parent was ready or wanted it, bringing the child home from the hospital signified that they had regained total control. At one moment, the child was a ward of the institution and was watched over by experts; the next, the child was once again solely the parents' responsibility. Indeed, most parents wanted to take their child home, even if the child was not fully recovered, because the time spent at the hospital interfered with their life with other family members. Moreover, the parents were tired. Those who slept at the hospital did not sleep well. Those who travelled back and forth were tired from the travelling and from worrying about the child when they were not there. Once the child was home, they felt that they could develop a more satisfactory routine. One parent described her own illness right after the child was discharged; she attributed it to fatigue and stress. It certainly did not simplify life with the newly discharged child.

Once the child came home, a parent's presence was required. If one parent was normally home during the day, this was not a great problem; but both of the single mothers in this sample spoke of losing more time from work after the child came home than they did during the child's hospitalization.

Also, once the child was at home, the parent regained responsibility for all decisions. Usual daily activities were modified to suit the situation, but decisions about analgesia or other treatments were also required. Parents involvement in these types of decisions and the fact that they had actually undertaken the required treatments in the hospital setting enhanced their ability to cope at home. Parents in this sample did not call the ward staff if they had questions. They saved them for the next doctor's appointment.

Every experience during hospitalization is a learning experience. Indeed, future instances of unusual behaviour were interpreted on the basis of what had been learned. One mother commented on her son's remark that his stomach hurt several weeks after discharge from the hospital. She said that she immediately reacted with "Oh no, here we go again. At least this time I'll know what it is," when in fact the pain went away shortly. Another said, "You know, so you think, Okay, so for the rest of your life, every time you have these signs and symptoms you are going to panic and wonder."

Consequently, the experience can increase both parents' personal resources and their vigilance, or it can leave them in a depleted situation facing an unfamiliar situation, the newly discharged child, alone.

CHAPTER FIVE

DISCUSSION

In this chapter, the findings of the study in relation to the literature review in Chapter Two and a secondary literature review are discussed. The term "secondary literature review" refers to books and articles read in search of existing theories relating to emerging concepts. As the researcher tried to make sense of the interview data, it became important to read about the concepts being identified. New areas of library research were uncovered. The removal of restrictions from the sample also led the researcher to an examination of research on hospitalization of chronically ill children. Research which relates to the individual phases of the steps of the process will be discussed as they related to a selected literature search. Connections will be made to existing theory by comparing the findings in Chapter Four to three related theoretical interpretations of the illness process, those by Morse and Johnson (1991), Wuest and Stern (1990), and Robinson and Thorne (1988).

Parental responsibility is defined by Brooks (1981) as "establishing a warm nurturant emotional relationship and providing opportunities for the development of competence and individuality" (p. 2). This denotes a process in itself, the series of interactions between parent and child, a process which changes both. How these two responsibilities are enacted varies from parent to parent, but they have two requirements: The parent and the child must be able to interact, and the parent must have control over the environment in order to stimulate the child's development.

The historical review of parental involvement with their hospitalized children shows that at one time the relationships between parent and child and the parents' responsibility for providing opportunities for development were both felt to be secondary to the child's physical health when a child was hospitalized. Researchers later demonstrated that depriving children of interaction with the parent or parent substitute led to both physical decline and emotional disruption. As a result, visitation prohibitions were relaxed, and in most hospitals parents may now be with their children twenty-four hours a day, seven days a week if desired.

The belief that the second aspect, that of parental responsibility for providing opportunities for development of their child's competence and individuality is as important to the hospitalized child's welfare, is not discussed in the research literature, and efforts made by hospitals to support parents in the activities necessary to fulfil this aspect of their responsibility are not apparent. The process of parenting the hospitalized child is in itself developmental, and parents cannot provide for the child's ongoing development until they reach the step of realizing their own potential.

As well, there is no discussion in the research literature about the changes to the parent role throughout the hospitalization of the child. Care-by-parent literature concentrates on the value to the child of being cared for by their parent when hospitalized and to the institution in relation to costs: Parents who participated in their child's care learned better parenting skills and became more confident in the care of their child (Pickerill, 1954; Spence, 1947).

The process proposed in this research suggests that parents can relinquish responsibility for the ongoing care of their child to the health care system and regain responsibility at discharge even while being present and comforting the child, or they can assume responsibility during the hospitalization process, the earlier the better, and develop as parents through the assumption of new knowledge, skills, and understanding. In addition, the benefits to the child and to the institution from this perspective are hypothesized.

The core category and Basic Social Process involved in parenting the hospitalized child is the relinquishment and regaining of responsibility for your child during hospitalization. Smith (1989) expresses his frustrations at being unable to control the care his child was receiving: "At issue here is the matter of responsibility for the care of the child, the issue of who is ultimately responsible for the child and who is best placed to know what is best for the child"(p. 145-146). He later regained control, but it was unusual in that he recognized the problem early in his first experience of being a parent of a hospitalized child.

Losing Control

Parents are in control of the day-to-day decisions affecting their child until changes in the child's behaviour are noticed and cause alarm. When this occurs, the parent is not in a position to offer any alternative strategies and loses regulation of activities relating to the health problem. It is the doctor who has power of position and knowledge.

Pappas (1990), in a discussion of doctor-patient interaction, defines power, domination, and exploitation. He describes power as a part of relationships which is put into operation through the use of resources:

> It is truism that to be human is to have power to make a difference, or to have acted otherwise. Even the most seemingly "powerless" individuals are able to mobilize some types of resources which give them control over aspects of their day-to-day lives or over the lives of others. (p. 200)

Parents did have the power to make decisions about their response to their child's unusual behaviour, but one decision, to take the child to the doctor, is a decision which most would recognise as one of giving power to another. Parents expressed their attempts to be in control of the situation as long as possible by keeping the child at home and making their own diagnoses.

Power can both enable and restrain. When it has a restraining effect it is seen as domination. One assumes that physicians have the best interest of their patients at heart when they wield their power and make decisions which could potentially change the patient's life (Pappas, 1990). Exploitation is a type of domination. It occurs when "resources are used to bolster the particular interests of one group, class or individual over another's" (Pappas, 1990, p. 200). One example of exploitation, cited by Pappas, is when doctors use their privileged position to do unnecessary tests. The comment by Evans and Robinson (1983) that children being cared for by their parents have fewer tests performed on them, even with the same medical diagnosis, makes one wonder about exploitation. No parent in this study gave a description of an experience that sounded like exploitation, although the behaviour of the doctors always sounded like domination in the fact that power was unbalanced in the relationship.

Sensing change

All parents have some resources to mobilize when their child is ill or injured. Unfortunately, lack of past experience, either situational or educational, and lack of family support, which is witnessed with the decline of the extended family network and the increase of single parent families, may indeed limit the informational and supportive resources available to a parent. A parent, with limited resources and/or who is preoccupied with personal or financial problems and is therefore unable to tap what resources they might have, is less likely to sense variation in their child's behaviour as something upon which they should act than a parent who is not under stress. Maslow describes this phenomenon in his hierarchical motives theory (Santrock, 1989). Unless one's survival needs are met, he hypothesises, an individual cannot deal with higher level needs such as security and love. Personal survival needs decrease one's ability to deal with the needs of others. Delay in recognition or action until a behaviour becomes visible enough to force action leads to delay in treatment. Home remedy, which may have been all that was necessary when the behaviour was beginning to develop, may be useless at later stages. As well, alarm may not be raised as early and professional advice not sought at a time when it might have been most helpful to the child. On the other hand, becoming alarmed about a minor behaviour variation also increases with decreased resources.

The mobilization of resources by the parent is as important to child health as medical skills for, as Spencer (1984) notes, "If parents fail to recognize or respond appropriately to warning signs of significant illness, medical treatment cannot be started"(p. 100).

Miller (1983) lists the power resources of chronically ill patients as physical strength, self-concept, energy, knowledge and insight, motivation, and belief system. These are the power resources of everyone, including the parent of a child. The access that a parent has to positive aspects of these resources will determine what they know about their child's normal behaviour, how carefully they observe their child, and what they see.

In discussing the relevance of parental involvement programmes in developing countries, O'Toole (1989) reminds those of us in highly developed medical systems that "overwork, poverty, severe social tensions and sheer exhaustion can make parental involvement a demanding proposition in developing countries" (p. 330). Time, an important resource, is scarce, and what time parents do have is often required for survival. O'Toole is specifically interested in the time parents have to spare for children with special needs. The same could be said of any child, particularly one with a subtle, non-descript medical symptom. There are parents in our country who are poor, overworked, and exhausted, and their resources are very limited.

Showing concern

Every parent has a life experience to search, but they will all be different. That experience will include their own childhood, their experience with other children, either in direct contact or education, and their experience with this child. Obviously, the experience of a first time parent with a very young child will be limited. The experience of a single parent will be less than that of the collective experience of two parents and far less than that of the extended family. If the child had been ill before, particularly with similar behavioural manifestations, the parent's experiential information search will be much richer. Interpreting the child's behaviour on the basis of past experience may lead to home remedy at an early stage. Nothing was found in the literature about remedies instituted by parents before seeking outside advice.

Becoming alarmed

Spencer (1984) conducted a study in Nottinghamshire, England in which "mothers reported that they took their children to the doctor not because they thought their symptoms were serious but because the symptoms caused anxiety and might become serious" (p. 101).

Roskies et al. (1975) conducted an observational study in a large Canadian institution of eighteen children being admitted to hospital. Nine were elective admissions, and nine were emergency admissions. In discussing the emergency admissions, she stated that even they did not "come out of the blue." "Instead, a crisis linked either to an exacerbation of a preexisting illness, or maternal anxiety concerning this condition, or both, gradually builds up" (p. 574-575). This study is sixteen years old and many parent and child hospital orientation programs have been established since, but replication studies have not been attempted. This Roskies study is still frequently cited as the latest word.

In achieving proper medical care, what appears to be important is not only recognition of a problem, but enough alarm to cause a parent to seek expert advice. Alexander et al. (1986) found an inverse relationship between education and state anxiety in parents of hospitalized children. One might presume then that parents with fewer educational resources would become alarmed more quickly and seek expert advice sooner and more frequently. Alexander's additional finding that social status (determined from a combination of education and occupation) accounted for one-third of the variance in mothers' anxieties. Alexander et al. (1986) concluded that differences in social status between the parents and the health care professional might lead to social distance and difficulty for the parent to initiate contact. The data and the secondary literature do indicate that parents do not initiate communication with the health professionals, but the effect that this may have on their taking the child to the doctor in the first place is unknown.

Seeking confirmation

Parents took their children to the doctor because the doctor is recognized as the authority in medical concerns. At all emergency departments, drop-in medical clinics, and doctors offices, a child will be examined by a doctor. Indeed, "throughout most of the western world physicians are the sole or primary source of aid for biological and psychological ills" (Whitcher-Alagna, 1983, p. 131). Public health clinics are seen as places to get advice about prevention of disease through immunization and understanding of development. It is unusual for a parent to take an ill child to a public health clinic.

Parents in this study took their children to the doctor to get treatment to correct the child's condition or to understand the nature of the condition so as to care for the child appropriately. In seeking out a specialist for advice it was difficult for them to ignore the advice because they had no other alternatives.

On the other hand, parents wanted advice. Non-advice such as "there is nothing wrong with the child" did not relieve the parents' anxiety if the behaviour causing their initial concern was still present. In this situation, they had to go to another doctor and seek another opinion. They needed an expert to agree that something was wrong.

Physicians are virtually the only members of the health care professions with powers to prescribe medication, order tests or treatment, do surgery or admit the child to hospital. Pappas(1990) identifies the relationship as "structural asymmetry." The balance of power is with the doctor" (p. 200) and the patient/parent becomes dependent. Whitcher-Alagna (1983) describes medical help as a mixed blessing:

> It may be beneficial (e.g., provide symptom relief) and give rise to positive reactions (e.g., improved health, satisfaction with care, additional help seeking), but it may contain elements (e.g., subservience to the physician, dependency) that precipitate negative reactions (e.g., dissatisfaction, rejection of help, iatrogenic illness) (p.133).

The doctor's advice, unless it is to deny a problem exists, is the only answer. The only parent who would question the advice is one who for some reason feels as powerful as the doctor. Parents in this study who felt that they had regained control also described a more balanced relationship with the doctor.

Relinquishing Responsibility

Letting Experts Do It

The doctor's advice is to admit the child to hospital. In most cases, it is the best decision for the physical needs of the child, and parents want the best for their children, particularly where their health is concerned. What is not taken into consideration and indeed might be insignificant in relation to the physical concerns of the moment is the effect the hospitalization will have on the child, the parent, and other family members.

Knafl, Cavallari, and Dixon (1988) questioned parents about the decision to hospitalize their child. They divided their sample into groups with asymptomatic children, acutely ill children, and injured children. Seventy-one percent of the asymptomatic group, ninety percent of the acutely ill group, and eighty-five percent of the injured group reported that the decision to hospitalize was made by the physician alone. The physician presented the hospitalization as the "treatment of choice," so the parents felt that there was no choice for them (p.19). The other parents reported that they felt that the decision had been made mutually.

The parents in this study agreed that their child needed to be hospitalized under the circumstances. They felt at that time that they did not know what was best for their child and that the hospital staff did know. The doctor-parent relationship has been described as a dependent relationship before hospitalization is even suggested. This dependence, compounded with the depersonalizing factors of hospitalization itself, turns to "hopelessness, depression and alienation on the part of the helpseekers" (Dunst, 1988, p. 71). The parents in this study did express a sense of alienation in the strange hospital environment. They did describe depression but they did not describe feelings of hopelessness.

Patients have the power to disregard medical advice and protest against specific medical treatment. But in the situation of making decisions about the medical treatment of a child, parents have limited power. If medical professionals deem treatment to be in the child's best interest, they can override the parent's rights by making the child a ward of the social services department and then provide the treatment. This is the extreme situation, but one that happens not infrequently.

One of the primary informants in this study had sued a doctor for wrong diagnosis. The case was settled out of court. One of the secondary informants had been faced with legal action to apprehend her child so that unwanted surgery could be carried out. The family fought the apprehension order in court and won. The child did not have the surgery and, as expected by the family, died shortly there after.

Parents let the experts decide on the course of treatment that was required. Initially, it appears that they do not even want the responsibility of explaining to the child what will be happening. Of course, that presumes that they know what will be happening. Roskies et al (1975) were surprised to find that children admitted for elective reasons were no better informed about hospitalization and what might happen to them than the children admitted under emergency circumstances. They observed that parents prepared their children of all ages for pleasant things such as going to the play room and the expectation of a gift but "almost universally" avoided mentioning anything unpleasant. There may be an element here of not wanting to upset the child or the parent-child relationship. Thorne and Robinson (1988) discuss a relationship stage called "naive trust" which may represent this "letting experts do it stage," and Wuest and Stern label this "acquiescing."

Being There

Knafl, Deatrick, and Kodadek (1982) interviewed 24 sets of parents, with both parents working outside the home, with the purpose of identifying factors which influence time and timing of visits to a hospitalized child. They divided the families into those with acutely ill children and those with chronically handicapped children, describing the two patterns of visiting that they found. They describe parents with prolonged exposure to the health care system as those who had regained some control and made their own decisions about when to visit based on gained information, relationships, and their own skills. These were the parents of chronically disabled children. They also describe parents with little control, who did not know what was going on, who did not know whom to trust because they were new to this alien system and therefore "had" to be there. These were the parents of acutely ill children. They did say that the parents of the chronically handicapped children had learned to set priorities, but the labelling of the divisions sounds as though the child's diagnosis has something to do with the parents' presence, while the data from this study suggest that diagnosis is not the relevant factor, that confidence in the staff and knowledge of the system are.

The findings presented in Chapter Four indicate that parents stayed because they recognized that there were hazards to the hospitalization process, both physical and emotional, and they wanted to make sure that everything possible was being done to protect their child. The parents in this study identified the need to protect their child from harm, to support the child emotionally, and to find out what was going on as reasons to stay with the child. Confidence in the staff to meet the child's needs, rightly or wrongly assumed, was cited as a reason to leave. Obviously, the needs of the child and the child's familiarity with the system vary over time.

Interestingly, in staying to protect the child from harm, the parents in this study subjected themselves to the same dangers to which the child was exposed. Visintainer and Wolfer (1985) identify five hazards common to all hospital experience. The first is harm or injury such as physical discomfort, pain, mutilation, and death. The child may have been in pain or in danger before entering the hospital, but the hospital itself also has its own dangers. Medications ordered and administered by strangers, operations, injections, exposure to other ill people, and so forth all have risks. The parent can protect the child by making sure that medication is given correctly or by ensuring that certain treatment is indeed necessary, but in doing so, they put themselves at risk. They deny themselves adequate rest and nutrition. They are also exposed to germs. The second is separation from routines, parents, peers, and trusted adults. In protecting the child from separation, the adult is separated from the routines, from work, from usual leisure activities, and from their other children. The unknown, new, and strange things in the hospital environment and strange behaviour of workers were cited as the third danger. Parents again buffer the child, but they are experiencing the unknown as well. As the parents in this study increased their resources by getting more information they also decreased the chances of surprises, even in the medical condition. The fourth danger cited was uncertain limits such as unclear definition of acceptable and expected behaviour. This hazard applies to parents and older children. The parents do not know what is expected of them, and they often do not know who is supposed to be setting limits for the child in this setting. Finally, loss of control, either loss of competence or loss of ability to make decisions, was stated as a danger. The health care system experienced by the parents in this study, stripped the parents of control by withholding information. Some believe that the medical care system is paternalistic and that all patients and parents are treated as children. These five hazards are postulated as descriptive of the situation for adult patients. They appear to be relevant for child patients and their parents in relation to the findings presented in Chapter Four.

Being Liberated

Becoming frustrated

The relinquishment of responsibility seemed like a good thing for parents in this study to do at the time of admission. Besides, the doctor-patient relationship had the parents in the dependency mode before they even got to the hospital. Parents soon realized, however, that this was paradoxical. They were supposed to be responsible parents, and yet they were being treated like children. They were treated as though they had nothing better to do than sit all day waiting to see what was going to happen next or who the night nurse might be. Their needs were ignored. All of the parents in this study spoke of the feelings of frustration. Some parents did nothing about the feelings, while others reacted. The parents were more concerned about their children than themselves. Being with the children allowed them to see treatment that they did not like.

Hill Beuf (1989) centres her observations of care of children in hospital on Goffman's "total institution" theory: 1.) that all institutionalized individuals are in the same place under the same single authority, 2.) that daily activities are carried out in the company of others, 3.) that daily activities are tightly scheduled, and 4.) that enforced activities are designed to fulfil the official institutional aims. Goffman's four main characteristics of institutionalism are all applicable to a degree to children's wards. The depersonalization found by Goffman in the "total institution" will be found to the extent that the hospital matches these four characteristics.

The large numbers of tasks by a large staff lead not only to depersonalization, but also to error and thoughtlessness. Whatever the reasons, parents in this study witnessed things happening to their children that should not have happened and that caused unnecessary grief. Hill Beuf (1989) says that "many parents witness the humiliation and hurt inflicted on their children by the hospital without raising an eyebrow, let alone filing a protest." She attributes this to their "lifelong socialization to conformity and obedience to authority" (p. 132). Hill Beuf describes herself as an anthropologist and a parent whose child(ren) have been hospitalized. One cannot imagine her sitting passively while her child(ren) were harmed. Many of the parents in this sample did protest. They appeared to have a threshold of tolerance in relation to their children, some protesting more quickly than others, but once they began protesting, or once they realized that they could protest, they actively did protest.

Miller (1983) edited a book entirely devoted to powerlessness of patients. Her focus is the chronically ill, but it includes both adult and child patients. Parents, as powerless individuals, are not included, but many of the concepts can be transposed to parents as a group. The book contains descriptions of patients as powerless, resources for patients, and strategies for nurses to help patients regain power. There is no suggestion in the book that patients become increasingly frustrated with their powerlessness and eventually confront the system. Indeed, the powerlessness is attributed to the chronic illness and not the system. Perhaps being in the dependent sick role makes patients too vulnerable to react with anger. Parents, on the other hand, worry about the vulnerability of their children, but they have access to their usual power resources once they realize that the professional players in the system are fallible.

From a phenomenological study of parents of chronically ill children, Robinson (1985) concludes that parents assume that on admission they will "relinquish their job as primary health care providers. However....they assume that the responsibility for managing the child's illness will be shared, and that mutually satisfying care will be negotiated" (p. 62). Instead, "all described being caught in the situation of not knowing what to do for their hospitalized children because it seemed that their every attempt was denigrated or disregarded" (p. 61).

Robinson's parents were compliant and patient because they trusted the "good intentions" of the staff, but they were angry, and they became "vigilant." She does not tell us if parents ever felt they had reached a threshold of frustration, but she does mention a parent's comment that she realized that she had to fight if she wanted something.

The compliance encouraged in the hospital setting is described as the Medical Model of Helping (Brickman et al., 1982) because attribution to self of responsibility for the illness and a solution of the problem are both low in the patient. The Medical Model of Helping encourages the patient to believe that only the expert knows what's wrong and what to do about it, leading to a dependency which health care professionals encourage.

Recognizing own potential power

Dunst (1988) postulates three conditions that health care professionals need to recognize before family-centred care can become a reality. In this study, the conditions were recognized by the parents who became liberated before they were recognized by the staff. They are 1. "people are already competent or they have the capacity to become competent"; 2. "the failure to display competence is not due to inherent personal deficits but rather to the failure of social systems to create opportunities for competencies to be displayed"; and 3. "clients must have the necessary information to make informed decisions, to be able to deploy competencies to obtain resources to meet needs and attribute behaviour change to their own actions, if they are to acquire a sense of control over life events" (p. 72). Dunst (1988) labels these three conditions as the requirements for "empowerment" and says that "effective helping" is empowerment. The parents in this study who became liberated empowered themselves. They could not wait for the helpers to recognise these conditions. They also knew that to mobilize their power they needed to increase their resources.

Being Resigned To It

Knafl, Cavallari, and Dixon (1988) state that parents used the term "resigned to" in their feelings about the decision to consent to their child's surgery. The parents stated that "they had no strong positive or negative reaction since they felt that they had no real choice in the situation" (p. 20).

Repression

Not all parents recognize their own potential power. Some recognize their frustrations but do not act because of a fear of the effects on their children's care. The concern that one's child's care might be jeopardized by the parent's behaviour has been documented in other studies as the "double bind" (Krefting, 1990: Robinson, 1985). This scenario describes not only decisions about specific treatments, but the entire system of hospitalization for children:

> Parents are faced with the dilemma of either complying with the unspoken professional medical injunction to relinquish responsibility or of assuming a non-compliant position by advocating a more positive involvement with the illness. Either action carries the inherent threat of causing suffering for their ill child. (Robinson, 1984, p.63)

Secondary informants agreed that this is always a concern of parents but that sometimes parents must take that risk and interfere. Robinson and Thorne's 1984 study suggests that professionals should encourage interference by parents, inferring that the repression is unhealthy for the parents.

Increasing Resources

As stated, the recognition of one's own potential power spurred parents to think about what they needed to make the use of that power more effective. Getting more and more specific information was by far the greatest need.

Getting information

The parents in this study obtained much of their information from doctors and the literature. In describing women during childbirth, Kirkham (1989) identifies the ways they obtained information as questioning, joking, self-denigrating, watching and drawing conclusions, learning and using jargon, and eavesdropping. Parents in this study also used many of these techniques, but they had the advantage of not being patients themselves and having access to outside sources such as libraries.

Beisecker and Beisecker (1990) analyze information-seeking behaviour by patients in doctors' offices. They found that although the patients stated a "strong desire for information about their medical conditions they engaged infrequently in information seeking behaviours" (p.26). They conclude that situational factors and not demographic variables better explain this behaviour. The situational factors identified were length of the interaction, patient's diagnosis, and the specific reason for the visit. The parents in this study who were early on in their hospitalization experience, may resemble Beisecker and Beisecker's participants in that they did not engage in information seeking behaviours. The length of interaction relates to length of exposure to the health care system and the time available to move through the stages of the process of parenting a hospitalized child.

Developing relationships

The doctor, from whom the parent received the most accurate information, often became the "trusted" one. This trust relationship is much different than the generalized trust exhibited by the parents in this study when their child was first admitted to the hospital.

Thorne and Robinson (1988) label the earlier trust "naive trust" and the trust developed later as a "guarded alliance" which followed their "disenchantment" phase. The parents in this study who had consciously involved themselves spoke of solid relationships with close to equal power between themselves and the doctors. They did not necessarily like the personality of the doctor but they could communicate with the doctor and they knew what to expect from the doctor.

One mother called the physician at eight o"clock in the evening at home. A youth who answered the phone informed her that "no one of that name lives here." The mother said " I know that this is Dr. X's home. Please tell him to call me." The doctor called her within five minutes. In the mother's opinion, this was an example of her power. She knew that she could get through to the doctor, and she knew that he would be honest with her, but she did not like him as a person.

In trusting relationships, one-way, unconditional trust is not a factor. The parent learns about the strengths and weaknesses of the other party in the relationship, and the two work together. Honesty, courtesy, and familiarity are required conditions.

Brown and Ritchie (1990) found that the 25 nurses in their study did not build reciprocal trust relationships with parents because the nurses did not believe that the parents could care for their own children. The nurses in this study did not build reciprocal relationships because they were not consistently assigned to care for the child, and familiarity did not develop. It is not possible to say from this study if reciprocal relationships would have developed through different staffing arrangements.

Doing it yourself

The survey research identified in the historical review at the beginning of this thesis indicates that parents want to do things themselves but that they recognize limitations in their own abilities. The parents in this study also wanted to do things but did not expand their capabilities until they became frustrated with what was the current hospital practice. Additional energy, generated by the frustration and anger before the realization of their own potential power, was expended in achieving this desire because nurses do not want parents to do the "nursing" care. Brown and Ritchie (1990) state, "While these nurses believed in the value of family-centred care, they had difficulty providing that care in many situations." According to them, the nurses lacked trust in parents and their abilities to care for their hospitalized child and "reciprocal trust did not seem to be dominant in these nurses' experience" (p. 28)

One secondary informant in this study, a nurse who worked in neonatal intensive care, related her experience in NICU after the birth of her own premature infant. She said that the staff allowed her to do everything except the medications and the intravenous monitoring, but she felt terrible about it because they put screens up around the incubator so that other parents could not see her. The nurses did not want the other parents to think that they could do any of these things. The mother said she felt as if she was doing something wrong.

In fact, when parents do want to assume more responsibility than staff feel comfortable with, the staff sometimes distance themselves, leaving the parent very alone. One mother in this study described this distancing experience as having no colleagues in the care of her child once she started providing most of the care herself.

In the researcher's personal experience, upon asking to keep her newborn in a private room over night, the nurses presented a printed release form to sign, absolving the institution of all responsibility should the researcher *be negligent* in the care of the infant during the night. The nurses then closed the door to the hospital room and did not open it again until the next morning. The release form seemed inappropriate in this situation, and the researcher felt that the nurses were particularly negligent in assuming that the signing of a piece of paper meant that they never had to even look at the patient again. This is also an example of the fact that nurses seldom encourage parents to assume responsibility for their own children within the institutional setting.

Arranging to go home

There is one reference in the literature to support the finding that parents who become competent in the care of their hospitalized child realize that not only could they care for this child at home, but that it would be much more convenient for them. Evans and Robinson (1983), in discussing reasons for decreased cost in a care-by-parent unit state, "gentle parental prompting encourages the physician to discharge the child earlier" (p. 776). The Knafl, Cavallari, and Dixon (1989) book, Paediatric Hospitalization, has a large section on admission to hospital but nothing on the time of discharge.

Parenting Again

Park (1989) reports on a study of the parents' experience of resuming responsibility for their children following hospitalization. The notion that some parents actually come home advantaged by the growth that occurred in the acquisition of additional personal resources was not discovered. All parents were found to be in a disadvantaged situation upon the discharge of their children from hospital. The activities of the parents in the first twenty-four hours post-discharge were categorised as giving special treats, carrying out prescribed treatments, managing symptoms, involving relatives, normalizing, and worrying.

In retrospect, these parents had all experienced short stay hospitalizations on a ward where the parents are treated very nicely but where they do not actually participate in care. The parents were asked only about the post-discharge experience, but it was evident that they came home with prescriptions for medications and treatments that they had never attempted with their children in the hospital before discharge. Fatigue of the parents was also identified as a common factor in that study, a factor which would influence ability to manage at home.

Gillis and Sony (1990) describe behaviour changes in infants post-discharge but also state that "this behaviour, in combination with parents' self reports of post-discharge changes in themselves related to anxiety, fatigue, lack of confidence and frustration, interfered with the resumption of satisfying parent-infant interactions" (p. 39).

Making Connections to Existing Theory

Comparing illness experiences

Morse and Johnson (1991) reviewed five grounded theory studies of different illness experiences and created The Illness Constellation Model. The five studies had been of the experiences of both patients and families of individuals with different types of diagnoses. The topic of interest for Morse and Johnson was the commonalities in these five theories. None of the original five theories included the child patient or the parent of a hospitalized child; however, there is definitely a relationship between the theory presented in this thesis and The Illness Constellation Model.

The constellation aspect denotes the families or significant others relating to or revolving around the patient. Parents of a hospitalized child are certainly within the constellation of the child in this respect.

The Illness Constellation Model defines four stages, with categories for the patient and for others being separately identified in each stage. This researcher's hypothesis would be that parents of hospitalized children come somewhere between the self and others as depicted in this model because of the dependency nature of childhood and the enmeshed bond between parents and their children, making the parent almost the patient themselves. The Illness Constellation Model is presented here with the Parent superimposed between the patient and the other (see Fig 2).

The basic social process of the Illness Constellation Model is minimizing suffering: "The goal of those involved in the experience is to decrease the suffering of the ill person or the shared suffering, thereby increasing wellbeing." (p. 363) Parents of hospitalized children certainly want to minimize the suffering of their children, but the experience is one of losing powers that enable them to carry out their responsibilities and the struggle to regain them.

Stage One, *The Stage of Uncertainty*, begins when the individual (the **self**) suspects that they have an illness. That stage begins for others when they begin to suspect the illness of another. Because many children cannot verbalize or do not understand the symptoms they are experiencing, it is another, the parent, who usually suspects first. Then the individual or the parent tries to make sense of the symptoms by "reading the body" and evaluating their findings against norms or past experiences. The evaluation concludes with a decision about how abnormal these symptoms might be and if there is something the individual or the parent can do about it. The other in the constellation, if they have suspected an illness, is monitoring the situation but possibly not involved at this stage. If home interventions are not satisfactory and the symptoms do not get better or even get worse, all three players, self, parent and other have a phase of being overwhelmed. The parent's category of becoming anxious is similar to being overwhelmed, which Morse and Johnson describe as worry or concern.

The break between stage one and two in the Illness Constellation Model is between being overwhelmed and realizing that medical intervention is needed. In the parenting model, the break is between seeing the doctor and hospitalization. Morse and Johnson (1991) state that "once the sick person enters the medical system, he or she no longer really makes decisions: choices become a medical prerogative" (p. 370). This loss of control is recognized in the parent model as the *Losing of Control* with the hospital admission being the outright relinquishment.

Distancing is an interesting concept. Parents are not the patient

EXTENDED ILLNESS CONSTELLATION MODEL

PARENT	OTHER	SELF
	1. THE STAGE OF UNCERTAINTY *Losing Control*	
Suspecting Reading the body Being overwhelmed Seeking confirmation	Sensing change Showing concern Becoming anxious overwhelmed	Suspecting Monitoring Being
	2.THE STAGE OF DISRUPTION *Relinquishing Responsibility*	
Relinquishing control	Letting experts do it	Accepting Responsibility
Distancing oneself	Being There	Being vigilant
	3. STRIVING TO REGAIN SELF *Being liberated* or *Being resigned to it*	
Making sense	Becoming frustrated/ repressing	Commiting to the struggle
Preserving self	Recognizing own power	Buffering
	Increasing Resources	
Renegotiating roles Setting goals Seeking reassurance	Getting information Developing relationships Doing it yourself Arranging to go home	Renegotiating roles Supporting
	4.REGAINING WELLNESS *Parenting again*	
Taking charge Seeking closure		Relinquishing control Making it through Seeking closure

Fig. 3 Fit of the Process of Parenting the Hospitalized Child into the Illness Constellation Model (Morse & Johnson, 1991, p.321)

so they do not have the illness as a cause of "fogginess or loss of reality" as expressed by adult patients. Perhaps the children feel distant. Parents, at this time, move more closely to the *other* role, being vigilant and being an advocate for the child.

Parents play both the **self** and the **other** in the next stage, *Striving to Regain Self*. They try to make sense of the situation; they want to be more active in the treatment; they seek information; and also, they buffer the patient and support the patient. Morse and Johnson (1991) describe a point when patients and families re-examine their values and either re-direct their lives or are devastated by depression, conflict, and withdrawal. There is a similarity in the parents' choice to realize their potential and grow with increased resources or to be resigned to the situation and repress their feelings. The stage of frustration, experienced by the parents in this study and noted by both Wuest and Stern (1990) and Thorne and Robinson (1988), is not evident in the existing Illness Constellation Model. This is potentially an additional feature for the model.

The last stage in the Constellation Theory is *Regaining Wellness*. The **self** takes charge, and the **other** relinquishes control. For parents, it is a time to take charge of their children again. The only one relinquishing control is the system.

The greatest difference in the two models is that in adult illness situations Morse and Johnson (1991) postulate that the self (patient) relinquishes control and the **other** accepts responsibility, giving it back to the self (patient) at the stage of regaining wellness. In the parent model, the parent relinquishes control to the hospital system and either regains it consciously through efforts that increase the parents' resources or receives it back at discharge because the system no longer wants it. The individual patient has the support of the other and has someone to accept control for them. In the case of the hospitalized child, even though in many respects the parent is as much the patient as the child, no one accepts responsibility for the parent. The parent moves from the self to the other and also down the middle of the process, depending on the phase of the process being experienced.

The Wuest and Stern Model (1990) and the Thorne and Robinson Model (1988) are both models of parenting relationships in situations with ill children. These two will now be compared to the theory postulated in this thesis. (Fig. 4, p. 137)

Wuest and Stern (1990), using grounded theory methods, interviewed the families of 12 children suffering from chronic otitis media (middle ear infection). They devised a continuum labelled *Learning to Manage*, with the dimensions of acquiescing, helpless floundering, *Becoming an Expert* and *Managing Effectively*. This is an illness continuum not a hospitalization continuum. Nevertheless there are obvious commonalities between it and the parenting model presented in this thesis.

Acquiescing occurs when families use passive management strategies. They entrust the care of their child to the professional. Throughout this stage parents suffer from lack of sleep. They are constantly juggling responsibilities as they learn to cope with their children's symptoms.

Helpless floundering begins with a disillusionment with the health care system. Families have been living in chaos. They are uncertain about how long their child will be ill and do not know what to expect. Time and the quality of the relationship with the health care system mediate this stage. Parents feel that their input is devalued, that professionals do not care about them or their children: they doubt the abilities of the professionals, but they also doubt their own abilities.

When the parents realize that they must do more, they try to become experts. They learn the rules about the health care system and about otitis media. This knowledge increases their confidence and gives them a greater willingness to risk participation in the care. Wuest and Stern (1990) talk about perceptive knowing by parents as the ability to interpret clues and skilled observation. At this stage, parents experiment with care and try new things. The family's sense of control, competence, and self-esteem is increased. They are now managing effectively. Their expertise has given them a base of power to equalize their relationship with the health care system. They negotiate with professionals and minimize the effects of the illness on their child and on the family.

This description is compatible with the experience of the parent of a hospitalized child. Both require parents to face an unknown medical condition, changes in their child, and a system of expert caregivers who they probably did not know in the past. The hospitalization situation is perhaps more extreme because of the relocation of the child and the loss of additional powers relating to institutionalization. In light of the theory presented in this thesis one might wonder if all parents "learn to manage" and increase their self-esteem and so forth as proposed.

Thorne and Robinson (1988) combined two studies, one which explored the experiences of families with an adult member with cancer and the other which explored the meaning of hospitalization for parents of a chronically-ill child. Their results produced a conceptualization of the relationship between the parent and the professional health care provider as an evolving process with three stages: *Naive Trust*, *Disenchantment*, and *Guarded Alliance*. These categories also have some striking similarities to some of the categories in this thesis.

Naive Trust occurs early in the child's illness experience. It is based upon the assumption made by parents that "their perspective was a shared or commonly held perspective with professionals" (p. 296): "They expected to be understood, acknowledged and respected and that care would be collaborative and cooperative with decisions being mutually negotiated" (p. 297). Families found that these assumptions were naive. The medical goal did not match the parents' goal, which was to minimize the effects and ramifications of sickness.

This led to *Disenchantment*, dissatisfaction with care, frustration, and fear. Thorne and Robinson (1988) say that this was manifested as anger, and adversarial relationships developed. The parents' feelings of vulnerability for their children led to a double bind.

Disenchantment gave way to guarded alliance, created by a reconstruction of trust on an informed not naive level. Parents remained vigilant but did negotiate mutually satisfactory care.

In situations like those described by Thorne and Robinson (1988), the hospitalizations could be very long. They felt that parents who had been passive had to change because the stage of disenchantment required more energy to maintain than could be sustained over long periods of time.

Park	Wuest and Stern	Thorne & Robinson
Parenting the Hospitalized Child	Learning to Manage	Parent/Professional Relationships
Losing Control		
Relinquishing Responsibility	Acquiescing	Naive Trust
Being Liberated or Being Resigned to It		Disenchantment
Increasing Resources	Becoming an Expert	Guarded Alliance
Parenting Again	Managing Effectively	

Fig. 4 Parenting the Ill Child

Conclusion

Examining the findings of this study in light of the primary and secondary literature review reveals support for the concepts of losing control and relinquishment of responsibility in the parent/health care professional interaction. In the Illness Constellation Model (Morse & Johnson, 1991) adult patients appear to relinquish control although some of this is assumed by others in the constellation of the patient. The other, may have similar experiences to the parent of the hospitalized child if the adult patient is viewed as a dependent of the other. Chronically ill patients frequently relinquish control and experience feelings of powerless.

The five studies combined in the Illness Constellation Model lead to categories of renegotiated roles, goal setting and regaining wellness. The two parenting models (Wuest & Stern, 1990; Thorne & Robinson, 1988) discuss the recovery from the acquiescence or naive trust stage. There is no discussion about parents or patients who do not recover from the relinquishment of responsibility. Perhaps in all long term conditions parents have time to recognize their own potential eventually. This is certainly an area for further study.

Some categories, such as *developing trusting relationships* have been the topic of extensive research in other disciplines, i.e. psychology and family studies. Others, such as *doing it yourself* have not been studied. No where is there an explanation of the parenting experience in total.

There is reason to believe that this theory describes not only the experience of parents of hospitalized acutely ill children and chronically ill children, but is a part of the description of the parents experience with all aspects of contact with the health care system, even outpatient experiences, as suggested by the relationships between it and the findings of Wuest and Stern (1990).

The theory is broad enough to encompass much of the existing research on parents and hospitalization. Many studies are specific and examine parts of this theory only, such as stress or juggling responsibilities, but they add theoretical justification to this overall theory.

CHAPTER SIX

SUMMARY, CONCLUSIONS AND IMPLICATIONS

This chapter provides a summary of the study and proposes some conclusions and implications. The summary section reviews the statement of the problem, the significance of the research and restates the research question. The research design is summarized and discussed, followed by an overview of the findings. Part of the conclusions are a discussion of the validity and usefulness of the theory. This is followed by implications of the theory for practice, and implications for future research. A discussion of how the findings related to the assumptions held by the researcher at the beginning of the study concludes the thesis.

Summary of the Study

Statement of the Problem

The purpose of this study was to investigate parents' experiences of the hospitalization of their children. Federal health policy and current institutional economic problems are encouraging a shift in health care provision from professional care-givers to self-care. In child health self-care is parent care. Current nursing literature also calls for more parent involvement in the care of their hospitalized children, while at the same time research indicates that hospital personnel do not encourage involvement by parents. Parents who insist on caring for their children during hospitalization are finding "care-by-parent" units which meet their needs, but these units are scarce and pose admission criteria which most parents cannot meet.

The Research Question

The stated research question for this study was: What is the parents' experience when their children are hospitalized in a traditional ward setting?

The Significance of the Research

This research is significant because paediatric wards, experiencing decreased numbers of nursing staff are encouraging earlier discharge of children and more involvement by some parents in the form of care-by-parent units. Increased care by the parent is seen to be advantageous, but is being implemented in a way that discriminates against some parents, those who do not know about care-by-parent units and those not meeting the criteria for admission to the units. The advantages of increased involvement must be achieved in a logical, rational way. Knowledge about parents, their experience, their needs and their feelings will be useful in planning and implementing paediatric hospital policy.

Research Design

This study was grounded theory research based upon the assumptions of symbolic interaction theory. The model for the design was based upon Glaser and Strauss' work, specifically Theoretical Sensitivity (Glaser, 1979), which specifies the strategies used in the process of grounded theory. Grounded theory requires the researcher to create theoretical constructions of the behaviour observed in the situation under study to make the behaviour more meaningful to others. Because behaviour is ever changing as an individual interprets a situation, based upon the symbolic meaning he or she places upon each facet of the event, it can not be described in a quantitative static way.

Twelve parents were invited to describe their experiences when their children were hospitalized. The parents came to be known to the researcher through communication with a head nurse on a paediatric ward and through communication with other nurses and parents. The interviews with these twelve parents and data from four published accounts by parents were analyzed by the constant comparative method. Categories of behaviour were discovered from common experiences and were theoretically linked to the core category, thus a theory that described the overall experience was developed.

As the researcher had never attempted to use the grounded theory method of data collection and analysis before much of the methodology did not make sense until it was actually undertaken. The concept of "good informant" for example, became clear when an articulate, intelligent mother, who had experienced many hospitalizations of her child, began to speak. Her story was not unlike the stories of the parents interviewed before her, but she added detail and richness to her story. She also described the entire process, from beginning to end, because she had experienced it all. As well, originally the researcher had imposed criteria on the sample relating to age of children, type of illness and number of hospitalizations. These became a hinderance because they prevented theoretical sampling.

Findings

Parenting a hospitalized child is a social psychological process. Parents initially allow control over the welfare of their child to be assumed by professionals within the health care system because these professionals have expertise relating to the health of their child that the parents do not possess. Parents do not use the professionals as consultants or advisors in their own care of their children. They relinquished their responsibility for most aspects of the child's care to the professionals. The parents soon realized that they had relinquished more than they had intended, as more and more of their routine practices were ignored. Their role was usurped and their opinions disregarded. All of the parents became angry but they did not all express their anger in the hospital setting. Some parents felt that they could not show their anger to the professionals for fear of negatively influencing the care which their child would receive in the future. Others could not show their anger because of their previous socialization in regards to anger against others generally, a religious belief, or anger against authority figures in particular, a learned value.

Most of the parents did express their anger and felt liberated when they did so. Once they were liberated, they decided to use and develop their personal power. They learned as much as they could about their children's conditions and the hospital system. They chose at least one professional to trust and developed a relationship of more equal power with that professional. Then they felt the confidence and ability to begin to care for their children themselves, including physical care. These parents arranged for the discharge of their children as soon as they felt that they could carry out the care at home, and went home with the children and with an increase of their own personal resources and strengths, even when their children had unfavourable diagnoses.

Unfortunately, the parents who did not express their frustrations, did not realize their own potential. They did not assume as much control in the hospital setting as the liberated parents and when their children were discharged they were often unprepared. They went home in a disadvantaged situation, even in situations where the children's diagnoses were favourable.

Although the professional staff were the experts in the medical/nursing care they were often not skilled in utilizing the resources of the parent. The parents who developed their resources on their own felt that once they had assumed most of their children's care they were left alone and did not have enough support. They did not have colleagues in the care of their child.

Conclusions

The conclusion that can be drawn from this study is that parents have a common pattern of experience when their children are hospitalized. This experience is the process of parenting the child, from the time that an unusual behaviour of the child is noticed until the parent resumes total care of the child following the child's discharge from hospital. Accepting the common experience as the theory of parenting a hospitalized child, does not exclude other common experiences that may exist simultaneously. This represents one perspective on one part of a larger social process.

The theory can claim validity because the criteria of validity for grounded theory research have been met. The sample was adequate, in that the theory is relevant, complete and contains a great deal of information (Morse, 1991, p. 134). The theory accounts for the behaviour of parents during their children's hospitalizations. This description is relevant to health care professionals in paediatric settings because parent behaviour is often problematic to staff. It is also relevant to the parents, who do not realize that other parents share their experiences. The theory accounts for much variation in parenting behaviours with as few concepts as possible and is therefore complete and parsimonious (Glaser, 1979, p. 93). The theory was appropriate because emerging data led to the theoretical sampling.

The theory can also claim usefulness. The four criteria of usefulness (Glaser, 1979) are achieved. All of the data collected from primary and secondary informants "fit" the categories generated by the researcher. Some of the categories "fit" the categories presented in other recent studies. The theory is relevant to health care professionals and to parents. The theory "works" in that it explains what happens and predicts what will happen. Professionals and parents can look at past situations with parents on paediatric units and describe the behaviour in relation to this theory. They can also determine at which stage of the process a particular parent's behaviour classifies them and predict what might happen next. Finally, the theory is modifiable as social processes change. If physicians and nurses were able to influence the experience of the parent upon admission of the child to hospital, by encouraging or allowing the parent to retain more control, then frustration of parents might decrease. Parents might *increase their resources* without having to *liberate* themselves. As well definitions within categories can change. Parents might spend more time *being with* their child because they recognize the advantage to their child of being cared for by them.

The concept of symbolic interactionism, as presented in the methodology section of this thesis, dictates constant updating of the theory. How the informants experience a situation is dependent upon the interactions that occur. As times change and people in the institutional setting change, so does the interaction.

Towards the end of Theoretical Sensitivity Glaser (1979) discussed logico-deductive completeness and scholarly completeness. He indicates that grounded theory will never have logico-deductive completeness because "Any colleague can always logically think up what was incomplete about the theory, by just a brief deductive elaboration" (p. 126). But, this theory is grounded in the data, not in the literature review. Scholarly completeness, according to Glaser "depends upon the analyst's knowledge of the literature" (p.126). The analyst must read in the area of the theory and compare the generated theory with the research in the field, but "he (sic) can never approach scholarly completeness. To do so is not his intent, pretention, or his interest. His job is to contribute to this literature, not completely to master it. His contribution is integrative and recognitive, not reverent" (p.126).

Implications

Failing a change of the system generally, this theory would lead one to believe that the next best course, if one desired increased parental involvement, would be to make the parents angry quickly and to encourage all parents to express their anger so that they might be liberated from the oppression of the system.

The answer to the research question, it was claimed in Chapter One, will have significance to those parties involved in the planning and implementation of programs intended to increase the involvement of parents in the care of their hospitalized child. This theory points out that the process of involvement by parents in the care of their hospitalized children is not simple. Parents can not just be involved because they so wish or because the institutional structure includes a program in which they are to be involved. Assuming this theory to be fact, parents must have certain information, and understanding and be able to form a trusting relationship with a health professional before they can become involved. The traditional system does not foster this understanding and these relationships so the parents must go through relinquishment, anger and liberation before they begin to accumulate these resources.

Of what value is this theory?

Parents, professional staff, hospital boards and researchers can all use the findings of this theory to influence their future behaviour.

Parents could infer that:

1. it is to their child's and their own advantage to become involved in their child's care while that child is hospitalized;

2. it is important to *be there*;

3. one must ask questions until one understands;

4. it is useful to espress one's frustrations; and,

5. it is important to make suggestions and tell the staff one's pre[illegible] with regard to the care of one's child.

Professional staff could infer that:

6. it is important to listen to parents and respect their wishes;

7. it is important to encourage parents to become involved;

8. information should not be withheld from parents;

9. parents should be included in the health care team, including conferences about their child;

10. staff rotations should be planned to minimize changes of staff experienced by parents;

and, 11. parents need to form trusting relationships with the professional staff.

Hospital Board Members could infer that:

12. mission statements need to articulate the important role of the parent in the care of a hospitalized child;

13. hospital policies must support parental involvement;

14. parent advisory committees might be a valuable part of the board

structure; and,

15. renovations or construction of pediatric units should accommodate 24 hour-a-day living in facilities for parents.

Researchers could infer that;

16. this description of the parents' experience is a theoretical framework;

17. gaps in the research literature can be determined by comparing publications with this framework; and,

18. each category in this theory is a hypothesis made up of many smaller hypotheses. They all need testing as do the theoretical relationships postulated in this theory.

Other professionals who work with children and their parents could infer that:

19. parents' experiences while interacting with them might also be processes, the description of which may promote theory development in their fields.

Concluding Statement

In June of 1989 the researcher listed assumptions that she held about parents' involvement in the care of their hospitalized child. Review of these assumptions demonstrates that the researcher did not know what the findings of the research would be, or the format that they would take. Many of the assumptions are neither substantiated or disproved by the findings because they do not directly relate to the issue at hand. For example, the assumption that parents are more willing to "be involved" than nurses think they are, is supported in the literature review but not by this research because nurses' perceptions were never an issue and parents did not talk about what nurses think about parental involvement.

An assumption was stated that parents know their children's needs and ways of communicating them better than nurses. This was peripheral to the theory. Parents did describe their knowing of their children and their need to "be there" to interpret their children to the staff. This indicated their perception that they knew their child better than the nurses. An assumption that not all parents want to be or are able to be involved to the same extent or for the same period of time is supported by the theory in relation to existing conditions. The hypothesis that a different system of health care, which supports parents in maintaining responsibility for parenting through the hospitalization is a viable outcome from the theory.

The assumption that parents can learn about their children's care and can make decisions about the care was supported to the extent that some parents did this. Some parents did not become involved and it is impossible to claim that they could have under different conditions.

This type of research is very stimulating and very exciting. The researcher was pleased to find other theoretical articles in the nursing literature which supported the theory that was generated from the data in this study. Several of them were published towards the end of the writing of this thesis, indicating independent determination of similar conclusions almost simultaneously, from different data sources. It is time to develop formal theory about parents' involvement in the care of their hospitalized children.

References

Alexander, D., White, M., & Powell, G. (1986). Anxiety of non-rooming-in parents of hospitalized children. Children's Health Care, 15(1),14-19.

Algren, C. L. (1985). Role perception of mothers who have hospitalized children. Children's Health Care, 14(1),6-9.

Ayer, A. H. (1978). Is partnership with parents really possible? Maternal Child Nursing, 2,107-110.

Beck, M.(1973). Attitudes of parents of pediatric heart patients towards parent care units. Nursing Research, 22(4), 334-338.

Beisecker, A. E., & Beisecker, T. D. (1990). Patient information seeking behaviours when communicating with doctors. Medical Care, 28(1),19-28.

Bell, J. E., & Bell, E. A. (1970). Family participation in hospital care for children. Children, 17(4),154-157.

Blumer, H. (1972). Society as symbolic interaction. In J. G. Manis & B. N. Miltzer, (Eds.), Symbolic interaction: A reader in social psychology (2nd ed) (pp 145-154), Boston: Allyn and Bacon Inc.

Bomar, P. J. (1989). Nurses and family health promotion: Concepts, assessment and intervention, Baltimore: Williams & Watkins.

Brain, D. J., & MacClay. I. (1968). Controlled study of mothers and children in hospital. British Medical Journal, 1,278-280.

Brickman, P., Rabinowitz, V. C., Karuza, J. Jr., Coates, D., Cohn, E., & Kidder, L. (1982). Models of helping and coping. American Psychologist, 37(4),368-384.

Brink, P. (1989). Issues in reliability and validity. In J. M. Morse (Ed.), Qualitative nursing research: A contemporary dialogue, Maryland: Aspen Pub Co.

Brown, J., & Ritchie, J. A. (1990). Nurses perceptions of parent and nurse roles in caring for hospitalized children. Children's Health Care, 99(1), 28-36.

Beuf Hill, A. (1989). Biting off the bracelet: A study of children in hospitals, Philadelphia: University of Pennsylvania Press.

Caldwll, B. S., & Lockhart, L. H. (1981). A care-by-parent unit: its planning, implementation and patient satisfaction. Children's Health Care, 10(1), 4-7.

Chenitz, W. C., & Swanson, J. M. (1986). From practice to grounded theory, Don Mills, Ont.: Addison Wesley Pub. Co.

Clarke, M. (1990). Memories of breathing: a phenomenological dialogue: Asthma as a way of becoming. Phenomenology and Pedagogy, 8,208-223.

Comaroff, J., & Maguire, P. (1981). Ambiguity and the search for meaning: childhood leukemia in the modern clinical context. Social Science in Medicine,15B,115-123.

Denzen, N. K. (1972). The research act. In J. G. Manis & B. N. Meltzer (Eds.), Symbolic interaction: A reader in social psychology (2nd ed) (pp 76-91), Boston: Allyn and Bacon Inc.

Dunn, B. H. (1979). Who's resisting parent participation? Pediatric Nursing, 5,54.

Dunst, C. J., Trivette, C. M. Davis, M., & Cornwell, J. (1988). Enabling and empowering families of children with health impairments. Children's Health Care, 17(2),71-81.

Epp, J. (1988). Achieving health for all: A framework for health promotion, Ottawa: Government of Canada.

Evans, R. G., & Robinson, G. C. (1983). An economic study of cost savings on a care-by-parent ward. Medical Care, 21(8),768-782.

Fagin, C. M., & Nusbaum, J. G. (1978). Parental visiting privileges; a survey. Nursing Administration, 3,24-27.

Field, P. A., & Morse, J. M. (1985). Nursing research: the application of qualitative approaches, Beckenham, Kent: Croom Helm Ltd.

Fleetham, S. L. (1984). Family research: issues and directions for nursing. Research on Nursing Practice, 2,3-26.

Fore, V. C., & Holms, S. S. (1983). A care-by-parent unit revisited. Maternal Child Nursing, 8,408-410.

Gill, K. M. (1987). Parent participation with a family health focus: nurses attitudes. Pediatric Nursing, 13(2),84-96.

Gillis, A. J., & Sony, S. D. (1987). Infant readjustment from rural hospital to home. Children's Health Care, 16(1),37-42.

Glaser, B. G. (1978). Theoretical sensitivity, Rolling Mills, Calif: Sociology Press.

Glaser, B. G., & Strauss, A. L. (1967). Discovery of grounded theory, Chicago: Aldine Pub Co.

Goodell, A. (1979). Perception of nurses toward parent participation on pediatric oncology units. *Cancer Nursing*, *2*,38-46.

Green, M., & Segar, W. E. (1961). A new design for patient care and pediatric education in a children's hospital: an interim report. *Pediatrics*, *11*,825-837.

Graves, J. K., & Ware, M. E. (1990). Parents' and health professionals' stress during a child's hospitalization. *Childrens' Health Care*, *19*(1).

Guba, E. G., & Lincoln, Y. S. (1981). *Effective evaluation*, San Francisco: Josey-Bass Pub.

Hardgrove, C. B., & Dawson, R. B. (1972). *Parents and Children in Hospital*, Boston: Little, Brown and Co.

Hardgrove, C. B., & Kermoian, R. (1978). Parent-inclusive pediatric units: a survey of policies and practices. *American Journal of Public Health*, *69*(9),847-850.

Hutchinson, S. A. (1984). Creating meaning out of horror. *Nursing Outlook*, *32*(2),86-90.

Jackson, P. B., Bradham, R. F., & Burwell, H. K. (1978). Child care in the hospital-a parent/staff partnership. *American Journal of Maternal Child Nursing*, *2*,104-110.

James, V. L. (1972). Care-by-parent unit cuts costs, benefits hospitalized child. *Hospital Topics*, *9*,73-74.

James, V. L., & Wheeler, W. E. (1969). The Care-by-parent unit. *Pediatrics*, *43*(4),448-494.

Jessop, D. J., & Stein, R. E.(1985). Uncertainty and its relation to the psychological and social correlates of chronic illness in children. *Social Science in Medicine*, *20*(10),993-999.

Johnson, B. H. (1990). The changing role of families in health care. *Children's Health Care*, *19*(4),234-242.

Katz, G. (1964). Mothers help care for sick children in experimental unit. *Hospitals*, *38*,38-42.

Kirkham, M. J. (1983). Labouring in the dark: limitations on the giving of information to enable patients to orientate themselves to the likely event and timescale of labour. In J. Winslon-Barnett (Ed.), *Nursing research: Ten studies in patient care*, Chichester: John Wiley.

Knafl, K. A., Cacallare, K. A., & Dixon, D. M. (1988). Paediatric hospitalization: Family and nurse perspectives, Boston: Scott, Forseman & Co.

Knafl, K. A., & Deatrick, J. A. (1986). How families manage chronic conditions: an analysis of the concept of normalization. Research in Nursing and Health, 9,215-222.

Knafl, K. A., Deatrick, J. A., & Kodadek, S. (1982). How parents manage jobs and a child's hospitalization. Maternal Child Nursing, 7,125-127.

Knox, J. E., & Hayes, V. E. (1983). Hospitalization of a chronically ill child: a stressful time for parents. Issues in Comprehensive Paediatric Nursing, 6 (4), 217-227.

Krefting, L. (1990). Double Bind and disability: the case of traumatic head injury. Social Science in Medicine, 30(8),859-865.

Lalonde, M. (1974). A new perspective on the health of Canadians, Ottawa: Government of Canada.

Lerner, M. J., Haley, J. V., Hall, D. S., & MacVarish, D. (1972). Hospital care-by-parent: an evaluative look. Medical Care, X(5),430-436.

Lynn, M. R. (1986). Mother's reactions to their child's hospitalizations. Journal of Pediatric Nursing, 1(4),274-277.

MacCarthy, D., Lindsay, M., & Morris, T (1962). Children in hospital with mothers. The Lancet, 1,602-608.

MacDonald, E. M. (1969). Parents participate in care of the hospitalized child. Canadian Nurse, 62(12),37-39.

Marburger, C. (1985). Who controls the schools? Columbia, Maryland: National Committee for Citizens of Education.

May, K. A. (1989). Interview techniques in qualitative research: concerns and challenges. In J. M. Morse (Ed.), Qualitative Nursing Research: a Contemporary Dialogue, Maryland: Aspen Pub. Inc.

McBride, A. B. (1984). The Experience of being a parent. Research on Nursing Practice, 2,27-36.

Mishel, M. H. (1983). Parent's perception of uncertainty concerning their hospitalized child. Nursing Research, 32(6),324-330.

Monahan, G. H., & Schkade, J. K. (1985). Comparing care by parents and traditional nursing units. Pediatric Nursing, 11,463-468.

Morse, J. M., & Johnson, J. L. (1991). *The illness experience: dimensions of suffering*. Newbury Park: Sage Pub.

Morse, J. M. (1989). *Qualitative nursing research: a contemporary dialogue*, Maryland: Aspen Pub. Inc.

Morse, J. M. (1986). Qualitative and quantitative research; issues in sampling. In P. Chinn (Ed.), *Nursing research methodology (pp181-191)*, Maryland: Aspen Pub. Inc.

Munhall, P. L.(1988). Ethical considerations in qualitative research. *Western Journal of Nursing Research*, *10*(2),150-162.

Nielsen, D. (1990). One parent's perspective. *The Canadian Nurse*, *1*,18-19.

O'Toole, B. (1989). The relevance of parental involvement programs in developing countries. *Child Care, Health and Development*, *15*(5),329-343.

Pappas, G. (1990). Some implications for the study of the doctor-patient interaction: power, structure, and agency in the works of Howard Asizkin and Arthur Kleinman. *Social Science in Medicine*, *30*(2),199-204.

Park, C. (1989). *The experience of resuming responsibility for your child following discharge from hospital*. Unpublished report for the University of Alberta Central Research Fund.

Park, C. (1990). In hospital care-by-parents as a childrens' rights issue. In J. Ross & V. Bergum (Eds.), *Through the looking glass: Children and health promotion*, Ottawa: Canadian Public Health Association.

Pickerill, C. M., & Pickerill, H. P. (1954). Hospital cross infection in children, nursing by the mother. *The Lancet*, *1*,425-429.

Robinson, C. (1984). Strengthening family 'interference'. *Journal of Advanced Nursing*, *9*,597-602.

Robinson, C. (1985). Parents of Hospitalized chronically ill children: competency in question. *Nursing Papers*, *17*(2),59-69.

Robinson, G. C., & Clarke, H. (1980). *The hospital care of children: A review of contemporary issues*, New York: Oxford University Press.

Rock, P. (1982). Symbolic interaction. In R. B. Smith & P. K. Manning (Eds.), *Handbook of social science methods Vol. 2 Qualitative methods (pp 33-47)*, USA: Ballinger Pub. Co.

Roskies, E., Bedard, P., Gauvreau-Guilbault, H., & Lafortune, D. (1975). Emergency hospitalization of young children: some needed psychological considerations. Medical Care, XIII(7), 570-581.

Roy, M. C. (1967). Role cues and mothers of hospitalized children. Nursing Research, 16(2), 178-182.

Sainsbury, C. P. Q., Gray, O. P., Cleary, J., Davies, M. M., & Rowlandson, P. H. (1986). Care by parents of their children in hospital. Archives of Disease in Children, 61, 612-615.

Santrock, J. (1989). Life span development, (3rd Ed), Dubuque, Iowa: Wm C. Brown Pub.

Seidl, F. W. (1969). Paediatric nursing personnel and parent participation. Nursing Research, 18(1), 40-44.

Smith, S. J. (1989). Operating on a child's heart: a pedagogical view of hospitalization, Phenomenology & Pedagogy, 7, 145-162.

Spence, J. (1947). The care of children in hospital. British Medical Journal, 1, 125-130.

Spencer, N. J. (1984). Parents' recognition of the ill child. Progress in Child Health, 2, 100-108.

Strauss, A. L. (1987). Qualitative analysis for social scientists, New York: Cambridge University Press.

Stull, M. K., & Deatrick, J. A. (1986). Measuring parental participation: Part 1. Issues in Comprehensive Pediatric Nursing, 9, 157-165.

Thorne, S. E., & Robinson, C. A. (1988). Health care relationships: the chronic illness perspective. Research in Nursing and Health, 11, 293-300.

Torrence, C. M. (1981). Socio-historic overview. In D. Coburn, C. D'Arcy, P. New, & G. Torrence (Eds.), Health in Canadian society, Canada: Fitzhenry & Whiteside.

Turner, B. A. (1981). Some practical aspects of qualitative data analysis: one way of organizing the cognitive process associated with the generation of grounded theory. Quantity and Quality, 15, 225-247.

Van der Schyff, G. (1979). The role of parents during their child's hospitalization. Australian Nurses Journal, 8(11), 57-61.

Vass Fore, C., & Holmes, S. S. (1983). A care-by-parent unit revisited. Maternal Child Nursing, 8, 408-410.

Vermillion, B. D., Ballantine, T. V. N., & Grosfeld, J. L. (1979). The effective use of parent care units for infants on the surgical service. *Journal of Pediatric Surgery*, *14*(3), 321-324.

Webb, N., Hull, D., & Madeley, R. (1985). Care by parents in hospital. *British Medical Journal*, *291*(7), 176-177.

West, P. (1990). The status and validity of accounts obtained at interview: a contrast between two studies of families with a disabled child. *Social Science in Medicine*, *30*(11),1229-1239.

Whitcher-Alagna, S. (1983). Reveiving medical help: A psychosocial perspective on patient reactions. In A. Nadler, J. D. Fisher, & B. M. DePaulos (Eds.). *New directions in helping (Vol 3)*, Toronto: Academic Press.

Williams, D. K. (1985). *Handbook for involving parents in education*. Atlanta: Humanics Ltd.

Wuest, J., & Stern, P. N (1990). Childhood otitis media: the family's endless quest for relief. *Issues in Comprehensive Pediatric Nursing*, *13*,25-39.

Zurlinden, J. K. (1985). Minimizing the impact of hospitalization for children and their families, *Maternal Child Nursing*, *10*,178-182.

APPENDIX 1

Table 1: Demographic Characteristics of the participants

Participant number	1	2	3	4	5	6	7	8	9	10	11	12
Sex	F	F	F	F	F	F	F	M	F	F	M	F
Marital status	M	M	M	W	M	S	M	M	M	M	D	M
Age	41	40	37	35	39	38	39	39	34	34	42	30
Education	MEd	BEd	RN	HS	HS	BA	PhD	LLB	BEd	MSW	MD	HS
Hours employed /week	50+	0	0	35	22	37	50	0	40	60+	50	0
number of children	3	2	2	2	4	1	2	2	2	7	3	3
number of hospitalizations	0	many	many	1	4	0	0	0	62	many	0	many
distance from home to hospital	14km	14km	7km	420k	620k	4km	1.5k	1.5k	7km	21km	28km	14km
support from others	no	yes	no	no	no	yes	yes	yes	yes	yes	yes	yes
community involvement	no	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	no

APPENDIX 2

University of Alberta
Department of Educational Administration

Informed Consent Form

Project Title: The Process of Involvement by Parents in the Care of their Hospitalized Child

Investigator: Caroline Park RN MEd Phone: 492-6389

Advisor: Dr. D.A. Mackay Phone: 492-2073

The purpose of this research project is to increase nurses' understanding of parents' experiences when their children are hospitalized. Data will be collected by indepth interview. The process for interviewing will be negotiated (see process consent form). Negotiated interviews will be tape recorded. Tapes will not be shared, but the final report, containing anonymous quotations, will be available at the end of the study.

There may be no direct benefit to the participants of the study, but it is possible that changes in parent orientation and teaching will occur following the completion of this study.

THIS IS TO CERTIFY THAT I, ____________________ HEREBY, agree to participate as a volunteer in the above named study. I understand that there will be no health risks to me from my participation in this research.

I give permission to be interviewed and for these interviews to be tape recorded. I understand that the information may be published, but that my name will not be associated with the research.

I understand that I am free to deny any answer to specific questions and that I am free to withdraw my consent and terminate my participation at any time without penalty.

I have been given the opportunity to ask whatever questions I desire, and all such questions have been answered to my satisfaction.

I give my permission for the interviews to be used, if required, for secondary research, provided the project(s) is approved by the appropriate review committies.

____
participant

____
researcher

____
date

____
witness
(carbon copy to participant)

APPENDIX 3

DEMOGRAPHIC DATA

Subject No.______ Date ____________________

Gender M__ F__ Marital status_____________

age _____ education __________________

employment ______________________ #hrs/wk ______________

number of children and ages ____________________________

number of hospital experiences to date ____

number of days of hospitalization _____

distance from home to hospital _____

support system as described by subject___________________

____

____

involvement in community or school activities___________

____

____