MOTHERS' EXPERIENCES OF CARING FOR THEIR CHILD AT HOME FOLLOWING 
AN ACUTE SURGICAL PROCEDURE

by

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ABSTRACT

The purpose of this phenomenological study was to determine the meaning mothers' give to their family's experience when caring for their child at home following an acute surgical procedure. The information gained will provide direction for nurses' who prepare parents to care for their child at home after discharge from hospital.

A purposive sample of eight primary care-givers, all mothers, were interviewed for data collection. A total of 21 interviews were conducted. The children were from 7 months to 14 years of age, all from dual parent families. A semi-structured guide of open-ended questions was used for the interviews. Analysis of the verbatim transcriptions began concurrently with data collection and continued during the formal analytic phase.

The mothers' experiences were closely linked to a series of events beginning when the child became ill and ending when the family's activities were back to normal. The mothers' accounts were synthesized into a descriptive framework of their experiences which described three chronological phases: (1) the onset of symptoms leading to help seeking and hospitalization, (2) the hospitalization, treatment, and preparation for discharge, and (3) the care of the child at home and getting back to normal.

The study's findings revealed that mothers perceived their experience as disruptive for themselves and for family life. The mothers described how uncertain they felt especially concerning the child's diagnosis, surgery, and after discharge. Related feelings of worry, anxiety, and stress were reported in varying degrees of intensity throughout their experience. New responsibilities were added to their lives and they became exhausted.

The mothers used a range of coping strategies to manage the child's care as well as their own feelings. The study findings were compared to related literature for discussion. General implications for nursing practice, education, and research were presented.
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CHAPTER ONE

Introduction

In the last decade there have been major changes in the hospitalization of children. Hospital stays are becoming shorter, and parents are not only allowed to be with their child in the unit, but are encouraged to participate in the child's care. In British Columbia for example, the average length of hospital-stay (all admitted cases) for 1 to 14 year old children was 9.2 days in 1978, but 4.2 days in 1988-1989 (Statistics Canada, 1978, 1989). Pediatric nurse practitioners are now placing more emphasis on parents providing support for their hospitalized child and, as a result, are concerned about giving care which best meets the needs of both parents and child (Chan and Leff, 1982; MacKenzie, 1981; Meng and Zastowny, 1982; Whaley and Wong, 1989). This has led to an increased awareness of the need for discharge planning and teaching (Ratliff, 1981; Berlin, 1981; Whaley et al., 1989), however time limits before discharge often prevent adequate preparation of the parents to take care of their ill child at home (Finnsdottir, 1984; Knafl, Cavallari, and Dixon, 1988).

The shorter hospital stay and increased parental involvement in their child's care influences the nurse's role in many ways. For example: (1) The nurse has to focus on the whole family as client. (2) Because of rapid turnover, increased work needs to be done around admission and discharge of a child and his or her family. (3) It is difficult for the nurse to get to know her/his clients well enough to be able to develop the important nurse-client relationship.

Finnsdottir (1984) studied what information nurses gave young children and their parents in pediatric units in Iceland. In her findings it was apparent that parents thought they had received less teaching in the hospital than the nurses stated they had given them. These findings evoke many questions about nurses' knowledge of parents' experiences. For example, do parents' feel they are well enough prepared to care for their child after short
hospitalization? Parents function as primary care-givers in managing the child's illness on a day-to-day basis and, as a result, contact with health professionals is limited; however, a family's contact with the health care system during a child's hospitalization affords nurses a valuable opportunity to gain insight into the family's illness experience. At this juncture, nurses may assist the family in meeting their needs during the hospitalization and could positively affect the family's functioning upon discharge.

My clinical experience with families and nurses in pediatric units as well as my personal observations of the nurse/parent interaction has provided the initial impetus for this study. It is the parent who most frequently transacts with health professionals regarding the ill child's care and so shares the role of client. This indicates the need for nurses and parents to establish a good understanding from which optimal care can be negotiated. It is this writer's belief that pediatric nursing practice has been too limited to the hospitalized period or setting, therefore this study was designed to explore parents' attitudes and abilities to cope with post operative health care after hospital care was terminated, and to collect information about what parents felt was helpful through this period in order for nursing to better meet their needs.

A review of the literature on pediatric illness revealed that most work in this area has been focused on seriously or chronically ill children and their families, except that of Knafl et al. (1988) who based their study of 62 families on short-term (2 - 14 days) hospitalization experience. There were three groups of children, asymptomatic, acutely ill, and injured children in their sample. They studied the disruption of family life prior to admission, how families manage pediatric hospitalization, as well as how pediatric patients (3 - 13 years), parents, and nurses view the child's illness and hospitalization. These children were hospitalized for relatively routine, nonlife-threatening conditions. Knafl et al. (1988) report in their findings that the length of disruption of family life is different between the three studied condition groups. Eighty-two percent of the asymptomatic group and 77 percent of the injured group had returned to normal within twenty days. In contrast, only 35 percent of the acutely ill children had returned to normal within twenty days, and over a third (37%) had symptoms
or reactions that lasted more than thirty days from the onset of initial symptoms or hospitalization (p. 61). If the time span of the illness is used as an indicator of the amount of disruption of family life, these data suggest that families of acutely ill children experienced the most disruption. These findings support the need for further knowledge about the parents' perspectives of their needs, as well as knowledge about how parents of acutely ill children manage their home-care and family-life after discharge from hospital.

Other researchers also support the need for further studies in this area. Otterman (1988) explored the parents' perspectives and personal interpretations of the meaning of their childrens' first time day care surgery. Her study focused on parents of toddlers and preschoolers who went through a planned and predictable period with preparation-time for the parents and their children. Otterman's (1988) findings support that parents report their experience of having a child undergo surgery as a stressful one - more stressful than health professionals may perceive or understand. In Finnsdottir's (1984) study about nurses' information and teaching to young children and their parents in Reykjavik's hospitals, she stated that only 25% of parents perceived that they got information from nurses before discharge (p. 42). One of her recommendations was that nurse/parent communication needs further research. She also stated that nurses need further knowledge about what information parents' feel they need before discharge (Finnsdottir, 1984). One of Ogilvie's (1990) key findings, in her qualitative study of nine parents who explored their experience when their child was hospitalized for surgery, was the need for health care professionals to make themselves available to parents for supportive nurse-parent communication, as well as to negotiate roles with parents. She recommended further studies to identify what strategies are used by nurses who provide effective care for parents, including teaching, and to develop methods of teaching those strategies to other nurses.

This author did not find any research focusing primarily on the parents' perspectives of managing the home care of their acutely ill child who has been discharged from short hospital stay. Most of the literature describes the hospitalization period and the chronic illness
experience, and indicates that when a chronically ill child is cared for in the home, implications for family life are broad and pervasive (Chan et al., 1982; Hayes et al., 1984; Ratliff, 1981; Robinson, 1983; Robinson, 1985). A child's illness is, indeed, a focal stimulus which provokes adaptive responses from everyone who is close to the child. Due to the limited research on the impact of an acute surgical procedure on the child and his or her family more knowledge is needed about factors that influence their experience after hospitalization.

**Problem Statement**

The general problem that this study addressed was a lack of nursing knowledge of how parent's manage their child's care at home after a short hospitalization for an acute surgical procedure. It is vital for nurses to know what meaning is assigned to this experience from the parents' perspectives to be able to understand and meet their needs. We know that parents need preparation to be able to manage their child's care, however we do not know if they feel they get sufficient preparation from the professionals.

The average length of hospital stay of pediatric medical and surgical patients is becoming shorter (day care patients are excluded), so does the time for parents' preparation. Of the population of children 1-14 years of age in B.C., 3.15% was hospitalized in 1988/89 for 5.2 days as an average length of stay (Statistics of Hospital Cases, table 3, p.8, 1988/89). Surgical patients have shorter average hospital stay (3.8 days) than medical patients (6.7 days) and are often discharged home with a new wound that needs specific care, therefore the sample for this study was drawn from this population.

Research to date has focused on parents who had advanced notice of hospitalization, this study involved parents who's children became acutely ill and therefore were hospitalized unexpectedly.

Traditionally nurses have a role in preparing people to manage their illness after discharge as this is thought to be important for their recovery. If we are to provide advanced preparation to parents it is essential that we know what parents' concerns are, what
information they receive, and whether the information they receive is perceived as helpful in caring for their child at home following discharge. Therefore, this study was designed to gain an understanding of parents' experience of caring for the child at home following hospitalization. The participating parents' personal explanations, perceptions, and definitions provide information for nurses that can contribute to effective discharge teaching. Hence, this research addressed the following question: What is the parents' perspective of their experience of caring for a child at home after hospitalization for an acute surgical procedure?

**Purpose of the Study**

The purpose of the study was to obtain an enriched description of the parents' thoughts, feelings, and reactions regarding the child's home care after discharge from a brief hospital stay. The information gained will provide direction for nurses who prepare parents to care for their child at home after acute surgery.

**Conceptual Framework**

Kleinman, Eisenberg, and Good (1978) presented a framework that conceptualizes the health care system in a broad manner; this framework was used to guide this study. The Kleinman et al. (1978) framework adheres to two fundamental notions: The first is a distinction among the concepts of "disease", "illness" and "sickness". The second is a conceptualization of a health care system with three different but interacting social arenas of "professional", "popular", and "folk" which will be described. The framework holds that a clear understanding of the perceptions and explanatory models of individuals in each of the arenas in the health care system will lead to improvement in the areas of patient communication, compliance, and satisfaction.

Kleinman et al. (1978) describe "disease" as a biological malfunction, and "illness" as "a personal, interpersonal and cultural reaction to the disease" (p.252). Diseases are treated and illnesses are experienced. Illness is culturally shaped in the sense that how we perceive,
experience, and cope with disease is based on our explanations of illness, specific to the social positions we occupy and systems of meaning we employ (Kleinman, 1975). Illness behaviour is a normative experience governed by cultural rules; we learn “approved” ways of being ill, resulting in variation as to how disorders are defined and coped with. Neither disease nor illness should be regarded as entities. Both concepts are explanatory models mirroring multi-level relations between separate aspects of a complex, fluid, total phenomenon “sickness”.

Sickness is defined as a human phenomenon encompassing both disease and illness (Kleinman et al., 1978). The experience of illness and the resulting changes of daily living is of primary concern to clients in the health care system.

Individuals in the professional medical sector understand, explain, and respond to illness in terms of the biological and psychological phenomena of disease. The inattention to illness is in part responsible for patient non-compliance, patient and family dissatisfaction with professional health care, and inadequate clinical care (Kleinaman, 1975). In order to overcome illness, or to successfully complete the healing process, there must be a resolution of both the biological disease and the illness experience (Kleinman, 1978).

![Figure 1. Kleinman’s Health Care System (1978).](image-url)
Kleinman's second fundamental notion is the three social arenas which are referred to as the popular (family, social network, community), professional, and folk arenas. The professional arena includes scientific medicine and indigenous healing traditions, while the folk arena includes non-professional healing specialists.

Each of these arenas "possesses its own explanatory systems, social roles, interaction settings, and institutions" (Kleinman et al., 1978, p. 254). The three arenas serve to socially legitimize illness and health care for the individuals they represent. According to Kleinman et al. (1978) an estimated 70% to 90% of all self-recognized episodes of illness are managed exclusively outside the perimeter of the formal health care system and takes place in the popular arena; "most illness episodes never enter the professional or folk domains" (p.254). Explanatory models are constructed or shaped by an individual's culture, society, knowledge, beliefs, values, and past experiences. The models are used by individuals to describe what is wrong with them, and also to recommend what they believe could be successful treatment. Because individuals from different arenas have different explanatory models for the same health care situations, the result is often "discrepant expectations and miscommunication" (Kleinman, 1978, p.88).

Kleinman (1978) views all attempts to understand illness and treatment as explanatory models which differ among the health care systems due to differing health value hierarchies. Kleinman's conceptual framework alerts health professionals to patient and family views of clinical reality and encourages understanding of those views. If nurses are to improve the care provided to parents, they must be concerned with the ways in which parents view their child's illness. According to the Kleinman et al. (1978) framework, interpretation of a situation may be made very differently by parents and professionals. Parents of pediatric patients are family members representing the popular arena. The parents' explanatory models for post discharge experience can be understood by eliciting their perceptions and explanations about this experience. An understanding of the parents' explanatory models will facilitate effective nursing intervention by providing a solid basis for communication between the nurse and the
parents. The relevance of this framework in nursing research has previously been

Assumptions

Researchers inevitably make certain assumptions about their topic that lead them to ask
certain questions and examine certain phenomena. The assumptions underlying this study
reflect this researcher's background in both teaching and pediatric nursing and were as
follows:

1. Parents were able to identify and were willing to articulate their experiences in managing
   their ill child's care.
2. The information parents gave was valid and reliable when they were talking about their
   own experience and they promoted further understanding of the phenomenon under study.

Definition of Terms

Terms which may be subject to ambiguous interpretations were defined as follows:

- Acute surgical procedure: unexpected surgical intervention in order to obtain correction
  or resolution of non-recurrent health problem, disease or injury
- Care-giving: the day-to-day caring for and management of life and treatment for the ill
  child after discharge from the hospital.
- Child: male or female from one month to seventeen years old who does not have an
  on-going health problem.
- Disease: malfunctioning or maladaptation of biologic and psychophysiologic processes
  in the individual (Kleinman et al., 1978).
- Illness: personal, interpersonal, and cultural reactions to disease or discomfort
  (Kleinman et al., 1978).
- Post discharge: that period of time which commences when the parent and child leave
  the hospital setting, and ends when the child has recovered from the surgery.
Primary care-giver: a parent or a person who is responsible for the day-to-day caring and management of life for the ill child.

Short hospitalization: between two to ten days in the hospital for surgical treatment and nursing care.

Limitations

(1) The location of the study was limited to one pediatric unit in one hospital in an urban area in Canada. The possible participants, who met the study's criteria, were approached by one nursing staff member in the unit.

(2) Every qualitative research situation is "ultimately about a particular researcher in interaction with a particular subject in a particular context" (Sandelowski, 1986, p. 31). The reality of an experience constructed by the mothers in interaction with the researcher was influenced by their personal, cultural, and social contexts of the situation. Generalizability of findings based on this type of research is limited to similar meanings found in the data (Omery, 1983).

Significance of the Study

As Kleinman et al. (1978) argues, health professionals hold different explanatory models than do individuals in the popular culture system. Nurses should not assume they know what the parents need and so must take the parents' perspectives into account. The only way to gain this knowledge is by asking each parent for his or her viewpoint, as perspectives vary from person to person in accordance with differences in their illness experiences.

Most literature on pediatric illness concentrates on events in the hospital, not in the home. Several authors have considered how children react to such hospital situations, with some suggestions for minimizing negative responses (Chan et al. 1982; Finnsdottir, 1984; Whaley et al., 1989). Others have dealt with parents' reactions to pediatric hospitalization (Bishop, 1981; Graves and Ware, 1990; Ogilvie, 1990) or programs designed to maintain and support family ties and interaction during the hospital stay (Meng et al., 1982).
No studies were found that focus on the parents' perspectives of their child's home care. Further understanding of how parents experience child's acute illness and how it impacts on the family life could add to the knowledge base to guide nursing practice for meeting families needs in the future.

Summary

This introductory chapter has provided the background to the research problem, which is the lack of knowledge of how the growing numbers of parents are experiencing the home care of their child following discharge after an acute surgical procedure. A description was given of the theoretical framework, methodological theory, purpose, definition of terms, assumptions, and limitations of this study. Kleinman (1978) purports that eliciting clients' explanatory models enhances health professionals' understanding of illness as a personal, social and cultural experience and facilitates the provision of care that is mutually satisfying. Chapter two presents a review of selected literature based on the theoretical framework.
CHAPTER TWO

Review of Selected Literature

In examining the health literature, three areas were particularly relevant to the research problem delineated in this study: (1) the impact of a child's acute illness on family life and the parent as a care-giver, (2) the nurses' role in preparing the parents for discharge, and (3) the parent/professional relationship. This selected review of literature included both clinical and research-based publications in order to establish a background of information about the study's research question.

Until recently, researchers have focused on the child rather than the family and conclusions reached by these authors support the need for family-centred care and lend credence to other professional literature advocating needs for research regarding family perceptions of care and family participation in care (MacKenzie, 1981; Ogilvie, 1990; Robinson & Thorne 1984). On searching the literature this author was unable to locate a study that focused on parents' perceptions of their experience when caring for their child at home after a short term hospitalization for acute surgery. The intent of this review was to establish a background for understanding parents' experience of caring for their child after discharge from hospital following an acute surgical procedure.

The Impact of Child's Acute Illness on The Family

Many authors have acknowledged that when a child is ill, it impacts on the whole family (Friedman, 1986; Knafl et al., 1988; Otterman, 1988; Whaley et al., 1989). Most of the literature about family life after discharge from hospital has referred to the on-going home-care demands of chronically ill children. Parents of children with chronic illness learn over time how to cope with to their child's symptoms and therefore have different experiences beyond those of caring for a usually healthy child.
Knafl's et al., (1988) work served as an exception. They described the pathways to admission of a child in their study "Pediatric Hospitalization: Family and Nurse Perspectives". Knafl et al. (1988) compared the impact of the circumstances and events on family life of 62 ill children who became hospitalized because of variety of illnesses. These authors divided the children in to three groups: asymptomatic, acutely ill, and injured children. After a year-long study Knafl et al. (1988) reported that families in the acutely ill group experienced the most difficult circumstances prior to the child's admission to the hospital. These authors stated that when a family experiences illness, each member interprets the illness in a personally meaningful fashion according to the social and cultural determinants that are significant to the situation. Thirty two of the participating children were hospitalized for a variety of acute illnesses and their parents presented themselves as either exhausted, frightened, or at "the end of their rope" (p. 26), at the time of the child's admission.

The Knafl et al., (1988) study reflected the process by which parents constructed their participation with the hospital staff. In the study they employed a grounded theory approach, or the discovery of theory from the data. The sample of parents was purposefully narrow, and the resulting conceptual framework or theory was therefore at a very beginning stage. These researchers described two types of parent participation, level I parents who comfort their children, and level II parents who also comfort their children but expand their parental responsibility to include information gathering and care monitoring. The data were summarized and related to a conceptual framework of parent participation and then the two levels of parent participation were compared. Demographic characteristics did not differ greatly for the two levels of parent participation. The relationship between prior pediatric hospitalizations and participation level was unclear. For example 44% of parents who had never hospitalized their child were in level I and 44% in level II, while 56% of parents who had experience from 1-3 prior hospitalizations were in level I and 31% in level II (p. 143).

Knafl et al.(1988) reported in their findings that it took the acutely ill children longer to return to normal (35% had returned to normal within 20 days) than asymptomatic (82% had
returned to normal within 20 days) or injured children (77% had returned to normal within 20 days (p. 61)). These findings support that we need to know more about how acute illness affect's the family's life, and how these parents manage their child's care after discharge.

Litman (1974) emphasized the importance of the family's response to any member's illness in his study of the family as a basic unit in health and medical care. Litman's study explored the care-givers experience and stated that when the illness affects a child the response of the primary care-giver, most often the mother, is important. Litman noted that because of the demands of her usual role, a mother often found it difficult to fulfil her obligations to all members of the household when a child was ill.

While's (1991) study of an evaluation of a paediatric home care scheme for children with variety of illnesses, support the parent's perspective in Litman's study. While (1991) revealed that 1502 home visits had been made to 319 children and their families during an 11-month period. Most of the parents (87.5%) expressed a preference for home care and cited a variety of reasons for this preference which included: the maintenance of normal family life; care as good as that in hospital; access to decent meals and familiar toys; and care in the home permitted earlier and quicker adjustment to a long-term illness. The conditions of the children in While's study varied, but one-third of them had surgical conditions (95 children) comparable to the participants in current study, and were receiving post-operative care at home.

It was estimated in While's study that the 1502 home visits by a nurse resulted in 573 less in-patient nights and 278 clinic's visits were avoided. There was no evidence of patient safety having been compromised. The interview data was gathered from the parents who revealed that the supportive and teaching role of the Home Care Team nurses were greatly valued by parents who also stated they prefer continued contact with one nurse rather than a number of nurses. The majority of parents (90%) said they would choose to have home care rather than hospital care should the need arise in the future (While,1991). However, neither While's nor Litman's studies described what parents like nurses to assist them with to ease the transition from hospital to home care.
The Nurses’ and Parents’ Roles in the Care of the Hospitalized Child

Four decades ago, the roles of nurses and parents were clear, because parents were expected to leave their ill children at the hospital and to pick them up either at discharge or death (Johnson, 1990). Parents and nurses had relatively uncomplicated relationships; parents were only allowed to visit their children for a brief period of time and nurses were responsible for all child care. Johnson (1990) pointed out how well-intentioned, but misinformed, health professionals were who commonly felt that since children often cried when parents arrived on the ward, it was best if they were not there at all. Johnson has discussed the changing role of families in health care which started in the mid forties as researchers began to report findings indicating that the failure of many young children to thrive in institutional setting was related to the lack of parental nurturing in these environments (Johnson, 1990). This called for a change in many hospital’s policies where mothers became admitted with their young children. Dr. Jeppson (1981) directed a survey to capture basic information about a wide range of policies and programs that encouraged or discouraged the participation of families in the care of infants, children, and adolescents in hospital settings. The data from the survey showed that 75% of general pediatric units had 24 hour visiting policies for parents in 1981. The data were used by many in advocating for change within hospitals. In 1988 this survey was expanded and replicated under the direction of Michael Roberts and showed that 98% of general pediatric units were open to parents 24 hours. However, many hospitals are still closed for siblings younger than twelve years of age (Roberts, Maieron, and Collier, 1988).

Currently most parents have access to their hospitalized child 24 hours a day and are free to participate in their care. However, the roles of the parents in the hospital and the roles of the nurses in caring for parents of hospitalized children are poorly defined in the literature, and their rights and responsibilities in relation to each other are not clear. Knafl et al. (1988) stated that the hospital is a foreign territory to most parents, and often parents are not aware of what they can do. In addition they may fear the child’s illness or the technical equipment involved in the child’s care and treatment. Such parents may simply choose to do nothing rather than do
something wrong. When confronted with this situation the nurses will explain to the parents that they can assume certain care responsibilities for their child and then show them how and what they can do. Ogilvie (1990) stated that strengthening family participation in a child's care and responding to the family's concerns are viewed as legitimate goals of the health care team.

There is an agreement in the literature that a parent's role changes when a child becomes ill (Knafl et al., 1988; Knox et al., 1983; Kodakek, 1986; Robinson, 1983). When the child's illness necessitates hospitalization, changes in parental roles and responsibilities are compounded (Friedman, 1986; Ogilvie, 1990; Otterman, 1988). During the child's hospitalization most parents, although willing to participate in their child's care, are unsure of their role in the hospital setting (Algern, 1985; Finnsdottir, 1984; Knox et al., 1983). Lack of understanding about hospital routines and the child's treatment may lead to this feeling of uncertainty for these parents (Ogilvie, 1990; Mishel, 1983) and some parents consider events that occur during their child's hospitalization annoying (Knox et al., 1983).

Algern's (1985) study revealed that parents receive minimal direction from nursing staff to clarify their role uncertainty and Finnsdottir (1984) findings support this. Parents may also experience feelings of anxiety, guilt, and even embarrassment due to the illness and behaviour of their children during hospitalization (Knafl et al., 1988; Ogilvie, 1990).

Discrepancies between parental and staff perceptions of the parental role may be the basis for parent-staff conflict when a child is hospitalized (Ogilvie, 1990; Robinson, 1983). Therefore family roles must be acknowledged, parental roles in hospital must be negotiated, and parents need to feel that they retain part of the care-giver's role for their child. This could decrease parents anxiety and help them to cope with the care after discharge.

Child and Family Behaviour Change

Literature supports that the period after discharge may be difficult for parents. This is particularly true when parents have more children and other family responsibilities, however this depends on the parents coping ability (Carlson, Simacek, Henry & Martinson, 1985;
Otterman, 1988). The parents in Otterman's (1988) phenomenological study about the post day care surgery experience for parents of toddlers and preschoolers viewed the post-hospitalization experience in relation to what their concerns were in the hospital and prior to the hospitalization. The parents in her study stated that their experience was stressful and they reported feeling worried and anxious. Parents' interpretations of the events as stressful included "new responsibilities for the child's care and supervision of the post-operative child, changes in the child's behaviour and patterns of activity, and changes in family activities and routines" (p.127). However, these parents knew about their child's upcoming hospitalization in advance and could prepare themselves and their children.

Parents of newborns, infants, and toddlers have received comparatively more attention from researchers than parents of elementary school children and adolescents. Knafl et al. (1988) interviewed 62 parents of 3-13 year old children and while they stated that the child's behaviour contributes differently to the parents experience, they did not explore how the child's age affects parents' experiences. There is limited knowledge about how a child's age affects the parental experience of the child's hospitalization. In their conclusions Knafl et al. recommend further research to see if parents react differently depending on the age or other characteristics of the child. Otterman (1988) found that the younger the child is, the more difficult it is for parents to assign a meaning to the child's behaviour, therefore increasing parental stress. For example why is the child crying, is it because of a pain or is it hungry? The nursing literature supports that children from around 6 months to 4 years old show the maximum adverse effects of separation and stress of hospitalization (Finnsdottir, 1984; Friedman, 1986; Tackett & Hunsberger, 1981; Whaley et al., 1989).

Much is still not known about the parents' experience at home following the child's discharge from hospital, such as how parents adjust to role changes and new responsibilities. To be able to meet the parents' needs nurses have to know how parents' experience the discharge period, because the perception of an event is more significant than the actual
circumstances (Knafl et al., 1988). Some parents are challenged to an extraordinary
degree by the demands of caring for children with complex care needs at home. Once
home, parents duplicate the services provided by the various disciplines and departments
within the hospital. It is rare that a parent enters into this situation with prior knowledge
of how to accomplish these tasks (Ray, 1989). The demands for the child's care with
increased responsibility can cause parental stress and therefore a review of related
literature will add to our understanding of the experience.

Parental Perception of Stresses of Hospitalization

The hospitalization is a change force requiring energy for coping or readjustment to
new situation, which is also stress related for parents. Individuals and families who learn
that the stress signs and symptoms result when they are experiencing stress beyond
tolerable limits may be able to mobilize or adjust their coping mechanisms (Clemen-Stone
et al.,1991).

The general nursing literature argues that the most common stressor for parents is
the uncertainty about their child's diagnosis and treatment. How the hospitalization
impact's on the child's well-being and the unfamiliarity of these events are also stressful
for the parents, as well as the unknown impact on the child's future (Tackett and
Hunsberger, 1981; Whaley et al., 1989). However, the effects of a child's hospitalization
for the population such as the one being studied here, have not been empirically examined.
Clinical literature advocates that the parents are entitled to know the condition of the
child, why and how procedures are carried out, how the child can be expected to react to
the procedure, what medications are being given, why, and if they could expect any side
effects, as well as how to follow up on these procedures (Whaley et al., 1989).

Parental Coping with Child's Hospitalization

Garland et al. (1982) defined coping as the process by which an individual attempts
to alleviate, or remove stress or threat. This process may consist of a rather large
array of covert and overt behaviours. In other words, for the population of current study coping is what parents do when they have a problem, the efforts they make to meet the threats.

Research has supported that coping with stress could be fostered by parental support and interventions such as information giving (Finnsdottir, 1984; Knafl et al. 1988; Ogilvie, 1990; Otterman, 1988; Robinson, 1983). This author did not find any study addressing the issue of how parents cope after their child's discharge from a short hospitalization for a surgical procedure. However, the general nursing literature has suggested that the stress-crisis sequence evolves when an individual's usual coping mechanisms or ways of reducing stress are inadequate to deal with the threatening event(s) being encountered (Clemen-Stone et al., 1991; Whaley et al., 1989). The major task for the family that is experiencing stress or crisis, is to recognize that customary coping mechanisms are ineffective, and that new patterns for coping must be established. Some families, particularly those who have adequate situational supports and who have been flexible in the past, are able to accomplish this task with little or no assistance. Other families, especially those who have few or no situational supports, who rigidly define role patterns, and who lack maturity because of past experiences, will need help from others in developing new ways for handling stress. These persons are frequently unable to identify the nature of the stress they are experiencing or why their patterns of functioning are ineffective (Clemen-Stone et al., 1991).

It can be difficult for health care professionals to identify the coping behaviours a family is employing. Garland et al. (1982) suggested that professionals lack the skill for observation, or actually seeing what they are looking at, and that faulty listening habits are major reasons for failing to understand the family. These authors stated that nurses and other care-givers can facilitate the identification of the coping behaviours by using an assessment tool, which enables the care-giver to obtain the essential information in a systematic fashion. Clemen-Stone et al. (1991) suggested that nurses should have an awareness of behaviours which are commonly observed when individuals and families have developed ineffective coping mechanisms, because it enhances nurse's ability to quickly identify clients who are experiencing distress,
crisis, or dysfunctional family dynamics. Some families are more able to cope with changes or challenges in the family routine, like having an ill child who is hospitalized, while for others it is a crisis situation. For an example dual-parent families, who are flexible, educated, with a good support system, and living with stable income are expected to be able to cope well, while a single mother which would lose her income, in case of illness, would be facing a crisis situation. Timely supportive intervention may be the critical factor that determines if an individual or family has a positive or negative outcome during periods of crisis (Garland et al., 1982).

In summary, when a child becomes ill and is hospitalized, the reviewed literature suggests that parents have unique needs and roles as care-givers. A child's illness and the parental reactions to it may affect the functioning of the whole family. Parental coping is crucial for the recovery of a child, yet the child's hospitalization may be extremely anxiety provoking and stressful especially for the primary care-giver. A small amount of literature exists which supports the premise that the post-hospitalization period may also be particularly difficult for parents (Knafl et al., 1988; Otterman, 1988). Research findings about how families manage the home care of these children are limited, however the general literature suggests it is mediated to a large extent by the receipt of appropriate supports. The nurse is a key person to inform and prepare parents for this task and literature of the nurse's role will therefore be reviewed.

The Nursing Role in Preparing Parents for the Discharge of their Child

Traditionally nurses have a role in preparing parents to manage their child's illness after discharge. However, few studies have been done on whether the parents get the appropriate information or knowledge they feel they need, to be able to care for the child after discharge from the hospital.
Finndottir (1984), Knafl et al. (1988), and Ravenscroft (1980) have argued that well-organized discharge planning for the care of a child can reduce stress in both the child and his or her parents. Also, it can facilitate the successful transition into the home and community, as well as promoting effective rehabilitation. Knafl, et al. (1988) stated that the child and the family must be well prepared and supported through this critical movement into the home. This preparation includes helping the parents develop confidence in their ability to cope with the child's illness and become involved in the child's care to promote family self-care. In certain cases, it is possible that the well-being and recovery of the child may be at risk if recommendations are not followed (Otterman, 1988). The concept of family-care is promoted through education, giving rise to a more relaxed, informed, and cooperative parent (Knafl et al., 1988).

Knafl et al. (1988) observed and interviewed twenty-nine registered nurses working in pediatric units at three hospitals. They stated that parent teaching is an important component of the nurse's role, which occurs throughout the hospitalization. The nurses stated that they kept parents informed about what was happening to the child, including instructions on the child's condition and the care that the parents gave in the hospital to prepare them for the home care. The nurses in Knafl's study believed they must be prepared to share their knowledge, by answering questions, sharing important information with the family, and observing interactions between the child and his or her significant others. They also believed that when they were able to meet the parents' needs they have gone a long way toward helping the child, for the parents were then able to join with the nurse in caring for the child. There was however an inconsistency between the nurses' statements and the parents' experiences, because some parents stated that they felt unsure and not prepared to care for the child at the time of discharge (Knafl et al., 1988).

Otterman (1988) described how parents tend to focus their attention on areas where they, as parents, are directly responsible, such as instructions about medications and physical
activities. Both Otterman (1988) and Knafl et al. (1988) stated that parents often think of questions for health care practitioners after they leave the hospital.

Ray (1989) described the role of nursing in facilitating home care in terms of five areas of responsibility. These included: organizing or coordinating care, teaching the child and family, supporting the child and family, ensuring on-going assessment and evaluation of the child and family's progress, and providing outreach teaching to community professionals.

The general nursing literature has suggested that when nurses actively help parents to meet their child's basic needs it allows them to learn and participate in care more quickly. A parent's beliefs and values affect how s/he perceives problems and what priority s/he places on learning (Roden, 1987). Frykholm and Pontius (1981) described that the nurse in the acute care facility is in the most desirable position to determine parent's needs and to develop an appropriate plan for assisting the family with the transition from hospital to home. These same authors also state that the nurse's responsibility is to recognize the teachable moments, and to identify the families post-hospital needs, as well as to inform them about ancillary services. Roden (1987) has pointed out that health professionals often forget about the importance of a person's primary social world and how the illness experience affects their behaviour.

Professionals leave the burden of adjustment and adaptation to life outside the clinical situation entirely to the parent, sometimes returning the family to the same environment that caused the difficulty in the first place. Even though a nurse is not in a position to directly help with changes in behaviour that result from her teaching, she has a crucial role to play in helping the parent to organize her/his defenses against negative influences. The nurse can do this most directly by giving active support and assisting the family to meet their goals. It is also vital for the nurse to identify if the parents know about sources of help and support outside the clinical setting. Roden (1987) also stated that the parent who feels threatened by stressors is likely to seek out learning only when s/he perceives that it will reduce her/his stress level. The parent with a high stress level will find it difficult to learn effectively unless the nurse reduces hers/his overall stress level and approaches teaching in such a way that self-esteem is not threatened.
Uyer (1986) stated that a mother must accurately interpret the facts concerning the child's diagnosis, treatment, care, and follow-up, in order to understand and manage her child's illness. In a study of 200 young mothers who brought their sick children to an Out-Patient Clinic for treatment of a variety of minor illnesses Uyer found that 72% of them left the Clinic with incorrect or incomplete information regarding treatment and necessary care for their ill child. Uyer stated that implementation of experimental nursing approaches, such as client teaching and giving the mothers written instructions helped them to feel competent. These mothers comprehension of their sick child's treatment and care improved significantly, when Uyer repeated the measurement, thus demonstrating the value of nursing intervention in improving patient communication and education.

Otterman (1988) described that because the children in her study went through day care surgery their parents had little opportunity to learn the role associated with caring for the child after surgery. Therefore these parents implemented a pattern of protective behaviours in attempts to fulfil parental responsibilities for the care, protection, and nurturance of their child, especially the first 24 to 48 hours after returning home. Most parents in Otterman's study carried out post-operative instructions "to the letter" without any flexibility and identified a lack of information regarding the child's care. This was also true for participants in Finnsdottir (1984) study, of twenty four surveyed parents, 54.2% stated they did not get any information or teaching from the nurses before their child was discharged (p. 42). Even though 78.6% of the nurses who discharged these same children stated they had informed the parents about how to care for the ill child before discharge (p. 26). Finnsdottir stated that even though nurses spent a lot of time and effort teaching parents about their sick child's condition and care, parents did not recognize this as teaching. This inconsistency needs further research, therefore this current study might show what methods are appropriate for nurses to work with parents to further meet their needs.
Multidisciplinary teams have been providing discharge teaching, for example for burned or chronically ill children and their families, in some hospitals'. Berlin (1981) explained that first of all the comprehensive needs of the child and his or her family can be best met through a multidisciplinary, family-focused approach to discharge planning. Each discipline has a responsibility to provide the needed services. Secondly, Berlin stated it is imperative that discharge planning teams have a thorough grasp of the available community resources so that the child can obtain the necessary services and maximum benefits available to him or her. Resources and services vary from community to community; unfortunately there exists in some cities, as well as in rural areas, a gap between the needs of children and the services available. Berlin's third principle of discharge planning was that the child's family should be adequately prepared to care for the child's needs at home. Home care instruction should be initiated well before discharge so the parents and the child feel comfortable assuming the responsibility of the care at home. Finally Berlin (1981) stated that emotional preparation of the child and the family for discharge and long-term care at home is crucial if rehabilitation and treatment is to be successful.

In summary, the literature supports that nurses have an important role in preparing parents for discharge. However we don't know what the parents think are the best ways to receive information or what information they would like to get. Mothers do not always remember or value the information that nurses deem to be "important" and it is possible that the well-being and recovery of the child may be at risk if recommendation are not followed.

**The Parent - Professional Relationship**

Health professionals are coming to understand that the medical view of disease is not necessarily congruent with the client's view of illness (Kleinman, 1977; Kleinman, et al., 1978). According to Kleinman (1977) the illness experience is a socially and culturally located
phenomenon which is labeled, classified, explained, and controlled within the health care system.

The explanatory models used by the western society's health care system are founded on differing hierarchies of health values and beliefs which means that health professionals and their clients may have discrepant viewpoints with regard to clinical reality, and the decision making concerning the family.

Many researchers have documented the difficulties parents experience in learning to access various components of the health care system, and to communicate with professionals (Finnsdottir, 1984; Hayes, 1987; Kodadek, 1986; Robinson, 1985). Much of this struggle can be alleviated through provision of information. The Association for the Care of Children's Health notes that families, across all types of chronic illness, report that inadequate information is the single greatest deterrent to the caring for their child at home (ACCH, 1988).

Knafl et al. (1988) stated that: "As professionals we need to see beyond the child to the parents who are trying to maintain their life at home as well as support the child in the hospital" (p.200). These authors explained in their research that twenty-six of twenty-nine sets of parents said the physician determined the timing of discharge; three parents said the decision was mutual. Nine parents felt their child was discharged too quickly and expressed anxiety about their ability to care for the child at home: "The doctor said he could go home and he [the child] kept saying he had pain. And I felt a little doubtful and was thinking maybe the pain will keep on, maybe the 'Tylenol' won't help him" (p.116). None of these parents explicitly requested that their child stay longer in the hospital, even though they did not feel prepared to care for the child at home, since they did not view themselves as part of the decision-making process. However, this is not consistent with Litmans' study (1974) which stated that the family "in one way or another tends to be involved in the decision-making" (p.501). This given example shows us how helpless and stressful parents can feel at the time of discharge. Knafl et al. (1988) emphasized that the pediatric nurse is in a strategic position to initiate measures that could decrease the stress experienced by parents and enhance their coping ability.
Nurses spend a lot of time supporting parents (Finnsdottir, 1984); however it is difficult to measure the outcome. Ray (1989) stated that of all the nursing roles, the supportive one is probably the least visible. Support involves listening and helping parents and children cope with issues such as the impact of illness and daily care, its impact on the family, sibling reactions, uncertainty regarding illness outcome, and how to re-enter into the school system. When parents are first learning to manage their child's care they often need reassurance that they are responding to situations appropriately. Ray (1989) recommended that the facilitation of children's care in the home and community is a multi-disciplinary, multi-agency, and multi-Ministry issue. She stated that collaborative input from all sectors, including parents, is required for a comprehensive, coordinated, and communicative long term plan.

Knox and Hayes (1984) described that different expectations can result in misunderstanding and client's dissatisfaction with care. Based on observation and experience, Knox et al. stated that discrepancies between parental and staff perceptions of the parental role may be the basis for parent-staff conflict when a child is hospitalized. Interventions can only be appropriate and timely by placing human behaviours in their social context. The clients are considered the experts as they relate their own conception of reality (Oiler, 1982). Parents are the most appropriate persons to respond to the question posed in this study.

In summary, the literature has supported that the nurses role in preparing parents for the child's discharge is important. Parental knowledge will indirectly meet the needs of the pediatric patients who may be significantly affected by their parents' perceptions of the health care encounter. It is important to learn more about parents' experience of relationship with nurses in relation to child's illness. It is hoped that a study such as this one can provide insight into how nurses as health professionals can prepare parents for the transition phase, from hospital-care to home-care.

Summary

In order to establish what is known about parents' experience of caring for their child at home following an acute surgical procedure this chapter has reviewed selected literature related
to the impact of a child's acute illness on the family, including child and family behaviour change, parental perceptions of stresses, and parental coping with hospitalization, the nurse's role in preparing the parents for discharge, and the parent/professional relationship.

When a child becomes ill and is hospitalized, the literature suggests that parents have unique needs and roles as care-givers. A child's illness and the parental reactions to it may affect the functioning of the whole family. Parental support is crucial for the recovery of a child, yet the child's hospitalization may be extremely anxiety provoking especially for the primary care-giver. A small amount of literature exists which supports the premise that the post-hospitalization period may also be stressful (Knafl, et al., 1988; Otterman, 1988) as the parents try to cope with increased responsibility. How families manage the ill child's home care is mediated to a large extent by the receipt of appropriate supports, the nurses are in a key position to prepare these parents. However, the nurse can not assume that she knows the parents' perspectives, or how they experience this stressful discharge-period. The literature supports that parents and health professionals do not share the same view of what is important (Kleinman 1977,1978; Knafl et al., 1988). On searching literature this author was unable to locate a study that focused on parents' perceptions of their experience when caring for their child at home after surgery experience with short term hospitalization. However, the general nursing literature suggests that active participation by parents in providing some of the child's care during hospitalization helps parents to develop confidence in their ability to provide even complex care. When the child is discharged, the parents feel more comfortable because they have performed care procedures contributing to their child's recovery.

Nurses need to know parents perspectives and how parents cope with new responsibilities. Do parent's feel they are well enough prepared to care for their child after short hospitalization? This study was therefore undertaken for the purpose of eliciting parents' thoughts, feelings and reactions regarding the child's home care after discharge from a brief hospital stay.
CHAPTER THREE

Research Methods

This chapter describes the application of the phenomenological method of inquiry in a study of the parents' experience of caring for their child at home following an acute surgical procedure. The implementation of phenomenology is discussed in relation to this study's data collection, data analysis, selection of participants, implementation procedures, and ethical considerations.

The Research Design

The phenomenological approach of qualitative research was used to answer the study's research question. Qualitative research is the method in which the characteristics, attributes and meanings of the phenomena under study are identified, documented and interpreted (Leininger, 1985). Phenomenology is an inductive, descriptive research method which has the goal of collecting data through interviews, describing phenomena, including the individual's perceptions of the human experience and their effect on him or her (Omery, 1983). Therefore, this broad methodological category is useful when studying unexplored phenomena.

The literature review for this study revealed some attempts at understanding aspects of how parents' experience the child's illness process, however, the identified period after discharge from hospital was not well explored. Most of the home care literature was describing parents of chronically ill children. A qualitative method was an appropriate design for this study because it focused on a "human experience from the actor's particular perspective" (Knaack, 1984, p.107). Van Maanen (1983) described the qualitative methods as an umbrella term covering an array of interpretive techniques which seek to "describe, decode, translate, and otherwise come to terms with the meaning, not the frequency, of certain more or less naturally occurring phenomena in the social world" (p. 9).

Phenomenology is also an appropriate method for this study because it is congruent
with Kleinman's framework (1978), as both approaches emphasize that individuals give subjective meaning to the situations they experience in every day life. In applying this approach, the investigator tries to see things from the participant's point of view and thus understand the meaning he/she attaches to the experience (Giorgi, 1975a; Munhall and Oiler, 1986; Ornery, 1983; Woods and Catanzaro, 1988).

Giorgi (1975a) described that phenomenologists emphasize the "lived context" of life phenomena in the everyday world as it is understood and interpreted by the one living through the situation. In this study the parents were the actors sharing their own perspectives of the experience of caring for their child after discharge from the hospital. Giorgi (1975a) states that it is the phenomenologist's task to ensure that the participant's viewpoint of the situation under study is revealed through description in an unbiased way. It is the participant's point of view that provides the "rich data which must be obtained" (Giorgi, 1975a, p.100). Phenomenology depends almost exclusively on language to obtain a description of the experience under study, what the participant feels is worthy of mentioning is registered as data. The researcher accepts the data as they appear without trying to modify them to fit a preconceived definition of the phenomenon (Ornery, 1983). However, a truly presuppositionless description of a phenomenon is impossible because the researcher will presuppose implicitly in the questions and answers of an open-ended dialogue according to the intentions and aims of his or her research (Giorgi, 1975a). The goal of this method is to derive consensually validated knowledge from a systematic examination of a human experience (Munhall et al., 1986). The key criterion is not whether another position with respect to the data could be adopted, but whether a reader, adopting the same viewpoint and situation of the researcher, could also see what the researcher saw whether or not he or she agrees with it (Giorgi, 1975a; Sandelowski, 1986).

The validity in the phenomenological methods is "formulated in light of a client's conception of himself or herself in the world" (Ray, 1985, p. 89). Watson (1985) states that as a human science rather than a natural science, nursing can choose methods that "allow for
the subjective, inner world of personal meanings of the nurse and the other person" (p. 17). The description of how the phenomenological approach was used for this study follows.

**Data Collection**

The processes of data collection and data analysis will be described separately in this text to enhance clarity for the reader. However, it is important to note that it is difficult to draw a line between data collection and analysis in qualitative research (Van Maanen, 1983). Instead, the two processes are intertwined throughout the period of data collection.

The interview technique is frequently used in phenomenology and involves the researcher in several areas of concern. The researcher needs the skill to be a good listener and to know how to encourage people to describe their experience. In order to answer the research question posed by this study, the data collection process consisted of twenty-one interviews conducted by the researcher with the child's primary care-giver. The interviews were designed to explore the meaning of that experience as it unfolded for the participants (Omery, 1983).

Eight mothers who were the childrens' primary care-givers were first interviewed six to thirteen days after the child's discharge from the hospital, in a setting which was selected by them. The interviewees were told that the investigator wanted to hear about their experience, anything that was important to them. However, some of them did not feel they had much to talk about, one mother described her experience at home as "normal mothering".

The interview guide, shown in Appendix C, was used to facilitate the exploration of the general content areas. The guide consisted of six open-ended questions which had evolved from the study's theoretical framework, as well as the review of relevant literature in Chapter Two. For example: what has it been like for you to care for your child after discharge from the hospital? Open-ended questions are designed to create a conversational atmosphere and allow for free expression (Van Maanen, 1983).

Other questions were asked to either clarify what the parents had said or to further the investigator's understanding of a particular aspect of the experience being discussed. The
questions in the interview guide were asked if those particular aspects of the experience were not discussed as a natural part of the conversation. The goal of phenomenology is to describe accurately the experience of the phenomenon under study” (Field and Morse, 1985, p. 28).

It was the researcher’s initial intent to conduct the second interview within one month of the child’s operation. However, when the families were contacted to schedule the second interview, four participants stated that their children were still in the process of being treated for the health problem, therefore the researcher elected to conduct second interviews on the telephone with the care-givers and scheduled a third interview at a later date.

The third interviews were conducted with five participants in their homes between the tenth and sixteenth week after the child’s operation.

The time period, from six days to sixteen weeks after operation elicited parents' immediate responses to the experience, as well as giving them some time to assimilate its impact on themselves and the family. The content of the second and third interviews was drawn from an analysis of the materials discussed during the first interviews, consistent with the analytic method (Giorgi, 1975a). The researcher sought clarification and a deeper understanding of issues initially raised in each interview. Also the later interviews provided an opportunity to discuss new topics that were raised by the parent or other primary care-givers.

To obtain accurate verbatim accounts of the interviewee’s responses the interviews were all audio-recorded, as agreed to by the participants. None of the care-givers commented on the presence of the tape recorder as having any effect on the discussion. There were no requests to either stop tape recording or to erase a portion of the conversation. The tapes were transcribed by a qualified dicta-typist or the researcher. On one occasion it was necessary to record a portion of the parent’s interview as field notes, due to failure of the audio-recorder, which was made from the researcher’s memory immediately after the interview. Following transcription, the interview data were analyzed by the researcher.

When analysing the first interviews the researcher felt she needed further information
about what factors influenced how the family coped with hospitalization, for example did the mothers’ cope differently if who held a full time position outside their home. Therefore, the care-giver was asked to fill out a detailed demographic data form about the child's family (see appendix D). The approach to data collection as described in this section took eighteen weeks.

**Data Analysis**

As previously stated, data collection and data analysis are not distinct phases in a qualitative research methodology. The processes of collecting, coding and analysing data is continued until data collection is complete. Then the final stage of analysis became "a period for bringing final order to previously developed ideas" (Lofland & Lofland, 1984, p. 131).

For the purposes of this research the data were analyzed by the researcher following Giorgi's (1975a; 1975b) five steps of data analysis:

1. In order to get a sense of the whole interview with each primary care-giver, the researcher read through the entire description after the tape had been transcribed.

2. Then the transcript was reread slowly focusing on the phenomenon being researched. A series of "meaning units" were identified and when a transition in meaning was perceived by the primary care-giver it was noted with respect to the experience of caring for the child after discharge. Lofland and Lofland (1984) state that meaning units in qualitative data analysis "are the linguistic categories that make up the participant's view of reality and others' actions ... consciously singled out as important aspects of reality" (p. 71). Therefore, the meaning units describe, define, justify, and interpret behaviour. For example, one of the meaning units identified in the transcripts was fatigue and anxiety felt by the primary care-givers during and after the hospitalization period, related to their child's illness and the mothers uncertainty about the outcome of treatment.

3. Next the identified meaning units were compared to each other and to the whole to eliminate redundancies, clarify, and elaborate the remaining units. The comparative analysis was continued back and forth between the transcripts from the same primary care-giver, and
among transcripts from other primary care-givers. Then the meaning units were discussed with the participant in the second interview while clarifying, expanding, and confirming the data.

4. To reveal the identified meaning unit's contribution to the primary care-givers experience, each unit was "systematically interrogated" (Giorgi, 1975b, p.75). Then the common meaning units were transformed from the participants everyday language into the language used in nursing science. For example, a meaning unit across the primary care-givers accounts was a frequent need to ask questions and seek reassurance. This finding was transformed into a concrete classification called "coping behaviours".

5. In the final step the researcher integrated and synthesized the meaning units into common themes and concepts forming a descriptive framework of the meaning of the primary care givers' experiences.

The analysis concluded with a complete enriched description of the phenomenon's central characteristics (Oiler, 1982) and its communication to other researchers for the purpose of confirmation or criticism. This analytic process occurred on an ongoing way during and after the data collection for this study. The final result of the process was a synthesis of the primary care givers' accounts of their experience when caring for their child at home following an acute surgical procedure into the framework described in Chapter 4.

Selection of Participants

The participants in a phenomenological study must have lived or be living the experience under investigation. Also they have to be interested in understanding and expressing the feelings which accompanied their experience. "Purposive" or "purposeful" are the terms used to describe the sampling technique used in this study (Munhall et al., 1986). In this method, the participants were selected because they had certain characteristics or knowledge which were deemed important in answering the research question. The informants sought in this study were parents of children who had been going through an acute surgical
procedure with short hospitalization, therefore making them knowledgeable about this experience which enabled the researcher to collect the in-depth data.

The approached parents were asked to select who would be the child's primary caregiver at home after discharge from the hospital to be the interviewee. Omery (1983) states: "Because of the length of the data gathering interview(s) and the detail of the complete description, the sample size is usually small" (pp.49-63). Eight mothers participated in this study.

Criteria for Selection

The parent staying at the child's bedside, mother or father, was approached to participate in the study by the head nurse of a surgical unit in a pediatric hospital in an urban area in Canada. The Behavioural Sciences Screening Committee for Research and other Studies Involving Human Subjects required that someone from the agency should make the first contact with the potential subjects. The unit's head nurse identified the parents based on the researcher's sample criteria and told them/him/her about the proposed study.

The sample consisted of eight mothers who all met the following selection criteria, with one exception which will be subsequently explained.

1. Parent of a child that has had a surgical procedure during acute hospitalization.
2. The parent was willing to participate.
3. The family lived in an area accessible to the researcher.
4. The primary care-giver understood and spoke English, regardless of ethnic background.
5. The child was between the ages of one month to seventeen years old.
6. The child had been hospitalized between two to ten days.

Chronically ill children were excluded from the sample.

The third criteria was not met for one family in the study, since the family lived in the northern part of the province. The head nurse approached the child's father and told him about the study, he was interested in participating and signed the consent form before the child's discharge. Because of the parents' enthusiasm to discuss their experience and the fact that this
was the only child who had to go through surgery because of an accident, the investigator elected to include them in the study and to conduct the interviews on the telephone.

Selection Procedures

In order to implement this study the following steps were followed:

1. Permission to conduct the study was obtained from the University of British Columbia Behavioural Sciences Screening Committee and the British Columbia's Children's Hospital Research Review Committee.

2. The researcher met with the Head Nurse of the pediatric unit, to seek her co-operation in carrying out the first part of the project. She was informed about the nature of the proposed study and given a summary of the proposal as well as the sample criteria. She agreed to be responsible for approaching the parents.

3. The head nurse approached potential participants who met the study criteria and informed them about the study. She handed them the information letter about the purpose, nature, risks, and implications of the study (Appendix A). Potential benefits were also outlined in this written information letter. If the parents were interested in participating in the study they decided which one would be interviewed and then signed the information letter. Eight mothers participated in the study as interviewee's.

4. The researcher kept in contact with the head nurse by telephone and visited the unit to pick up the signed information-letters, as well as to keep informed about the dates of the childrens' discharge.

5. After discharge the mother was contacted by the researcher by telephone to confirm her willingness to participate in the study and arranged a convenient time and place for the first interview with her. The method used is based upon participant's being able to interact in the interview. However, as already described, the researcher chose to include one mother who lived a long distance from the hospital and was interviewed by telephone with data limited only to verbal interaction. The reason for including the mother in the sample was that her child was the only child who was admitted because of an accident and the mother was not able to be at
the hospital as she was awaiting the delivery of her second child by Caesarian section. The first interviews took place 6 to 13 days after the child's discharge.

6. Prior to starting the first interview, a written consent was obtained from the mothers (see Appendix B). The father who lived 14-16 hours drive away and signed the consent form before the child's discharge, was not the child's primary care-giver at home, because he worked away and only came home over weekends. Therefore the mother signed a consent form and mailed it to the researcher before the interview was conducted.

7. The mothers decided the time and setting for the first interview. All chose their home environment for the data collection, except one mother who chose the hospital setting because she was staying there with her other sick child, who was also having a surgical intervention. When using the phenomenological method it is essential that the interview take place in a relaxed atmosphere and that sufficient time is allowed for the parent to express their experience (Omery, 1983).

8. The second interview was scheduled within one month after discharge, however, because four participants were still caring for children in active treatment the researcher elected to do a second interview by telephone with these four mothers and postpone the third interviews until between the tenth and sixteenth week after the child's operation. Because the researcher needed more demographic data, mothers were asked to fill out a detailed demographic data form about the child's family before the third interviews were conducted (see appendix D).

Protection of Human Rights

In order to assure protection of the rights of the study participants, this research proposal was reviewed by the University of British Columbia's Sciences Screening Committee for Research and Other Studies Involving Human Subjects and the research review committee associated with the hospital in which the study's clients were contacted.

The study participants were provided with information pertaining to the purpose of the study and the expected time that they would need to devote to the study. The initial verbal
explanation and written consent gave the clear option of participation or nonparticipation without prejudice and that withdrawal from the study could occur at any time.

The researcher obtained informed written consent (see Appendix B), from the mothers prior to commencing the first interview. The written consent informed participants that they could refuse to answer any question, as well as request erasure of any tape or portion of a tape at any time during the study. The consent also informed the mothers that there were no known personal risks or discomforts for participants or their family members. Knafl et al. (1988) state that many parents experience the benefit of being able to talk to a health professional who gives whole-hearted attention to their concerns, this is also the writer's experience.

Confidentiality was highly regarded and access to the data was limited to the researcher, her thesis committee, and the transcriber. Tape recordings were stored in a locked cabinet drawer, at the researcher's home. Transcriptions were coded and all identifying data removed. Transcriptions were stored under lock and key. Participants were never identified with their responses, and their identities were not revealed. Upon completion of the study, all taped interviews were deleted. During the interviews participants' privacy was insured by meeting in a place selected by the primary care-giver.

When the mother was asked to fill in the demographic data form (appendix D) the investigator made it clear that the mother had the option of not answering any questions with which she felt uncomfortable.

Summary

The implementation of the phenomenological method was discussed in this chapter. Data were collected through twenty-one interviews with eight primary care givers, all mothers, who had been caring for their child at home following an acute surgical procedure. Sample selection was guided by a purposive sampling technique. A semi-structured guide of open-ended questions was used for the interviews with the primary care giver. The participants’ rights in terms of informed consent, privacy and confidentiality were safeguarded throughout
the research process. Data analysis occurred both concurrent with, and subsequently to data collection using the technique of constant comparative analysis.

In Chapter 4 the researcher’s represents interpretation and synthesis of the participants' accounts into a description of the meaning of their experience.
CHAPTER 4

Presentation of Findings

Introduction

"What is the parents' perspective of their experience of caring for a child at home after hospitalization for an acute surgical procedure?" The accounts given by the eight participating mothers of their family's experience when caring for an ill child will be presented in this chapter.

Although it was the researcher's original intent to describe the period after discharge, it became obvious that the experience was closely linked to a series of events, starting with their realization that something was "wrong" with their child and ending only when the family's activities and routines returned to normal. This is congruent with Otterman's (1988) and Knafl's et al. (1988) studies where parents expressed their experience in chronological phases, that were closely linked to one another.

The Chapter begins with a description of the participant families. Next is an introduction to the study's analytic framework and the presentation of the participants' accounts of their experience organized according to the structure of the analytic framework. The three phases are: "onset of symptoms leading to help seeking and hospitalization", "the hospitalization, treatment, and preparation for discharge", and "care at home and getting back to normal". The mothers' uncertainty was the predominant feeling state and was created by a number of events and circumstances through the course of the illness period. The characteristics of feeling uncertain and related feelings will be discussed as each phase of the experience is described. These feelings of uncertainty then led to the testing out of various coping strategies, the most common ones were: "managing the health problem", "trusting health professionals", "seeking support", seeking information", "assuming responsibility", "..."
"focusing on child's needs" and "meeting family's needs". These coping strategies will be described at the end of the Chapter. In Chapter 5 research and theory currently available in the literature will be used to examine the current study's findings.

Description of Participant Families

In order to familiarize the reader with the families who participated in this study, their general characteristics and demographics will be described here. As the intent was to interview care-givers, when parents were approached to invite them to participate, they needed to identify who would assume the care-giver's role.

Mothers from eight families participated in the exploration of the parent care-giver experience. All eight families were dual parent families although this was not one of the study selection criteria. In six of the eight families the parents were born and raised in Canada. One set of parents had immigrated to Canada from England, the other set of parents had immigrated from Europe seven years ago.

All the fathers were employed full time, as well as five of the eight mothers. Three mothers were health care professionals and indicated the hospital environment was well known to them. One mother had part time work and two mothers, who had the youngest children, were not working outside of the home. Five of these families had over $50,000 in income on a yearly basis, the remaining three families had between $21,000-49,999.

The fathers' ages ranged from 29 to 47 years (mean 38 years), the mothers' ages ranged from 22 to 45 years (mean 35 years). Two families had three children, five families had two children, and the remaining family had only the one child. Seven mothers had a child older than the ill child, and two of them had previous experiences of having hospitalized their child. The siblings ages ranged from newborn to 28 years old, all the siblings were living in the families home, except the 28 year old.

The majority of families lived within a short distance of the hospital, two others lived within an hour and a half commute that included taking a ferry. The third family lived a longer
distance from the hospital. Emergent themes from the first interviews were the unpredictable or unplanned nature of the event and the support needed to manage these events. It was decided this family's experience would further enrich my understanding of these factors because this was the only child that needed surgery because of an accident. The father took time from work and was the child's primary care-giver while the child was in the hospital, as the mother was awaiting the birth of their second child by Caesarean delivery and could not travel to the hospital. This father, like some other fathers, had several commitments after discharge leading to periods where the mothers' were coping with home responsibilities on their own. Because the mother was interviewed by the telephone the data gathering was limited to her verbal description. There were, nonetheless, multiple similarities in the experiences of this family and the others.

The age range of the children who underwent surgical procedures was from 7 months to 14 years old, their average age was 6 1/2 years old. These eight children were hospitalized for a variety of acute illnesses leading to a non-scheduled admission. One family had another child who was scheduled for a surgical procedure two weeks after the acutely ill child was discharged.

The children underwent a variety of surgical procedures: Four of them had an appendectomy, four needed an operation on the musculoskeletal system, and the remaining child needed surgery because of an internal abscess. The children spent from 3 to 8 days in the hospital (an average 4.8 days).

The mothers reported seven to sixty-three days (average 18 days) elapsed from the time of operation until the children were recovered or without symptoms. The mothers reported that it took the family seven to ninety days post discharge to "get back to normal". For seven of these families, one family was still coping with the results of the child's illness in the last interview, 94 days post discharge.
The Analytic Framework for the Study

It is the intent of this study to present data which will enhance our understanding of the shared aspects of the mothers' experiences. The common themes across all the accounts were woven into major concepts and themes which formed the analytic framework for presentation of this study's findings.

The three phases of the experience which incorporate these events are: (1) the onset of symptoms leading to help seeking and hospitalization, (2) the hospitalization, treatment, and preparation for discharge, and (3) the care of the child at home and getting back to normal. The presentation of the mothers' accounts according to these three phases allows the reader to see the impact of each phase on the following ones, as well as the overall impact on the family's daily life.

Each phase was characterized by different conditions. These included, for example, being believed by the physician, being alone, being separated from the child. The uncertainty associated with the experience was accompanied by characteristic feelings on the part of the mothers. These feelings will be discussed as each phase of the experience is described. As an example, when the first phase is discussed (the onset of symptoms leading help seeking and hospitalization) mothers experienced feelings of uncertainty because of an unknown diagnosis, worry, and anxiety related to not knowing what was wrong with the child. These feelings will be described using the mothers' accounts. The feelings then led to the use of various coping strategies by the mothers and their families. The major coping strategies employed by all parents were: "managing the health problem", "trusting health professionals", "seeking support", "seeking information", "assuming responsibility", "focusing on the child's needs", and "meeting the family's needs".

Figure 2 depicts the identified phases, the predominant feeling experienced throughout the three phases, the conditions contributing to uncertainty, and coping strategies utilized which comprised the process from onset of symptoms to return to normal routines.
Time continuum

from disruption to stability

Phase 1
Onset of symptoms leading to help seeking and hospitalization

Phase 2
Hospitalization, treatment, and preparation for discharge

Phase 3
Care at home and getting back to normal

Conditions contributing to uncertainty

Feeling uncertain

Coping strategies to decrease uncertainty

Managing the health problem

Managing the health professionals

Managing the support and information

Managing the responsibility

Managing the child's needs

Managing the family's needs

Decreased uncertainty

Figure 2. The study's analytic framework "from disruption to stability"
Phases of the Experience

The three phases of the experience will now be described with particular emphasis on the mothers' emotional reactions and how their feelings changed between phases. The coping strategies used by the mothers in relation to each phase will be described at the end of each phase. Verbatim accounts from primary care-givers' interviews will be used for illustrative purposes and to demonstrate how the researcher interpreted and evolved concepts directly from the data (Munhall & Oiler, 1986). The abbreviations used in this chapter to identify the speakers being quoted are M: mother and R: researcher. Individuals who have been named in the text of the interviews will be identified only by their connection to the speaker.

Phase 1 - Onset of Symptoms Leading to Help Seeking and Hospitalization

The first phase of the experience began with the onset of the child's symptoms and ended when the child was hospitalized. When mothers were unable to explain what was "wrong" with their child they all sought professional input.

The amount of time between the onset of symptoms, the decision to seek professional help, and the decision to hospitalize, varied among these families. For example one child woke up at about 4:30 in the morning, the mother called the physician, and the child was hospitalized immediately, while another child had pain for a month before he was admitted to the hospital.

The most common theme from the mothers accounts in this phase was feeling uncertain about what was "wrong" with the child and how to deal with the child's illness.

Conditions Contributing to Uncertainty

The mothers expressed feelings of uncertainty, because they did not know what would be "the right decision" concerning the child's illness: wait, call a physician, or go to the emergency unit. Most mothers were unable to diagnose their child's condition beyond reporting the observable symptoms. They knew that the child was "not normal", something was "wrong", and it was something more than "usual" illness for example, the child's behaviour was different than usual. However, the mothers had difficulty determining whether the condition was serious or not which resulted in feelings of uncertainty. For example one
mother described feeling uncertain about what to do about her child's pain. She decided to go straight to the emergency unit because she could not watch the child suffer. Her reaction to the knowledge about her child's condition and the decision to hospitalize the child was as one of "shock" due to the unpredictability of the event:

M: He's my baby, my littlest one and you don't expect it [surgery] to happen to them .... he was just so sick that he looked so pathetic .... and it happened so quickly, it was about two hours then he was operated on, so it was very quick, but it didn't really sink into me and it was just like I was in a state of shock.

While all the mothers eventually defined their child as needing medical attention, their exact understanding of the situation varied. Most of them sought professional input shortly after the onset of the child's symptoms, or when they realised that they were unable to explain their child's illness. Most mothers got the information about the child's diagnosis and treatment fairly quickly. However two of them had gone to their family physician without getting any specific answers about the child's condition. Therefore one of them decided to go to the emergency unit in a pediatric hospital, where the decision to hospitalize the child was taken with input from the mother:

M: We just thought we were coming over [to the hospital] to check and find out what was happening. Neither of us really thought it was the appendix. The surgeon thought "well maybe we'd better wait and just see what happens". They did a rectal exam at 6:30, it was really, really painful for her, so I don't know if that's what made him make up his mind or not. He said he was 80% sure that it was the appendix, and you know he left the decision whether to go ahead up to me and he knew that he could be going in for no reason. And so they went ahead and did the emergency surgery that evening.

The other mother also kept on searching for the solution to her child's health problem and went several times in to the community health clinic to describe her child's condition. She felt uncertain because she was not believed. The child was brought to the physician four times without getting any resolution of the child's illness, then an observable symptom appeared on the child which led of the hospitalization:
M: He was in pain for a month without any assistance. We were taking his temperature sometimes, even though we knew it wasn't that, but we just thought "there is something wrong" and we kept taking it [temperature] and there was nothing there, and I had been in to the doctor quite regularly saying "something's wrong with him" and they never even noticed the abscess and I change his diaper a million times a day and it was just never there and then I saw it "I couldn't believe it".

R: Then you noticed something on his bum, can you describe that?

M: Yes, all of a sudden after about a month he just sort of got a little bit hard thing on his bum, but it was hardly noticeable. I took him in [to the physician] they phoned ahead to the doctor at [hospital] and they set up time for an ultrasound and I talked with them and they said "to keep phoning if it got bigger". And I kept on phoning saying "it's getting bigger" and "it's really big". So I took him in [to community physician] within four days after it first appeared and it was the size of my fist and it was purple blue spot. They [community physician] said "he's going for his ultrasound in about 4 days" and I said "I don't think we can wait" and I took off the diaper and they couldn't believe how much it had grown in 4 days so they sent us to the hospital. This mother's experience of feeling uncertain before the hospitalization lead to her feelings of uncertainty after discharge, which will be described in the third phase of the mother's experience.

Another factor contributing to the mothers' feelings of uncertainty during this phase was the unpredictability of the event. When a child was brought to a physician or the hospital, the unpredictability regarding the course of the illness event and not knowing what to expect, influenced the mothers' experience of uncertainty. Here is an example of mother's description of how quickly their situation changed, without any preparation for her or other family members:

M: We were at the doctor's clinic in [home town] at 11:30 and we had to be at the ferry by 12:00 and I had to get my other child, arrange for someone to watch her - and - get myself ready and we didn't know we would be staying overnight - we ended up staying five days - so like - we were not prepared at all.

In this quote the concern for the ill child extends to other family responsibilities as the domain of care is moved from the home to the hospital.
Domains of Uncertainty

The domains of the mothers' uncertainty in the first phase were mainly focused on the impact of changed parental role, the illness on the child, and how the hospitalization would affect the other children at home.

All the mothers described how their parental role changed. Most of them felt increased responsibility without enough preparation or knowledge which influenced their sense of uncertainty. Not knowing how to deal with the health care system was one aspect that contributed to feeling uncertain for some mothers. It was evident that the younger mothers, who had not had any past hospital experience and who were not themselves health professionals, had difficulties in accessing the service they needed. This impacted on the mothers' feelings of uncertainty about how the illness affected their child. For example the major motivator behind one mother's persistence was that her child was suffering and she did not know how to resolve it. After the fourth visit to the health clinic the child was admitted to a pediatric hospital.

M: [Child] had cried basically straight for a month before hand and then once that morning, without any food or anything [preparing for possible surgical procedure], he pretty well cried the whole way into [hospital] .... he was in a lot of pain and then once we got there he cried the whole time in the hospital and until surgery.

This prolonged illness period contributed to the mother feeling uncertain about her own ability as a mother. She got different answers from the physician each time, like he is "teething", "spoiled", or having "a personality change".

Some mothers felt uncertain about how the hospitalization would affect the ill child's siblings. In spite of the unscheduled nature of their childrens' admissions, some mothers had made some sort of arrangements for the care of siblings within several hours of the hospital admission. In four families, mothers' had anticipated or expected the hospitalization and had thus made contingency arrangements with a relative or a friend to care for siblings. One mother described how difficult the sibling's experience was and that made her feel uncertain
about how she dealt with the situation, she felt guilty not to be able to meet the needs of both her children:

M: [sibling] was shocked at first, he didn't quite understand what was going on and how serious it was, but he did say to me, "You lied to me mom, you said you were coming right back after you took him to the doctor". I said: "Well I didn't know he was going to have to stay in the hospital", "well, still you lied to me you didn't come right back I was waiting for you" and this made me feel awful ....

The time before hospitalization was a difficult time for some siblings. This lead to feelings of uncertainty for the mother about the best way to manage all her responsibilities and not being able to focus equally on her children. One mother described how very disruptive the family life was before admission resulting in anxiety for her other child (2 1/2 year old):

M: My husband was away for two weeks straight while this was all going on and [child] had been crying a lot. One day it got so bad that I just phoned my mother-in-law and said "can you take him so I can do something with [daughter] just so we can sort of have some time without hearing him cry".

This mother said her healthy child was showing behavioural changes which contributed to her feelings of uncertainty about the best way to handle the situation and guilt because the mother had not realised how difficult this was for her other child. Not being able to plan, anticipate, or not having anyone providing suggestions contributed to their feelings of uncertainty.

The mothers were often uncertain about what to do, and because they felt they should know what to do, some of them felt guilty. Not knowing how to deal with the guilt was difficult, for example this mother describes her situation:

M: The thing was that it was an accident, that it had me really upset because I was with [child] at the park and she was so mad at me because I usually catch her when she comes down off the monkey bars and I wasn't with her to see this happen. All that day she kept saying: "Mommy, you weren't there to catch me",
The mothers feelings of uncertainty resulted in related feelings of "anxiety", "worry", "stress", "guilt", and "fear". Some mothers stated these feelings of uncertainty were so strong from the time of the first suggestion of hospitalization until after surgery, that they "could not think about anything else".

One mother stated that she was feeling more uncertain during her child's second treatment because the previous treatment had failed. She described how thankful she was that she had asked her community physician to get a second opinion from a pediatrician about her child's condition:

M: well - it's hard [to manage], and the fact that it had to be done twice [reworked on broken arm] makes it more difficult. The thing was - they had told us here [community hospital] that it could straighten itself out in five or six years. We might have taken that information - you know - if we never had looked into it a little bit more and questioned the doctors here. He [community physician] would never have sent those x-rays and we would have .... Here's our three year old going through life with only 45 percent use of her arm and we're not too impressed right now with the services, or that kind of stuff here. My husband and I have both said that if anything ever happens to us again - we won't hesitate to take them [their children] to specialists, we won't go through this again.

This mother was feeling responsible for her child's accident and the unsuccessful treatment. She was feeling uncertain because she had difficulty getting appropriate medical care for the child and expressed her concerns because the child had to undergo anesthesia three times.

**Coping with Uncertainty**

To reduce mothers feelings of uncertainty in this first phase the mothers focused on coping with the health problem right from the onset of the symptoms in order to manage the illness events. When usual home remedies did not work the mothers sought professional help and kept on being persistent until their needs were met. The mother who kept on persisting because she knew that something was "wrong" with her child is a good example of how mothers can cope when they need to do it for their children. This mother went four times over a one month period to the physician who did a thorough physical examination each time, but did not find anything wrong. The child kept on crying and she let the child cry when she was
in the health clinic to give the health professionals an opportunity to see how the child was feeling. Then she asked the child's father to "bring him [child] in" because "the physician did not take notice of her description". The father was told that the child (a seven month old) "was going through a personality change". The mother was feeling uncertain and kept on managing this event until the child got the service he needed.

The mothers' sought information from professionals about what could possibly be wrong with their child and they sought information about what they could expect as an outcome of the child's illness. They used the information they gathered to inform their husbands, the siblings, and others who also were worried about the child.

The decision to hospitalize the child was made by the family physician, or the emergency physician, in all cases. However three mothers had strong influence on the decision.

Further description of the coping strategies which the mothers used are presented in the end of this Chapter.

Phase 2 - Hospitalization, Treatment, and Preparation for Discharge

The second phase of the experience began when the child was in the hospital and ended when they were discharged. The parents decided with the child's admission to hospital how much time they were going to spend there. Six mothers cared for their child in the hospital all the time. One father took time from work to stay with his child because his wife was having their second baby. One couple took turns from work to be with their child, because the mother worked 12 hours shifts four days in a row and could only take two days off in a row. Therefore parental care was provided for most of the children night and day while they were in the hospital (3 to 8 days). The child's age or condition did not affect how much time the parents' spent with the child in the hospital. One typical description from a mother was: "I stayed in the hospital and I did his care, there was never any question about that....".
Conditions Contributing to Uncertainty

The conditions contributing to uncertainty in the hospitalization phase which influenced the mothers' interpretation of their experience were primarily related to not knowing what to expect due to lack of experience and/or unknown outcome of the child's operation and treatment.

Some mothers felt uncertain because of the lack of time to prepare the ill child before hospitalization and surgery. When mothers were explaining their experience they felt uncertain about how the illness and operation would affect their child. For example when this mother was asked about the child's preparation she said that the staff did not inform her child about the operation nor what to expect. The mother did not blame the staff and said "I guess because it was so quick or maybe somebody [a nurse] took a break":

M: [child] was not prepared [for the operation]. She didn't know, I did some teaching with her as far as what to expect when she wakes up and that's it. She said "no way, I'm not doing it", she wasn't gonna have the surgery. I told her there wasn't a choice, and I just told her that I would stay and she wanted her father to come over too. She was really scared. By the time she found out that she didn't have a chance. He [physician] told her at 6:30 and she was in the operating room by 7:00.

The surgical event contributed strongly to the mothers' feelings of uncertainty as did the expectations that parents would be participants in the decision to have the surgery or not. For example three mothers found it difficult to decide to go through with the surgery "if it was the right decision" on the behalf of the child or not. Two of them had experiences of having been misinformed by physicians in the past which impacted on their feelings of uncertainty because they did not know who to trust. Two mothers talked about the risks involved in a surgery, although they found it difficult to discuss. One mother did voice her fears about the risk of death:

M: He was just so sick that he looked so pathetic and I just kept thinking I know it's only appendix but you know people die from appendix and I was alone because it was late in the evening and my husband was home with our other son.
In this case the mother was feeling uncertain about the outcome of the surgery and the associated fear was magnified by being alone when separated from the child.

Some mothers described how uncertain they felt when they were physically separated from their child during the actual operation and while waiting for the outcome of the operation. One mother described her experience in the hospital like this:

M: When they took him - I was the one who was upset not him .... It was awful - more than ever - it was very bad. I was crying. I was really upset. And um - I stayed over the first night - but I couldn't handle it any more - so I just stayed during the days. But they were long days. They were long and tiring and um - I don't know. Um - they [the days] were just - it was - it was stressful.

The mothers also thought watching the child experience pain and being unable to meet the child's needs contributed to their feelings of uncertainty because they did not know what to do for their child. They tried to nurture and comfort their child, read them a story, or get them to relax. The mothers expressed their need for support and understanding as being important while the child was in the operating room.

Domains of Uncertainty

For most of the mothers the domains of uncertainty of the hospitalization were: figuring out the parental role, being there for the child, and being responsible.

Figuring out the Parental Role

Most mothers were uncertain about how much they should participate in the child's care. After a few days in the hospital the mothers' conflicting roles influenced their feelings of uncertainty, because they did not know how to divide themselves between the ill child, other siblings, their work, and other family responsibilities. The mothers described how they became exhausted because they were focusing on the child and their own basic needs were not met. They described that the staff did not provide parental care, for example, nurses did not ask mothers if they would like to take a break.

A mother described her difficulties when caring for her child in the hospital even though she felt confident about her own caring ability; the environment and the child's
behaviour influenced her feelings of uncertainty. She described how stressed she was because her child refused to be cooperative in the hospital. The child was feeling pain when moving, therefore the mother was having difficulties in implementing the child's care:

M: She [child] is quite stubborn and said "don't touch me". She would not speak or let me touch her. The nurse would not be able to turn her around because she would start spinning. I was trying to calm her down, read her a story - nothing would work - and then - there was an older girl next to her and she was watching T.V. and there were cartoons and all of a sudden she started relaxing and moving her arms, because before she would not just move it so every time the physiotherapist came - she would turn the T.V. on and while she was putting [child] on the chair, she would just sit up .... that helped me to go through all the kinds of things, she didn't want to do .... and to cooperate with the nurses and specialists who just cared for her .... At this time I could do anything - almost ....

An example about the dilemma that the mothers faced was that they felt their caring responsibility but they needed to read the staffs' expectation of how they should fulfil their role. Some mothers were thinking "when ever I am here a nurse hardly comes in to the room", even though mothers knew the nurses would care for their child while they were away, this thought had impact on them. The mothers' experiences contributed to feeling uncertain about the expectations of the parenting role in the hospital, therefore they took cues from the nurses and watched what other parents did. One mother described her feelings of uncertainty about not being able to fulfil her role:

M: When parents were not allowed in as much as they are now they had to go home by a certain time and weren't allowed to spent the night and even the nurses had to care for the parents. I don't know if that's better or worse but at least it made the parents go home and rest and I think that's good but on the other hand with staff shortages, you want to have the parents there to care for the kids you know there's not so many nurses around but then it makes you wonder what they're doing. The parent - if the mother or father is drained from being every day in the hospital with this child caring for him, they can't very well care effectively at home by themselves. You know - okay there's got to be a break sometime.

The demands on her as a parent "to be there all the time" was too much for her, however she felt very guilty for not being there.
Being in the Hospital for the Child

All the mothers believed that it was appropriate and even mandatory to be with the child all the time. Most of them felt confident in their knowledge of how to care for their child. But some mothers felt uncertain about the on-going events, they did not know what was expected of them in relation to the child's technical care or its treatment procedures. For example, they did not know if it would be alright to walk around with the IV pump and how to manage the pump. They said that by asking the staff they got the information they needed. The mothers stated that the staff expected them to care for their child and that was their own will as well, but they needed a break sometimes. Three mothers stated they did not feel relaxed when they went down for lunch, they felt they "had to hurry" as following account illustrates:

M: The only time I ever left him was when I got some sleep, and I'd run downstairs to have lunch, then run back upstairs. I think there's only one time he woke up and I wasn't there. I didn't feel like I was able to leave him, I felt like I had to be there all the time. I didn't think that they[nurses] really made me feel that way, but they never once said "We can handle it" and it was the week before Christmas. I needed to leave, but I didn't want to leave him. I did have other things to do and it would have been nice to know that it was okay for me to leave the hospital for 2 hours, and my goal was to get out, but I never even went out the front door for the whole 5 days we were there. I only left his side when I would get him to sleep first and I would tell the nurse I was going for lunch and they kind of "uhu" [the nurses just said it was okay to go, but the mother liked to get conversation]. The only thing I think they could have done that would have made me feel better was to let me know that I could go. But because I was always there I guess they felt I was okay. The nurses came in and just did their thing, their medical part and left. I didn't feel like if he woke up from his nap and needed something that anyone was there for him. I'm sure they would have filled in, but I didn't feel like .. I sort of felt like I had to always be there that they didn't listen enough. My husband kept saying "you can leave, what would they do if you just went home tonight then they'd have to do it" but I didn't feel like they wanted that then they'd have to do it but I didn't feel like they wanted that at all.

The siblings at home impacted on the mothers feelings of uncertainty in the hospital, because they were leaving their other children at home, and often they had to leave in a hurry without preparing the children. Most mothers felt they could fully or partially delegate responsibility for caring for siblings as they gave priority to the ill child. They believed that siblings could temporarily adapt to reduced attention from parents if they had a suitable
substitute care-giver while the mother was in the hospital. This mother's account describes how badly she felt:

M: I had to leave [sibling] with my neighbour and rush to the hospital with [ill child] and I was crying because I didn't know what was going on and she [sibling] was upset because I said "you have to stay with [neighbour]" and she was afraid because I was crying, and I said "[ill child] got to go to the hospital" and she didn't understand that so I kept phoning her and she did okay. Her grandparents said she was really good but at night she cried because she worries about [ill child] and I felt badly about leaving her.

The staff did not do a family assessment before the child's discharge and when the mothers were asked how they were prepared for discharge, for example, about the child's possible behaviour change the issue had not been discussed. One mother described her point of view:

M: No they don't ask anything about how you are going to manage the home life or if you could get time from work. I guess that's where their job ends, but there is a whole process after he gets home, all these "little things" become complicated.

Decreased sleep in the hospital affected the mothers' ability to feel they could manage all of the events associated with the hospitalization especially when there was so much uncertainty, because they felt they needed always to be ready for the child.

Feeling responsible

Feeling responsible for their child's care and the lack of fulfilling own needs led mothers to feelings of exhaustion. One mother described her experience in the hospital for more than a week:

M: I was there for seven days and eight nights .... I didn't get much sleep. You don't get much sleep if you are in a strange place - not to mention the hospital - not to mention the sick kids .... and there is more [people] in the room. But I was fine until I got home and then I was so tired ....you know - you kind of go beyond what you can do and if you can go for a long time - it was you had to. I had to in the hospital and nothing really bothered me - but when I got home - you feel - just you can't go any longer.

This mother was feeling uncertain about her ability to care for the child after discharge because she had already used up all her energy.
How to manage multiple responsibilities resulted in feelings of uncertainty for most of the mothers. A mother who had to attend her work said she felt uncertain and then guilty about not being able to be with her child all the time, and thought there were a lack of understanding from the staff point of view. Because when she phoned to ask about the child she only got short statement that "he is okay", but she liked to know if he had eaten anything and how he was behaving.

The older mothers and those who had experience with hospital life did not feel tired but stated that the hospital period was not too bad for them. However, the change of their daily life and their work responsibilities contributed to their feelings of uncertainty, because they did not know if it was possible to get some time from their work. One mother said that hospitalization was just one part of her role as a mother:

M: You always worry about the children - it doesn't matter what they do - the anxiety is always there - I mean - I have a daughter who is grown up and has two children of her own - and we still worry about her .... it's just the way it is when you're a mother.

R: Could you explain this further?

M: I am use to it [hospitalization], I have experience from my oldest daughter who was often sick and also my younger son .... It has become a part of our daily living, it is not an exceptional thing [to admit a child] this is normal mothering ... also I am not that kind of person, - not too worried - just tired.

Some mothers expressed feelings of uncertainty in regard to their child being ready for discharge when the physician ordered. They felt increased responsibility and some did not know if they were well enough prepared to care for their child after discharge. One mother described her experience this way:

M: .... If I had brought [child] home two or three days before I don't know if I would wake up if she called me -you know - you kind of go beyond ..... and [child] had trouble here [in the hospital] with oxygen, she didn't want to breath on her own ....as soon as they stopped using the oxygen -she would go very low in saturate the oxygen - so they [physicians] had to keep her on the oxygen for three or four days ..... they [physicians] wanted her to go home but she was not really ready .... and I asked if she could stay for another day ....
because I didn't feel comfortable taking her home - because she was not of the bed yet...and that was OK.

To keep the child for one more day made all the difference for this mother and her family and made her experience positive. She was really happy with the outcome of her child's surgery and nursing care.

The overall experience of the second phase, the hospitalization period, was contributing to feelings of uncertainty because of unpredictability and unfamiliarity of the events leading to use of different coping strategies.

Coping with uncertainty

The most common coping strategies the mothers' used during the hospitalization phase were: trusting health professionals, seeking support and information, and focusing on the child's needs. The mothers assumed their responsibilities in the hospital, home, and work arenas differently during their child's hospitalization. However, all believed it was important that the hospitalized child needed to be attended for most of the hospitalization time by one or both parents, which necessitated certain changes in family life.

The mothers believed that by interacting with the health professionals they acted in their child's best interests and shared their goal of returning the child to normal. These mothers coped with the uncertainty by focusing their attention on a set of tasks and learning the skills they needed. They sought support from the nurses to strengthen their ability to perform health-related tasks which increased their confidence. For example, a mother who was caring for a child using oxygen, learned about oxygen treatment to overcome her uncertainty and become confident in herself as the child's primary care-giver. The mothers participated in the child's care to become more confident in their own knowledge and ability to be able to meet the child's needs properly after discharge.

To assume increased responsibility was one of the coping strategies the mothers' used in this phase to meet their child's needs. They participated in the decisions that needed to be taken. Three mothers perceived that responsibilities related to decision-making about the
child's illness and treatment were added to the usual parenting responsibilities. Some mothers stated they were afraid to do something wrong, and that it was difficult to take care of their child when it was experiencing painful time in the hospital. These new responsibilities required role adjustments in order to enact them and resulted in "role strain" characterized by feelings of worry, anxiety, and guilt (Algren, 1985).

Further description of the mothers coping strategies are presented at the end of this chapter.

**Phase 3 - Care at Home and Getting Back to Normal**

This phase begins when the child is discharged from the hospital and ends when the family life is back to normal. Seven to 63 days (average 18 days) went by from discharge until the children were recovered or without symptoms from the mothers' point of view. This time period varied depending on the child's diagnosis, some of the children were still treated after discharge, for example wearing a hip spica. Seven mothers stated that it took their family life from seven to 90 days from discharge to get back to normal. One family was still coping with the results of the child's illness in the last interview, more than 3 months after the operation.

When the children were discharged from the hospital most mothers had been there all the time and felt relief that this period was over, but they felt uncertain about how they would manage the responsibilities of the child's care at home.

The extent to which family functions and tasks were changed for the families participating in this study varied in accordance with the child's diagnosis, family characteristics, and coping abilities.

**Conditions Contributing to Uncertainty**

The conditions contributing to the mothers' uncertainty was that they had to take total responsibility of the child's care at home. In addition some husbands were working away from home over the week, therefore limiting their possibilities to participate in the child's care and the family life during the week.
Also some issues that have been presented from the onset of the child's illness and hospitalization influenced the family's conditions after discharge, for example the child's and siblings' behaviour changes.

Uncertainty during the third phase, at home post discharge, was not as overwhelming an emotion as it was during the other two phases. However, it was present and became obvious at specific times. The main reason for mothers' feeling uncertain was related to managing the disruption on family life, including changed behaviour in some family members and returning household tasks to normal routines. The mothers felt uncertain about their own condition because they had put their own life "on hold" over the hospitalization period. Many of them were exhausted and needed time to rest, to be able to meet the demands of their work and family life.

The ill child's behaviour contributed to feeling uncertain for some mothers; they were not prepared for behaviour changes and did not know how to deal with it. The mothers of the youngest children described that their child had been "spoiled" at the hospital:

M: [child] was longer in the hospital because he had an IV, he had been ready to come home sooner. He was used to having everything done for him and liked having all the attention and I guess because everybody came and brought him stuff and just he was kind of spoiled. I didn't like him to go all over me and it took about a week until he had settled down.

The families whose children were immobilized because of casts, and therefore unable to do activities of daily living, had more difficulties coping with the change factors than families with children going through, for example, an appendectomy. One mother described her experience as very time consuming:

M: It has not been too complicated, but it has taken all my time and energy so I have not been able to do much more. He [child] has been spoiled at the hospital and likes me to play with him all the time and when he is tired I have to hold on to him ....Everything is difficult. The fact that he can't stand, that he can't walk, that he can't bend, he can't sit, he get's angry because he can't move as he is used to because of the cast.
This mother has less ability to perform the activities of daily living because it was not easy to bring the child with her, for example to get the groceries. She describes how she brought the child in to the physician for his check up after discharge:

M: we rolled him up in a blanket and then laied him out flat [in the back seat of the car] and strapped him in both seat belts.

Lack of information contributed to the mothers feelings of uncertainty. Three of the mothers had been dealing with unanswered questions when the researcher interviewed them one week after discharge. The things they needed to know were "all the little things" that they did not think about in the hospital, for example the child's bed at home was not as suitable as the hospital bed. They found out that they had to re-schedule how to perform the activities of daily living with different circumstances than in the hospital and needed practical information:

M: They [nurses] never mentioned to me that the leg that is in the cast - that it's so important to tuck the diaper in there because - what happened - is it [poop and pee] ran down through the cast so that his foot and cast was wet - and I didn't know that this was really important ....and the cast is getting smelly....and I didn't have the tape to re-tape the cast [for cast protection].

This mother was also trying to cope with uncertainty because she was not told how to use a Bradford frame or what she could expect when using it. She was told in the hospital where she could rent it, but she did not know how to use it and did not get enough instruction. She was really concerned and upset that she had not known that the child could slide down in the frame:

M: When you are using the Bradford frame and you strap them [child] in - I didn't think that they would really go anywhere. But [child] was crying a few times, -and it seems as if they slide down they get it caught around the neck and then they get stuck. Lots of times. This is happening over and over and over - and nobody ever mentioned that to me that they could slide down and I made it very tight so it shouldn't go of - like I don't even use it any more because of this.
The mothers in this study described themselves as tired after being with the child in the hospital and participating in their care. They did not meet their own personal needs and kept on sometimes longer than they could, because "you had to keep on". One mother described how tiring it was caring for two children who went through a surgical procedures. The mother was surprised that caring for the five year old in the home after discharge was easier than caring for a fourteen year old. She was not prepared for that even though the physician told her what she could expect before they were discharged:

M: Well, I thought it was going to be easier with [14-year old son] because - he could tell what hurts and stuff - but [5 year old daughter] was fine the second day after we came from the hospital, but he has been miserable for a month .... And he is six feet tall so it was very hard on my back and everything, and we didn't sleep through the night. He usually woke up every two hours. He needed some comforting or pain killers or something. So the first week - just through the Christmas and until New Years - it was quite tiring - but - he didn't need me that much during the day - just to turn him - and kind of read him a story and stuff.

One type of uncertainty resulted from the siblings' behaviours. The mothers did not know how to react when the result of hospitalization was behaviour changes in the siblings:

M: The kids were a little bit miffed at the attention she [ill child] was getting. I sort of wish that we had brought them in to visit her at the hospital - you know - even though it was an excursion, but because they were - kind a upset .... Jealous, I guess.

For the older siblings the main reason was jealousy, but younger siblings had symptoms of separation anxiety, because the mother had been away for too long:

M: When I came back home [sibling] was kind of strange - I felt she just wanted to be with her father all the time, she didn't want to be with me. She said a couple of things - and a couple times when I left to go somewhere she'd say "where's [ill child] going?" She really worries and any time we'd go for an appointment she likes to go too. I suppose she gets upset because she thinks we are not coming right back that day. When I got home from the hospital she was not very good either. I said "was she like this when I was away?" .... and they said "she wasn't" but she was for me and I didn't want to get mad at
her but then I didn't want her to just totally walk all over us so, but she was alright. She was kind of unsure about her self but she got over it.

The impact of family events other than the illness experience also contributed to the mothers ability to cope. For example a mother described her experience with many stress factors limiting her ability to get easily back to normal. She was having her second baby by Caesarean section, at the same time her first child has been injured while playing, and her husband is working out of town aduring weekdays. This mother has many stressors influencing her state of wellness, and she was feeling tired:

M: She [child] was a little bit uncomfortable with the arm and that - yeah .. I'm still having to do everything for her .. you know - like in the bath and washing the hair and even to pull her pants down to go to the washroom.... So her whining and her wanting that extra attention with her arm is probably also due to the new baby being brought home too .... and it's twice as bad because my husband works out of town - so I'm here with the two kids sort of thing .... he [husband] comes home on the weekends.... I'm getting by doing things. There's lots of things that aren't getting done because you have to basically leave them, so it's quite the load right now for me. You know - I am finding it hard.

When thinking back most mothers did not find their overall experience of the care at home after discharge too difficult because they had enough support.

Coping with Uncertainty

The mothers found that one of the best ways to cope with feeling uncertain after discharge was to seek information about what they did not know or were unsure about. Some of them sought this knowledge from health professionals they knew, but most of them asked the physician at the first post-discharge appointment, but sometimes this strategy failed. For example, one mother thought her child could not take a deep breath, and was going to ask the physician when they went for the first appointment. However, when the researcher asked about the outcome in the second interview, the mother had forgotten to ask the physician because she had been waiting for 3 hours before she got to see him.
The mothers described in the interviews how they sought support, both for them personally and for helping them to provide the child's care, and to meet the needs of other family members. Talking with one or more members of a trusted support network provided them opportunities for testing reality, and to obtain valued feedback. For seeking support the mothers preferred to use several persons to help them to cope with the child's illness and other responsibilities effectively.

Some mothers felt uncertain about their own strength to keep on after discharge because they felt tired or exhausted which contributed to their feelings of uncertainty at home. Most often other family members took over some of the mothers' household tasks to help them get back to normal.

When asked if the nurses did some kind of family assessment before they were discharged, to see if they had the support they needed to help them to cope, the mothers did not recall that had been done and one mother said: "they don't look at caring after discharge as their responsibility".

When the child was discharged their ultimate goal was to get the family life back to normal, which they coped with mainly by using the coping strategies described in the next section of this Chapter.

Coping Strategies

The coping strategies were related to the kinds of uncertainty the mothers were dealing with in each phase: - onset of symptoms leading to help seeking and hospitalization, - hospitalization, treatment, and preparation for discharge, and - care at home and getting back to normal. Several coping strategies were identified which all of the mothers used during their experience: "Managing the health problem", "trusting health professionals", "seeking support" "seeking information" "focusing on child's needs", "assuming responsibility, and "meeting family's needs". 
Implicit in the mothers' accounts were a set of goals related to the three identified health
problem periods: These were: (1) ensuring that the ill child was properly cared for, (2)
maintaining family-life, and (3) getting back to normal. This delineation will include
information about when the strategies were employed, and how they worked.

**Trusting Health Professionals**

To trust someone generally means having confidence in that person. Trusting those
responsible for their children's health was a very important coping strategy for these mothers.
It enabled them to feel reassured that their ill child was being properly cared for by the health
care professionals and they were able to maintain a somewhat optimistic outlook. Most study
participants expressed a high level of trust and faith in their physicians. Two mothers had
negative experiences before this hospitalization with the physicians in the community hospital.
But even though this coping strategy did not work for the community hospital they seemed to
be able to put these experiences behind them when their child was transferred to the pediatric
hospital. In fact, some of them expressed relief at having their child at the pediatric hospital
because they had confidence in the health care professionals working there. This evaluation
may have been based on a contrast with the sometimes negative experiences at the community
hospitals and/or a need to trust in those ultimately responsible for their child's welfare. They
related their stories of negative encounters with their home physician but it did not affect their
ability to trust the specialist.

**M:** You see, I live up here [out of town], and um the medical system isn't as good
as say - down town - the doctor is not as good .... basically - and so, once I
got to [the hospital for children] um - I felt quite relaxed, because, even when
she [child] was having the surgery, I wasn't that concerned, really. Because I
knew - you know, the worst thing that could happen would be that she would
have a cardiac arrest or that she would haemorrhage or something, but I knew
that they would be able to do something, because there is all the pediatricians
there - do you know what I mean?

**R:** You trusted them?

**M:** Totally. Yeah. Whereas if it had been up here, I would have been very, very
anxious.
By trusting the health care professionals this mother was able to relax when her child was in their care. Trusting the health care professionals was particularly important when the child was hospitalized and the mother had to relinquish most of her control.

The common qualities that the mothers looked for in physicians included: demonstrating genuine concern by spending a lot of time with the families, being honest in answering questions, and preparing them for upcoming events by sharing relevant information.

One mother expressed how she coped with the fact that she was not believed by the child's physician. She had limited trust in the community physician because she got wrong information about another health problem, which would have damaged the child's sight, if she had not taken the child to a specialist. It also impacted on her coping that she did not get a solution about her child's present illness. She knew she needed to be able to trust the health professional, therefore she persisted until she got service from a pediatric specialist.

M: I think sometimes it's hard for them [for physicians to diagnose] because they didn't see it [the child's symptoms]. The mothers are with them [children] so much that they can feel it or see that something is wrong. It wasn't a gradual change, it happened - he was great and then he was terrible. I really think they [physicians] could listen to the mothers a bit more.... We went to the doctor about 4 times in about a month. I took him 3 times and I said something's with him and they kept saying "he's teething" and this and that and then finally I said to [my husband] "can you take him in because I think they don't believe me". So he took him to the doctor and he told them everything and the doctor said "It looks like he just having a personality change. He's gone from being a content baby to not so content". But my husband was telling him, it's not just that, he just wakes up about 12 times a night about every half an hour and he didn't want a bottle or a soother or anything and he just kept crying.

This mother did not know how she should cope with this health problem, but she kept on being persistent, and she asked her mother to take the child to see if the child's behaviour would be different, which it was not. The child kept on crying, it was not admitted to the hospital until an abscess was apparent on the child'. When the child was assessed by the hospital physicians they did not believe the mother and she felt badly about their lack of trust in her description:
M: These doctors [in the pediatric hospital] said that they had never seen an abscess this big on a baby and also it was really rare to get an abscess like that, they never see that and also they almost made me feel like - it was my fault - my Mom said: "They don't believe us, they think we're lying", because when they came out they said "I can't believe that this just appeared 4 days ago" and honestly I would have been the first one in if I'd noticed it. And they said "well we can't believe that he hasn't had a fever" and I said well he has never had a fever ...."they said "we can't believe it", then I woke up my Mom and I started to cry and said "I think they think that we just waited till the last minute to take him [child] in".

The mothers described their interactions with the nurses as being positive which included: they got their questions answered, got good explanations about the child's care, the nurses were supportive, and helpful. However, the mothers felt the nurses expected them to provide the child's care all the time. However, this was an area of ambiguity. The mothers never directly asked what was expected of them but observed what other parents did and read the nurses' cues.

One example of how a mother had to cope with dividing herself between her child and her work responsibilities:

M: It wasn't easy. It was always a fight to get time when you're on a limitation to be off but my manager was very good, she understood. So it was awkward and I had to juggle trying to get my husband to get time off to be with him [child] because I didn't want him to be alone for a whole day. I guess that he would have been able to, but I think that the staff there frowns upon it and the two days that I wasn't there he was acting up a little bit and one of the nurses said "because you weren't here" and I thought thank you, blame me, you know I mean Jeeze they've got it made, all the mothers do all the care on their children and they don't have to do anything, just get all the pills. But you feel guilty, but then he was fine, they have so much activity for children so he really didn't need me there. I didn't really need to be there but you felt like you had to be there and the whole eight days he was in there my whole life was everything devoted to him. And I was worried when I was at work wondering how he was doing because his temperature would go up and they had to put him off the antibiotics and it didn't start coming down for about three days after so I was phoning to asking how he was and they'd say "ohy, he's fine" but that's not telling me anything....

This mother felt the nurses needed to take her personal situation into account to ease her feelings of uncertainty and provide a family care.
Seeking Support

This section will encompass the theme of support networks that mothers relied on for assistance during the three phases of their experience. The mothers shared aspects of their experiences which they perceived as both supportive and non-supportive. Such aspects included interactions with family members and health professionals throughout all phases of the experience.

Two mothers described one particular health care person who seemed to be most trusted and sought out for support. This did not appear to be a generalized phenomenon. Emotional support and information to reduce anxiety and the distress of uncertainty were an obvious need during the diagnosis and surgical procedure of the child. This section focuses more on the informal social support network that families relied on for assistance during their experience.

For most mothers who participated in this study, the support of spouses was perceived as important.

M: My husband and I both took time [from work] - but we took it in turn, so he [husband] or I was home and then when she [child] was feeling better - she stayed home and my neighbours have been popping in to see her.

The support of relatives was important to most of the families. One mother's account describes her view:

M: My Mom and Dad came and [child] went into the surgery and it happened so quickly. It [surgery] was about two hours after we came in that he was operated on so it was very quick but it didn't really have time to sink in, although I had suspected it before we had even gone in. It didn't really sink into me and it was just like I was in a state of shock. When I came to sign the consent I almost couldn't sign it, it was really awful .... My Dad sat really calm, they're both [mom and dad] really good, they're really supportive to me and they were really upset too. They just couldn't believe it and were on the phone calling everybody telling them what was happening. But they were good, I couldn't have done it without them. I would have just broken apart.
Some mothers used crying as a way of releasing feelings and an indicator of a need for support. While some mothers did not know that the child needed to be hospitalized when they left home some did not have relatives with them. However, she sought support from staff and called for relatives.

The social support network was particularly important at the time of the surgery. Having relatives spend time with the child in the hospital gave the mother a needed break.

M: I sort of felt like I had to always be there that they didn't attend him enough. My husband kept saying "you can leave, what would they do if you just went home tonight then they'd have to do it" but I didn't feel like they wanted that then they'd have to do it but I didn't feel like they wanted that at all .... and then when my sister would come at night that was the only relief I had in the whole day.

Three mothers stated that they found particular nurses to be supportive and understanding when they had difficult time at the hospital. One mother had a close supportive relationship with one particular nurse:

M: I was lucky actually - the last day before discharge, he came home on Monday just before Christmas, then [nurse] was in charge and this nurse was the special one. She's really nice. She had been off - so she came back and we had a talk and she showed me how to do it [change dressings]. And she gave me supplies. I still didn't use them all. She gave me enough. I had two more left after everything [the need for changing dressing] was finished. We were leaving - you know -she made a point of you calling back if you needed anything and stuff. I was really glad she was there because she made you feel much more comfortable.

However, several mothers did not feel supported by nurses. Some commented that they did not feel they could leave the hospital for a walk or to visit relatives, because they felt the nurses would not like that.

Two mothers valued the unique kind of support that parents who have experienced a similar situation can offer.

M: They have a little parent support group here [at the hospital] - I don't know how often - but once in a while - maybe twice a week - I don't remember the
frequency because days and nights were extinct for me. You can go out and get a cup of tea or coffee .... it is left to the parents when to go - you know- when somebody else is taking care of their kids - and you can go and relax for a minute - that's nice. The nurses are really nice ....

Some mothers had considerably more resources than others for support. For example one mother asked her mother in-law to care for her young child at home, while she asked her own mother to be with her at the hospital while the ill child was going through surgery.

Three mothers described the importance of getting help with caring for the child after discharge. These children needed help with activities of daily living which added more tasks to the care-givers role.

M: Um, my help has mostly been when he [the father] does come home from work - he'll play with him [child] and give me a break that way .... but as far as the - like the general care - you know - he doesn't give help.

The mothers who had to go to work after the child's discharge depended on relatives for support:

M: My mother lives here [same community] - so she was able to come in and stay with her [child] through the week that she was home.

Some mothers said that the support that relatives gave was of a more meaningful quality than that offered by friends. At the same time however, relatives often demanded more in the way of explanations and reassurance about the mothers' care-taking abilities. Sometimes support and information was sought from friends or relatives who were also health care professionals.

Seeking Information

Being well-informed was important to all of the mothers. Most of them felt that their child's physicians did a good job of explaining what was happening, whether it was the surgeon or the pediatrician. However, two mothers doubted the family practitioners information. For example one mother sought a second opinion from a specialist leading to the
child's surgery. Most mothers stated that the physician informed them about the child's treatment and care before surgery, gave them enough time, and kept them well informed through the child's treatment.

M: We got the news from the doctors what needed to be done and how it would be done then. They were completely clear and took a lot of trouble to explain everything and to - you know - help us overcome our fears.

The eight mothers in this study stated that they had good communication with the nurses, and got the information they needed. However they felt if they needed explanations they had to ask for it: "If you need information you have to ask them - you'll get answers".

When asked most mothers stated discharge teaching was helpful. One mother who had a child going through hip surgery said she watched a video-program. When mothers were asked to describe specifically what information they received, they said: "if you see redness or the child gets fever to call them" also they got a note with the date of the appointment with the physician for post-operative check up. The mothers were not asked about their home situations, and only one mother was told that she could phone the unit if she had some further questions. Three mothers were health professionals:

M: I don't feel that they [nurses] missed mentioning anything to me, really ...... You know, because I'm a nurse, I didn't feel the least bit concerned about that [how to care for the child after discharge].

The mothers were quite satisfied with the teaching and information the nurses gave them before discharge and felt that they left the hospital convinced they could cope effectively with caring for their child at home, in a sense relieved to be able to go home:

M: I would say - I got good information - and that I felt quite confident [with the child's care and treatment]. The worst part for me was - you know - to be away from home. I was tired.

The overall coping strategy of "seeking information" includes goals to reduce uncertainty and prepare for the child's care after discharge. All of these mothers participated in
their child's care, their accounts describe their confidence and it was evident that if they needed some information they asked for it while working with the nurses.

**Assuming Responsibility**

Assuming increased responsibility was one of the coping strategies the mothers' used to meet their child's needs. They participated in the decisions that needed to be taken, even though they doubted their ability to think clearly because of anxiety. Some mothers perceived that responsibilities related to decision-making about the child's illness and treatment were added on the mothers role, and some of them said that they would have liked that the child's father could participate in these decisions.

Some mothers felt it was difficult to be responsible to take care of their child when it was experiencing painful time in the hospital. These new responsibilities required role adjustments in order to enact them and resulted in feeling uncertain about how to meet the child's needs.

**Focusing on Child's Needs**

Some mothers compared their situation to others whom they considered to be worse off and in this way minimized the seriousness of their situation. This tactic of minimizing enabled them to be satisfied for their own child. Also, a couple of mothers expressed that they did not expect the child to do well in the first post-operative hours. These negative expectations were based on their appraisal of the harm that an anaesthetic and operation can involve for a child. The intense feelings of fear and worry were replaced with ones of relief after the operation.

The mothers adopted a positive attitude; for example two of them described the assumption that the health care professional knows and understands what information is important to her in order for her to manage her child's care within the context of her everyday life.

The mothers were all fairly confident that the surgical procedure would result in a positive outcome and coped with feelings of uncertainty by being positive and focusing on the child's needs. However, when talking about the outcome one can sense their worrying:
You know, they [physicians] say you shouldn't worry, it's not gonna - I mean -if he's [1 year old child] in sports when he's twelve - it's not going to affect him or anything like that so .... I'm not going to be too worried....

All the mothers focused on the ill child's needs and ignored if other responsibilities such as; caring for siblings, household tasks, and/or their work had to be postponed or rearranged.

M: I am still having to do everything for her, so it is a lot .... I am getting by doing things. There's lots of things that aren't getting done because you have to basically leave them - aye, so it's quite the load right now for me. You know I am finding it hard, but like I said - the dishes don't get done .... today I'm having to tell her to slow down .... You know how you're worrying about them so much.

By looking at one day at a time this mother coped with the activities of daily life and strived to survive all the demands on her focusing on meeting the child's needs.

Meeting Family's Needs

Normalizing is an overall coping strategy that describes the tactics mothers used to facilitate their child's life and family life returning to normal. First of all four mothers who had the youngest children were afraid that their child would become "spoiled" as a result of getting an extra attention and being treated "differently":

M: He [child] was a little bit spoiled in the hospital and when he came home he expected the same sort of spoiling and I had to kind of get him back into his normal routine - which was a little difficult.

Despite having received information and instructions from the nurses about the child's care, the mothers were not prepared to expect a change in the child's behaviour. Three mothers described that the siblings were having hard times understanding all the extra attention the ill child got.
In their attempts to fulfil parental responsibilities for the care, protection, and nurturing of their child after discharge, mothers implemented a pattern of protective behaviours to keep the child from hurting themselves or damaging the surgical outcome.

Summary

The coping strategies which have been described enabled the mothers to attain, at least in part, the goals related to the period of their child's health problem under study here. Although all of the mothers used all of the strategies, some used certain ones more than others. For example a couple of the mothers talked about the importance of trusting the health professionals and seeking support so as to lessen their anxiety. Several of the others were more interested in seeking information and meeting family's needs in order to reduce uncertainty and adjusting to normal daily life.

Summary

The experiences of these families were closely linked to a series of events which provided the basis for the three phases outlined. The first phase began with the onset of symptoms leading to help seeking and hospitalization, which varied from a couple of hours to one month. The second phase consisted of hospitalization, treatment, and preparation for discharge, which varied from three to eight days. The last phase was the child's care at home and getting back to normal, which varied from seven to ninety days.

The illness related events evoked feelings of uncertainty in the mothers. Because of the discomfort and fear accompanying this state, the mothers tried to reduce this uncertainty. Mothers used a range of coping strategies to attempt to attain the goals implicit for this health problem period. The most common ones in the beginning phases were trusting health professionals and seeking support and information.

The ability to trust the health care professionals arose from an intense need to do so, as well as the presence of certain qualities in that professional. The most important characteristics
of the health professional were a confident manner and genuine concern demonstrated by spending quality time with the family and an ability to listen to parents' concerns.

A supportive network of spouses, relatives, nurses, friends and other parents was important to all of the mothers. This network offered assistance in the form of emotional, practical, and informational support thus helping mothers to attain the goals for the health problem period and discharge from hospital to home. The support was particularly important at certain more stressful times, for example when the child was hospitalized and when the mothers waited for the surgery and its outcome. In an attempt to lower the stress level the mothers focused on the ill child's needs and ignored the things usually done as household tasks. In adjusting to normal daily life two-thirds of the mothers had found their child's acute illness to be disruptive to family life.
CHAPTER FIVE

Discussion of Findings

Introduction

The purpose of this chapter is to discuss the findings of the study in relation to other research studies. Some of this empirical data was mentioned in Chapter 2 where a selection of both experientially and research-based publications were reviewed. In this chapter the discussion focuses on empirical data which either supports or refutes the specific findings of this study.

A number of studies were found which focused on the concerns of parents of hospitalized children. However, this author was unable to locate a study that focused on parents' perceptions of their experience when caring for their child at home after short hospitalization with surgery. Therefore, this author has used relevant studies about family disruption when caring for a chronically ill child at home.

Because of the limitations of the published research on families who are caring for children at home following short hospitalization this chapter will also include a look at more general family literature. Publications describing the experience of families after learning the diagnosis of a variety of defects and diseases and while coping with these illnesses will help to explain the findings of this study.

This discussion will follow the same basic outline as Chapter 4, however, the theme of "coping with uncertainty" which recurred throughout the three phases will be described separately at the end of the section to minimize repetition.

Phases of the Mothers' Experiences

Phase 1 - Onset of Symptoms Leading to Help Seeking and Hospitalization

The families in this study had undergone a variety of experiences from the onset of the child's symptoms to admission to a pediatric hospital. Specifically, the process by which a
child was defined as needing medical attention, the mother's response to the hospitalization, the ambiguity surrounding the hospitalization, the disruption to family life preceding hospitalization, and the arrangements made to manage the hospitalization, varied according to the nature of the child's condition.

In this study, children were admitted to hospital with acute illnesses. Approximately one-third of the mothers were unsure about the child's diagnosis. In the first phase the mothers were ambiguous about both the nature and the outcome of their child's condition. This phase was typically a period of decision making with feelings of uncertainty resulting in anxiety, worry, and fear. This is congruent with the findings of Knafl et al. (1988) who stated that the condition of the acutely ill children was most often comparatively ambiguous and difficult to define. These mothers had often been engaged in an exhausting and unsuccessful attempts to treat their children at home, and they usually arrived at the hospital unsure of the seriousness of their child's condition. However, Knafl et al. (1988) report that less than half of the couples that participated in their study had had an opportunity to arrange for the care of other children prior to hospitalization.

In the current study only two mothers had not arranged care for siblings, because they did not know that the ill child would be admitted.

Knafl et al. (1988) also reported that parents of acutely ill children were most likely to express relief about the hospitalization because they were no longer solely responsible for the child's care. This feeling of relief was not common for the mothers in the current study who described how worried they were and one third of them did not believe this could "be happening" to them.

The most common descriptions were to participate in the decision to hospitalize the child and be persistent enough to seek the "right" treatment. All this contributed to their feelings of increased responsibility. Other researchers reported similar parental accounts describing increased responsibility (Knafl et al., 1988; Ogilvie, 1990; Schepp, 1991).
Otterman (1988) reported similar findings in her phenomenological study of the day care experience for parents of eight young children. She found that when a young child needs surgical intervention to correct a short-term condition or illness it heightens the parents' awareness of their responsibilities and is perceived by the mothers to be a potentially serious event which contributes to the stresses of this experience.

**Phase 2 - Hospitalization, Treatment, and Preparation for Discharge**

The usual role of the mother before the child is hospitalized continues in the hospital, focusing on caregiving, protection, nurturing, and the fostering of social and independent behaviours (Friedman, 1986). However, the mothers in the current study described how hospitalization added to their roles, as well as their responsibilities, which some found difficult to fulfil. This is congruent with Otterman's (1988) and Knafl's et al. (1988) studies' findings where parents experienced role strain when they were unable to fulfil these role expectations. Role strain is defined as the stress generated within a person when one either can not comply or has difficulty complying with the expectations of a role or set of roles. The individual has difficulty in attempting to fulfill role responsibilities or obligations (Friedman, 1986). The mothers in this study believed that it was appropriate and even mandatory to care for the ill child continuously, therefore having less energy to expend on attending to their own needs, the needs of their other children, and their home-life. These mothers were in the hospital for three to eight days straight and described their experience as "hard", "difficult", "draining", and some were experiencing "fatigue".

Role strain was evident in this phase, particularly when mothers were physically separated from their child during the operation. Waiting during this period of time was very difficult for the mothers and contributed to mothers feelings of fear, worry, and anxiety. The mothers' described that most common issues that contributed to these feelings were the awareness that something could "happen" to the child, that mothers were not allowed to be with the child when it was put to sleep, and that they were concerned about the child's response to pain and their emotional response. These feelings were associated with this
experience as being "stressful" by most of these mothers. These findings are widely supported by other researchers (Edwards, 1987; Knafl et al., 1988; Ogilvie, 1990; Otterman, 1988; Schepp, 1991).

According to Lazarus and Folkman (1984) each situation or demand in the environment is cognitively appraised or evaluated by the individual according to its meaning or significance for the person's well-being. It is the meaning that the situation holds for the individual that determines if the situation is appraised as irrelevant, being positive, or stressful (Lazarus et al., 1984). The participants experience of the hospitalization period (average stay was 4.8 days) differed considerably in the current study. Three of the mothers did not find the overall experience difficult, some mothers felt "uncertainty "and "anxiety" at certain identified time points while others thought "the whole thing" was difficult for them and their families. These findings relate that certain characteristics and events influence how mothers cope with the hospitalization experience as supported by Knafl et al. (1988).

Sociologists have found women to experience more stress than men from "undesirable life events", especially when the event is one that affects an important member of their social network (Kessler and McLeod, 1984). The hospitalization of a child fits this category. Graves and Ware (1990) compared mothers', fathers', nurses', and physicians' perceptions of parents' reactions to stressful stimuli when their children were hospitalized. These investigators developed an inventory in which 36 mothers, 14 fathers, 27 nurses, and 23 physicians rated 36 stressful stimuli. Analysis of Variance and subsequent multiple comparison tests disclosed numerous differences between parents and health care professionals and between mothers and fathers on the Parental Uncertainty, Annoyance, Child discomfort, and Negative Emotional States Scales. Further analyses of ratings on individual items from the scales revealed the basis of the differences that physicians did not accurately predict mothers' stress ratings and similarly, nurses did not accurately predict fathers' stress ratings. These findings are consistent with Hayes and Knox's (1984) hypothesis that parents and health
professionals do not share the parents' model of stress. The result can alert health professionals to discrepancies between their perceptions of parents' stress and the parents' experience of stress.

Wyckoff and Erickson (1987) studied the effects of stress on 120 mothers of seriously ill children hospitalized for an average of nine days. These authors identified that the child's age was a factor in parents' ability to cope with the child's hospitalization. "Differences in parental coping in relation to the child's age may be related to differences in reactions to hospitalization, dependent on the child's developmental stage" (p.5). The children's age in the current study findings did not influence the mothers' participation in child's care or her coping abilities. However the mothers of the youngest children found it "difficult" to leave the child, for example, while they took a lunch break or shower.

Parental desire for full participation in the child's care (activities of daily living, therapeutic measures, stimulation, entertainment, comfort) was complete in current study, even though the mothers felt they needed to get a break sometimes. Four mothers felt they were "in charge" of the child's care and felt they got the information they needed if they asked the staff, however, the remaining four mothers felt uncertain about their role. Some other authors have reported that although parents' were willing to participate in their child's care, they were unsure of their role in the hospital setting (Algren, 1985; Knox et al., 1983; Otterman, 1988). The reason might be the that most primary care-givers are with the child all the time which influenced the atmosphere in the pediatric unit concerning the parents' care, as well as this sample's characteristics.

Ogilvie (1990) described the view of nine parents in her qualitative study about hospitalization of children for surgery as "difficult". Participant observation during the stress points identified in the literature and interviews with parents were the major sources of data in her study. She explored sources of parental stress, parental roles during the child's hospitalization, coping strategies used by parents, and parents' suggestions for health care professionals, particularly for nursing staff.
Ogilvie's (1990) findings support the current study's findings that parents found waiting for the outcome of surgery very stressful. The parents' in her study also commented on the boredom of staying with their child for long periods, on the fatigue engendered by lost sleep, stress, and the need to be there for the child, which is also congruent with the findings of current study. In her findings she reports that parents experienced not knowing how to help their children as being extremely unsettling, as well as lacking information, and they did not feel confident about preparing their children for tests or surgery which they felt stressful. This was not evident for half of the participants in the current study, who expressed themselves as being well informed by the staff while caring for their child, and if they did not feel confident they "just asked" the staff and got the information they needed.

Ogilvie (1990) reported also that parents expressed feelings of stress related to changes in home routines, lack of privacy in the hospital, and perceptions of infrequent checking of children by nursing staff. This was also true for most mothers in current study. Fear of AIDS was a major objection for one mother in Ogilvie's (1990) study, but nobody in the current sample mentioned AIDS.

Knafi et al. (1988) stated that parents' visiting time was very similar for level I and level II parents when the total amount of visiting was compared. However the percentage of hospitalized child's waking hours with one or both parents present varied considerably: 45 children (73%) had a parent (mostly the mothers) for 80-100% of the waking hours, while 18 children had parents from 20%-59% of their waking hours (p.37). This is different from the current study's findings where mothers did not talk about "visiting", they (or another relative) were in the hospital at least all the child's waking hours and most of them also stayed there over night and until the child was discharged (average stay was 4.8 days). The child's age did not affect how much time mothers spent with the child in the hospital.

Phase 3 - Care at Home and Getting Back to Normal

Some mothers' interpretations of this phase as disruptive for the family life was the most prominent dimension of their experience. Four mothers identified the period after
discharge as contributing to changes in family routines and activities. These changes affected all family members, not just the ill child. The impact of family disruption varied between these families, as well as the way the disruption was managed by the family members. Some mothers described how surprised they were of how disruptive it was to care for an ill child. The demographic data demonstrates the difference between the time when the child is symptom free (mean 12 days from operation) and the time when everything is back to normal in the family (the mean after 39 days from operation). These findings are supported by Knafl et al. (1988) who compared the relationship between the child's condition and the time span of illness. The findings regarding how families and individual family members responded to pediatric hospitalization raised several questions about factors that either contributed to, prevented, or ameliorated negative outcomes of the experience. Of the three groups of children in Knafl's et al. (1988) study the acutely ill children had the illness for longest time span in days (their illness still existed in 37% of cases after 30 days from operation).

These findings direct health care professionals to look at the nature of the intervention as a process which the family goes through, or an on-going problem rather than just few days spent in the hospital. The medical perspective is short disruption, but from the current family's perspective the disruption varies much longer, or until the family life is back to normal. The treatment context affects the disruption of family life, as well as the nature of intervention and the definition of stay in the hospital. This conclusion is consistent with another finding from Knafl's et al. (1988) study that parents of acutely ill children were the most likely to report that their child's condition had brought about a major disruption to family life prior to admission.

The findings of current study support that the family life was influenced by the child's treatment, reaction to treatment, and by the mother's attempts to manage the experience within the context of their everyday lives. Most of the changes were concrete in nature and related to the ill child's activities. For example the child's condition changed the activities of daily living because the ill child was immobilized and the mother became their resource night and day. Half of the sample felt they had already been "drained out" in the hospital, however they
expressed themselves as being "relieved" when they came home, even though these changes of
family life demanded energy and flexibility on their part. These findings of family disruption
are supported by Knafl's et al. (1988) study where it is evident that parents of acutely ill
children experience more family disruption than parents' of both asymptomatic and chronically
ill children.

The Mothers' Experiences of Coping with Uncertainty

Uncertainty was the major feeling state which persisted to one degree or another
through the entire illness period for most families in the current study. The characteristics of
this uncertainty varied during the three phases of the experience and from one family to the
next, but it did persist.

The concept of uncertainty has been studied and several instruments have been
developed by M.H.Mishel. Reference to one of her studies will help explain the findings of
the current study. According to Mishel (1983), "... the characteristics of uncertainty may
reside in the nature of the stimulus, in the characteristics of the perceiver, or in an interaction
between stimulus and perceiver in relation to four general classes of illness-treatment events"
(p.325). In her study (1983) she measured parents' perceptions of uncertainty concerning their
hospitalized child by looking at the four characteristics of ambiguity, lack of clarity, lack of
information, and unpredictability. She compared the perceptions of 171 parents of three
groups of children hospitalized for a variety of reasons. Mishel (1983) found that the absence
of predictability was not associated with a strong negative evaluation of the seriousness of
illness and thought that this might mean that unpredictability was preferable to a negative
predictability. The current study does not support her conclusion that parents prefer
unpredictability to a negative predictability. In fact, just the opposite, most mothers wanted to
know everything there was to know so they could be prepared.

In the first phase, the onset of symptoms with hospitalization, some of the most
troublesome types of uncertainty in the current study revolved around not knowing the child's
diagnosis. The dimensions of the pre-hospitalization experience that contributed to the
mothers' interpretation of their experiences as stressful were primarily related to lack of
knowledge about what was "wrong" with their child and event uncertainty, Knafl et al. (1988)
support this finding. In addition to the uncertainty of childrens' illnesses, the parents in their
study confronted uncertainty about how to behave in the hospital, however this was not evident
for most of the mothers in the current study, who expressed themselves as feeling confident in
caring for the child in the hospital.

The uncertainty in the second phase of this study was mainly connected to the waiting
period while the children were in surgery, and not knowing the outcome of the childrens'
operations contributed to the feeling of anxiety. This finding is congruent with Ogilvie's
(1990) findings in her qualitative study about the parental experience when a child is
hospitalized for surgery and has been described earlier.

Two mothers who participated in the current study expressed uncertainty about how to
care for their children after discharge from the hospital because they "forgot" to ask a specific
question or because similar situation did not occur in the hospital setting. Some mothers had
difficulties determining how much the child was allowed to move and most of them protected
them from doing physical activities. They got instructions from the physician about when the
school children were allowed to participate in PE. But since the instructions for the younger
children were that "they are allowed to do what they are able to do", this was a source of
uncertainty for three mothers.

These findings are supported by Carlson, Simacek, Henry, and Martinson (1985) in
their description of a home care program for terminally ill children. These authors state that
home care of an ill child is stressful and "potential sources of stress include uncertainty about
what to expect and about how to care for the child and the assumption of full responsibility for
the child's comfort" (p. 115).

Some mothers reported that in the first days following discharge they noticed behaviour
changes in their children, both the hospitalized one and the siblings. These behaviour changes
often influenced usual patterns of family life and as a result, contributed to the uncertainty in
this phase of their experience. Behaviour changes involving fear of separation from the mother was evident in young siblings, because the mother spent her time in the hospital with the ill child. Some older siblings also changed behaviour, were "jealous" over the attention and the "extra things" the ill child got. The most common behaviour change in the youngest ill children after discharge was "acting up" and some mothers said the child was "spoilt" in the hospital period. The mothers' felt these behaviour changes required extra time, patience, energy, and planning on their part during the first week after discharge.

The findings that indicate a change in the children's behaviour following hospitalization are consistent with the findings of other authors who have reported behaviour changes such as increased aggression is common following surgery (Hannallah & Rosales, 1983; Ogilvie, 1990). However, these authors findings also describe increased separation anxiety in the ill child, as well as increased sleep anxiety, which was not true for the children in the current study.

McClowry and McLeod (1990) examined the psychosocial responses of school-age children to hospitalization. The subjects were 50 children, between 8 and 12 years of age, who had unscheduled admissions. The children's usual pre-hospital behaviour was compared to their behaviour during the first week following hospitalization and one month after dismissal. Repeated measures of analysis of variance was used to demonstrate that there was no change in the school-age children's behaviour following hospitalization. A moderate relationship was found between the children's usual pre-hospital behaviour and the number of previous hospitalizations. Family function was related only to the children's behaviour one week after dismissal. The children's usual pre-hospital behavioural problems were related to their behaviour at all three times. No relationship was found between the length of hospitalization or the number of previous hospitalizations and their post hospital behaviour. These findings are congruent with current study findings; in addition one mother reported that the illness brought her "closer to" her teenager.
Some mothers in this study clearly identified when this phase of their experience had ended, that is when the child was free of symptoms and the family life was back to normal again. These mothers expressed their sense of relief from the stressful feelings of worry and anxiety. Some mothers expressed satisfaction with their experience because the child's response to the treatment allowed them to conclude that the experience was over. However, two children were still not fully recovered when the second and/or third interview was conducted with the mothers. The difference between these two mentioned time points, when the child was symptom free and when everything was back to normal, varied from seven to thirty days between them. The events that the mothers thought that influenced this inconsistency were siblings behaviours and other family events, for example a vacation abroad, a newborn baby, and a sibling's operation.

To summarize then, there are care areas that the parent may be prepared for while their child is in the hospital, those things that are predicted by the nature of the child's condition. For example, the signs and symptoms of infection and when the child can take a bath. Those care areas that mothers' might not be as well prepared for are how to deal with are "the little things", the activities of daily living which is more of a problem for some families than others. This is mostly related to the nature of the child's condition or the family's interventions. For example the more immobile the child was, he more involved the parent had to be in all interventions of daily living, and the longer it took the families' to get back to normal. Among the issues that were most problematic in some families were the activities of daily living, the routine, toileting, feeding, getting around, as well as the children's behaviour. The issues varied depending on the nature of the health problem and the family coping abilities.

**Coping Strategies**

The management of changes in family activities and routines often led to creative and flexible coping strategies used by the mothers to fulfil their responsibilities and minimize role
strain. However, depending on the ill child's condition, some mothers expressed these changes resulting in their feelings as being "exhausted".

When coping with the health problem in the hospital role strain was evident when mothers were physically separated from their child during the operation. Waiting during this period of time was very difficult for the mothers and contributed to mothers feelings of fear, worry, and anxiety. Crying was one way of releasing their feelings of fear and an obvious indicator of the acute need for support at this time.

The theoretical perspective of stress and coping developed by Lazarus and Folkman (1984) provides a basis for understanding how parents who participated in this study interpreted and assigned meaning to their experience and coped with it in their everyday lives. This theoretical perspective is particularly helpful because it holds that stress is an interactive phenomenon and takes into account one's ability to act on the environment. Individuals and families who learn that the stress signs and symptoms result when they are experiencing stress beyond tolerable limits may be able to mobilize or adjust their coping mechanisms. Persons who ignore signals of distress or who do not initiate appropriate defense mechanisms experience crisis (Clemen-Stone et al., 1991). Stress is by itself neither good nor bad, it is simply a response used to cope with the environment, as such, it is a normal and universally experienced response (Roden, 1987).

Graves and Ware (1990) studied parental stress during a child's (≤ 10 yrs.) hospitalization and stated that health professionals and parents do not share the same model of stress. These investigators developed an inventory which 36 mothers, 14 fathers, 27 nurses and 23 physicians rated 36 stressful stimuli on and compared them to each other. One of the results of their analyses revealed that physicians did not accurately predict mothers' stress ratings, similarly, nurses did not accurately predict fathers' stress ratings. These findings are consistent with Hayes and Knox's (1984) hypothesis that parents and health professionals do not share the same model of stress. The results can alert health professionals to discrepancies
between their perceptions of parents' stress and the parents' experience of stress, therefore supporting further need for knowledge of parental experience.

It has been suggested that parents often perceive their own anxiety as greater than that of the child (Ogilvie, 1990, Meng et al., 1982). In addition to their concerns about the child's illness the parents face changes in their roles as parents and they have to adjust to stressful situations (Ogilvie, 1990; Otterman, 1988). These stimuli often lead to parental stress, however, the degree of stress varies from person to person. Knafl et al. (1988) stated that parental stress is easily communicated to the child, with a potentially negative impact on adjustment and recovery. Ogilvie (1990) supported Knafl's et al. statement and suggested that reducing parental anxiety is an important potential intervention by nurses, because children are adept at perceiving parental cues. Increased knowledge, therefore, of the parents' experience, with particular focus on the sources of stress, may assist nurses in developing strategies aimed at reducing parental anxiety. Reduced anxiety and stress in the parents may lead to less anxiety in the ill child and thus minimize the chance of adverse long-term effects and encourage coping behaviours of both the child, and the parents.

Crisis is a term commonly used in our society for an instance in which circumstances are suddenly altered (Stanhope & Lancaster, 1992). Hospitalization of acutely ill child is an event that in itself need not be a crisis but which may predispose individuals and families to crises. The nature and characteristics of a crisis are distinct from other changes in circumstances.

A crisis progresses through a series of identified phases, each with its own possibilities for intervention. These crisis intervention techniques are used to assist individuals in crisis to resolve situations so that they are stronger after the crisis than they were before. Individual in crisis can not predict the outcome of the situation, the uncertainty increases the tension of the person, who may experience feelings of helplessness, tiredness, and ineffectually. This was true for some of the mothers in this study. In addition to feelings of uncertainty, anxiety, guilt, fear, or shame can occur. For instance, if a child is injured while playing, the parents may feel
guilty and think that the accident could have been prevented if they had been more attentive. The individuals in crisis often exhibit physiological symptoms, and these vary from person to person according to individual responses to stressors. Among the possible manifestations are sleep disturbances, muscle tension tiredness, shortness of breath, and exhaustion.

Schepp (1991) studied factors that influenced the coping effort of 45 mothers of young acutely ill hospitalized children. Her purpose was to test a theoretical model predicting the relationships among four concepts: predictability of events, control, anxiety, and the coping effort of these mothers. For each of the concepts, 16 events commonly associated with hospitalization of a child were proportionately ranked using magnitude estimation measurement technique. The psychometric properties of the instrument were estimated through reliability assessment and cross modality matching. Multiple regression analysis indicated that 97% of the dependent variable, coping effort, was explained by two of the three predictor variables - predictability of events and anxiety. This is congruent with the findings of current study where mothers who knew what events to expect expressed less anxiety and reported spending less effort to cope with the stressful events.

**Trusting Health Professionals**

Most mothers made the assumption that the health care professional knows and understands what information is important for her in order to manage her child's care within the context of her everyday life. Such a finding corresponds to the research done by Robinson and Thorne (1984) who identified one phase in the development of relationships between consumers and health care workers as "naive trust", where families "wait passively for the professional health care providers to fulfil their responsibilities" (p.599).

Most of the mothers got the information about the surgery's outcome directly from the physician after the operation and found that very helpful. This is supported by other authors (Hayes et al., 1984; Otterman; 1988; Terry, 1987) who have documented that parents want information directly from their physicians who they see as primary sources of information regarding their child's diagnosis, treatment regime, and expected outcome.
Interactions with health care professionals were not always perceived to be helpful or supportive by some of the mothers. In several instances, inconsistent information about the child's condition contributed to increased anxiety, worry, and/or lack of trust.

Knafl et al. (1988) examined how parents' participation fell into distinct categories based on their beliefs. They report in their conclusions that level I parents (29 couples) were characterized by overwhelming trust in and relinquishment of control to professionals. They voluntarily rendered themselves and the well-being of their child, powerless in the hospital system. This is not congruent with the beliefs of the mothers in current study who actively participated in their child's care and therefore have some similarities with level II parents in the Knafl et al. study. For example they asked numerous questions, cultivated information sources, validated the information they received with others, and became involved in decision making with nurses and physicians. However, one of the Knafl et al. findings about level II parents was their incoming attitude toward the health care system, doctors, and nurses was one of mistrust. This was not consistent with the mothers' attitude in current study. They trusted the health professionals in the pediatric hospital, even though some mothers stated they did not trust the physicians in their community hospital. Knafl et al. (1988) reported that parents' interactions with nurses involved requesting comfort items and asking permission to bend the rules. This is congruent for the mothers in this study who for example asked for permission for siblings younger than 12 years old to visit.

Parents (level II) in the Knafl et al. study expected to have to interact with the nurses on behalf of their child. If they needed to do so frequently, the parents did not trust the nursing staff to provide adequate care when they were not present. This led some mothers in their study to conclude angrily that they were in fact the nurse for the child. This is congruent with the findings of current study where the mothers felt they were the child's primary care-giver in the hospital. The mothers of the youngest children in the current study did not find they could go for a lunch break without worrying about the child, or because they felt that the nurses expected them to be at their bed side all the time. It is evident from the mothers' accounts that
the nurses did not ask them if they liked to take a break, or care for the mothers as their clients, even though two mothers stated they got emotional support during the operation period.

**Seeking Support**

The availability of support for day to day concerns in the family context was seen an important issue for most families in this study. The families who got back to normal easily had grandparents and friends to support them on a daily basis. The most common source of support sought by the mothers were the husband, a friend, child's older siblings, physician, or grandparents. Nobody mentioned getting support from a nurse after discharge. The mothers who had good network of support system did not have to worry about missing more time from work, or the child's care before it was well enough to attend day-care or school. While the rest of the family got back to normal the ill child was cared for in the home. These findings are supported by Knafl et al. (1988) who reported that those families who managed with help were most likely to have acutely ill children. When looking at some ways of how the families managed the disruption, the findings of current study are similar to those of Knafl et al. For example, by increasing siblings' responsibilities or expecting the hospitalized child to spend limited amounts of time alone.

The primary sources of support after discharge were family members and friends. The most important components of support were to know that somebody else cared about what happened to the family and having someone available to listen. In the Morrow et al. (1982) study the parents of children with cancer rated their sources of support and identified relatives as the most often sought out along with physicians. This supports the finding of current study. However, parents in the Morrow et al. study ranked relatives only sixth in terms of perceived helpfulness which is not congruent with the findings of current study, where mothers' found relatives very helpful.

Emotional support was perceived by some mothers to be more appropriate at particular points of their experience, for example to relax and to reduce anxiety and the distress of uncertainty during stress points in the hospitalization time of their experience. These findings
are supported by Glen (1982) who studied parents perception of the hospital admission. This author stated that information and support given at the time of stress points decrease anxiety, expedite recovery, and reduce adverse psychological effects. Stress points were defined as points of high anxiety for parents and children. For example: the admission, late afternoon of the day before the surgery, the blood test, the preoperative medication, the exit from the ward for surgery, and the return from the recovery room, these points were also being perceived as stressful for most mothers in current study.

**Seeking Information**

It is evident that parents in this study had a prominent need for information during this experience. Terry (1987) conducted a study with 22 parents of children aged three to ten years who were hospitalized for a period of 14 to 30 days. These parents clearly identified that their most prominent need was for information. Particularly information about what was wrong with their child and what would happen to their child. Other authors have also supported that parents need information in order to cope effectively with their child's hospitalization and discern their roles as parents of sick children (Hayes et al., 1984; Horner, Rawlins, and Giles, 1987; Otterman, 1988).

Most mothers felt they got their need for information met in the hospital setting, however parental needs for information was seen much broader by the mothers than only concerning the hospital period. Important informational needs are acknowledged in the literature of chronic illness. Horner et al. (1987) discussed the information needs of parents of chronically ill children. These researchers studied parental perception of program, socioeconomic, and health care needs in their survey of 493 families with chronically ill or handicapped children. Nearly 41% of these children ranged from one to five years of age. A total of 164 questionnaires were completed (87% by mothers and 9% by fathers). Seventy-six percent of the respondents were from two parent families with average income of $15,000-$20,000 (US). Parents identified their greatest informational needs in the areas of (1) planning for their child's future (55%), (2) identifying appropriate community resources (49%), (3)
understanding how the illness or disability affects their child's physical and emotional growth (45%), (4) improving communication among the child's health care providers (44%), and (5) finding ways to provide for the child's emotional, social, and intellectual needs (43%). These findings support how broad the parents perceive their need for information. But, also the domains of impact of illness on a child and family's life.

Assuming Responsibility

In the society motherhood is looked upon as a life-changing event and profoundly affects almost every aspect of women's lives (Friedman, 1986). Responsibility for the child's well-being is a well-known and excepted part of the mother's role. This is supported in this study as it was all mothers who were primary care-givers. To seek a service from health care professionals at the right time and to be persistent enough, heightens the mother's awareness of her responsibility. This was evident in the interviews with these eight mothers. They assumed their responsibilities in the hospital, home, and work arenas differently during their child's hospitalization. However, all believed it was important that the hospitalized child needed to be attended for most of the hospitalization time by one or both parents, which necessitated certain changes in family life.

There were particular aspects of the mothers' experience that contributed to their interpretation of the child's surgery as an extra responsibility added to the usual role of the mother. To be responsible for signing the consent form on behalf of both parents not knowing if it was in the best interest of the child, to ask the right questions at the right time, to be able to understand, and remember given information and instruction, and being in the role of the child's primary care-giver, all this contributed to their feelings of increased responsibility.

The impact of the child's illness on family life varied between families depending on: (1) the severity of the problem, (2) how many days the child was in the hospital, (3) if the mother was employed, and (4) if there were young siblings at home. In this respect pediatric hospitalization affected all family members, although not everyone actively participated in the changes. For example, older siblings sometimes participated actively in the hospitalization by
assuming new responsibilities for the care of younger siblings. Some mothers felt stressed being away from the home and that they could not care for their other children.

Six of these mothers are employed and the professional woman tends to view motherhood as another role to be managed at the same high level of competence as she manages her other roles (Knafl et al., 1988). Two of the mothers, who had the youngest children in the sample, surrendered all other roles to focus solely upon mothering. The mother's responsibilities are ever constant and even though surgical procedure adds an extra burden on the mother's role, they prioritize the ill child’s needs.

**Focusing on Child's Needs**

Parents of ill children are continuously placed in the position of trying to maintain a balance between competing family needs. The mothers in current study focused on the need's of the hospitalized child.

The mothers were not prepared for the child’s behaviour changes and used different coping strategies, for example by increasing their attention, discipline, and/or affection. The findings of current study support that short hospital stay often includes children who are in need for medical involvement after discharge and what is more important from the family perspective is that the child’s treatment continues to impact on the child’s return to normal and the family life stability for weeks after discharge. The findings of this study support that the child's physical activity gets back to normal sooner than the family's ability to return to normal. The length of family disruption is supported by Knafl et al (1988) as already explained.

**Meeting Family's Needs**

The term "normalization" has been widely used in the chronic illness literature. Krulik (1980) defined this therm as meaning "as normal as possible" versus "as normal" as some authors (Comaroff & Maguire, 1981) have defined normalization. In her study, Krulik (1980) interviewed 20 mothers using a structured interview schedule. The children in the study had chronic life-threatening illnesses and ranged in age from 8-10 years. The normalizing tactics used by these mothers were directed at two targets; the first was altering the environment to
compensate and accept the child, and the second was strengthening the resources and coping abilities of the child. These findings are in some ways applicable for the families in current study, where mothers where told they could treat the child "as normal", however, some mothers changed the environment to be able to meet the child's needs, as well as using support to strengthen the child physical condition and lessen the emotional anxiety in the child after discharge. The current study findings support that health professionals compartmentalize their service. The mothers value continuity of the care they receive and care should be organized in such a way that there is an ongoing service process including a series of events in a broader context for the family. Family assessment was not done before discharge. However by knowing the ways which mothers approach events makes a difference of how nurses prepare them for discharge. The findings of the study support that if nurses would make them accessible for the mothers after discharge it would lessen their uncertainty.

Summary

Many of the findings of this study have been corroborated with empirical data from a variety of research reports. In the phases of the experience, the findings were supported with literature primarily dealing with families having hospitalized children. These studies supported current findings although some of them had limitations which must be considered. The study by Knafl et al. (1988) lends the most support to the findings of this study. Literature relating to families having children with a variety of chronic illnesses lends some support to the current study because no research was found on home care of acutely ill children after discharge with short hospital stay. Several specific findings arose from the current study for which limited or no support was found in the research reports reviewed. One of these findings was that young sibling's of the ill child showed separation anxiety. Another finding was that some mothers perceive they can't leave the child's bedside. A third finding was that mothers feel their needs for information was met in the hospital phase, but they were not prepared for how disruptive family life can be after discharge. The cumulative outcome of these findings is the conclusion that family-centred care is poorly implemented.
CHAPTER SIX

Summary, Conclusions, Implications, and Recommendations

Summary

The family's experience of caring for a child at home after hospitalization for an acute surgical procedure was elicited from the perspective of the mother who was the child's primary care-giver. The study explored in-depth the mothers' perspective and personal interpretations of the illness experience within the context of everyday family life using a phenomenological method.

Pediatric hospitalization has been changing rapidly with more emphasis on parents' participation in the child's care and with shortening the hospital stay. The nursing literature (Clemen-Stone et al., 1991; Ogilvie, 1990; Whaley et al., 1989) about child health and pediatric hospitalization has supported this as a positive change. However, there is lack of empirical knowledge addressing this topic from the parents' perspective. This author did not find any research focusing on parents' perspective of home care after discharge from short hospitalization. Parents are responsible for their child and it is important for nurses to be consistent with parents in identifying the parents' needs as a first step in supporting them as the ill child's primary care-givers. It is mutually beneficial to truly understand the parents' perceptions and personal interpretations of their experience within the context of their everyday lives. The information gained provides direction for nurses who are working in both hospital and community settings who have opportunities to influence the experiences of parents whose children undergo surgery with short hospitalization.

Professional literature (Knafl et al., 1988; Knox et al., 1983; Otterman, 1988) supports the idea that parents and professionals may differ in how they identify and prioritize parental feelings and needs which can lead to unsuccessful interventions, unfulfilled parental needs, and less than optimal care for the children. Based on this premise, the investigator used
Kleinman's (1978) analysis of the health care system as the conceptual framework to guide the research. Kleinman's model adheres to two fundamental notions: the first is a distinction between the concepts of "disease", "illness", and "sickness", and the second is a conceptualization of a health care system with three different but interacting social "arenas": popular, professional, and folk arenas. These three arenas serve to socially legitimize sickness and health care for the individuals they represent. Within the context of this framework, diseases are treated and illnesses are experienced. Sickness is defined as a complex human phenomenon encompassing both disease and illness. In order to enhance health professionals' understanding of illness as a personal, social, and cultural experience Kleinman (1978) directs health professionals to elicit the perceptions and explanations about parents' experience.

Data collection and data analysis occurred concurrently until the interviews were completed and then the final analysis was done. The researcher's first interviews were conducted about one week following discharge, the second interviews were done by telephone about four weeks after discharge, and the third interviews were conducted in their home when the family life was back to normal. Verbatim transcripts of the taped interviews were analyzed as the data collection proceeded. Themes from the first-round interviews were verified with the parents at subsequent interviews and themes from other parents' accounts were also introduced at that time for discussion. Once the interviews were completed, further sorting and categorizing of data took place as suggested by Giorgi (1975a).

Major themes which came from the accounts were organized into three sections based on the researchers analytic framework to enhance clarity for the reader. The first section included three phases of the mothers' experience: "onset of symptoms leading to help seeking and hospitalization", "the hospitalization, treatment, and preparation for discharge", and "care at home and getting back to normal". The second section described the characteristics of the mothers' feelings in relation to the three phases. The third section subsumed the coping strategies employed by the mothers in their attempts to attain the goals specific to the illness period.
For discussion purposes, the findings of this study were compared to the findings of a variety of other studies, not only those specific to families after short stay in hospital with surgical procedure, but also from the chronic illness literature. These study findings provide more insight into the mothers experience in the context of caring for their ill child and how it impacts the family life. Based on these findings, a number of conclusions can be drawn.

**Conclusions and Implications for Nursing Practice**

Some specific conclusions about the findings of this study will be presented here. After each conclusion is discussed, the implications for nursing practice which evolve from these conclusions will be described. These conclusions have not been prioritized in any way as they are all considered important.

The first conclusion is that mothers view their experience as one which occurs over the time period of the child's illness, not only the time spent in the hospital setting, or the time after discharge. The mothers assign and interpret their own meaning to their experience within the context of the family life.

The implications for nursing practice are primarily that mothers of children with short hospital stay and nurses involved in the care of these children may differ in their perceptions of parental feelings and needs. Discrepancies between the explanatory models utilized by parents and health professionals often result in misunderstandings and dissatisfaction with care. In order to provide care that is mutually satisfying and supportive to the family during the illness period, nurses must elicit parents' perspectives and acknowledge the parents' interpretation of the events. Therefore, the parental primary care-giver should be involved in the assessment, planning, implementation, and evaluation of the nursing care, based on parental and nurse mutual agreement.

A second conclusion has to do with the mothers' interpretation of their experience as the ill child's primary care-giver. While some mothers perceived their experience as stressful
and identified particular feelings of uncertainty, others felt they were competent in the caring role with overall positive experience.

Differences in perceptions may be based on age, educational, cultural, and psychosocial experiences with health-related episodes, as well as on child's condition. Nurses need to enter into nursing interventions prepared to pay attention to the holistic needs of these children and their family members, particularly parents who are the primary care-givers. As interveners, nurses utilize many skills related to assessment, crisis resolution, teaching, advocacy, and counselling. It is important for nurses to anticipate the mothers' needs, concerns, and responses in order to provide empathic care to minimize the stresses associated with the mother's experience. For mothers, these experiences shape their coping behaviours, as they try to balance professional recommendations and needs fulfilment for all family members, including themselves. As primary care-givers, mothers develop nurturing power through the fulfilment of their personal needs. When parents and nurses come together in nursing interventions to co-manage the care of children the potential exists for this parental nurturing power to be either weakened or strengthened. Therefore, it is imperative for nurses to identify parental feelings and needs through collaborative and systematic assessment in order to develop mutually defined priorities and goals which will strengthen mothers' nurturant power. Mothers and nurses can work in partnership in a systematic way to reach specific goals and objectives, using different tools and methods for successful outcome.

A third conclusion is that mothers view this experience within the broad context of everyday family life and describe significant changes that take place and impact the family life as a result of the child's illness.

The implications for nursing practice therefore, is to evaluate current nursing methods and examine how nursing practice meets families needs for information and care. Mutual understanding between parents and nurses is the basis to build on. One way to meet this goal is to implement the philosophy of family centred care, Knafl, et al.(1988) state:
"Our results have convinced us of the usefulness of an interactive model of family-centred care. While certain policies may contribute to family-centred care by accommodation a broad range of family preferences, they do not make a unit family centred. To be family centred implies that consistent, systematic efforts are made to understand one another's viewpoints and that open negotiation between family members and nurses is encouraged and valued. Family-centred nursing care requires that nurses and family members work together as equals in defining and managing the pediatric hospitalization experience" (p.300-301).

In this way nursing intervention can proceed expediently, reaping the benefits of cost-effectiveness, positive parent-nurse relationships, fulfilled needs for parents, stronger parental nurturing power, and optimal care for the children. Nurses should be prepared to spend more time assessing and negotiating with mothers, to strengthen their roles as the primary caregivers' and influencing the provision of optimal health care for all families.

Nurses need to work together to assist families to use suitable coping strategies to attain their health related goals. Because of the varying levels of knowledge and skill of nurses working with families it is imperative that nurses consult the appropriate resources if they do not feel equipped to help. It is also important for nurses with expertise to make themselves available to other nurses. For example a clinical nurse specialist could act as a consultant to nurses in community hospitals and community health units.

The nursing profession needs to enhance family support efforts by teaching health professionals the value of family to family support, by encouraging the development of groups, and by creating parent liaison and consultant positions, staffed by parents with direct experience with child health care.

Implications for Nursing Education

Some general implications for nursing education which arise from the findings of this study will be mentioned here. It is clear that when a child becomes ill and needs surgery, the whole family unit is affected and the individual members need to work together to use suitable coping strategies to attain the goals of the family to "get back to normal". Therefore a major
implication is to incorporate a family focus, as well as an individual client focus into nursing curriculums.

A number of theoretical frameworks would provide direction for nurses and nursing students to gain the knowledge and acquire the skills needed to promote effective interpersonal relationships with family members. Family theory would enhance students' understanding of the family unit and the continuously changing needs of its family members. Family theory needs to be studied from the perspectives of structure and function, development, systems, and in conjunction with family assessment, and intervention theories. These theories teach nurses about the process of assessing the health of the family and its individual family members in addition to planning intervention strategies based on accurate assessments of family's individual needs. Other frameworks which support family assessment and intervention theories are those which support collaboration between health care providers and clients in the assessment, planning, intervention, and evaluation phases of the nursing process. Collaborative frameworks are based on other theories which should also be included in nursing curricula. These theories support the important view that professionals and clients may have different perceptions of health-related episodes, and these differences should be acknowledged in the intervention process. Nursing students need to understand that differences in perceptions of needs may be related to a number of variables such as age, gender, marital status, socio-economic status, culture, and geographical location. These theories would direct nurses to utilize systematic methods in order to accurately assess the needs of family members.

**Recommendations for Further Research**

During the research process, the investigator became aware of a number of questions which evolved from her study. Considering the dearth of research focusing on how families perceive caring for their children at home after short hospital stay, suggestions for further research in this area are appropriate.
The sample from the current study are mothers that could be expected to cope well because of their demographic data characteristics. However, it would be interesting to repeat this study with mothers who are considered at risk, for example, single mothers, unemployed families on social support, or families who cannot speak English.

One study might address a different question, for example: "What are parents' perceptions of their needs when caring for their child at home after surgery". Data collection at three points in time in the current study was the minimum to evolve the mothers experience and there is a need to follow the family's experience further to help identify the changing needs of the family.

Another study could focus on the fathers' perceptions of the experience having a ill child going through acute surgery. It would be interesting to find out about the experience of fathers and mothers by doing a comparative study on their experience of caring for their ill child. The results of such research could potentially guide nurses in effectively addressing the emotional and learning needs of mothers and fathers.

A finding of this study was that siblings behaviours change; therefore more knowledge about siblings perceptions might be helpful to study how they are affected in order to help parents to meet all their childrens' needs.

The above recommendations for further research would provide nurses with more information related to parental experience and contribute to a body of nursing knowledge that would direct nurses to strengthen the roles of parents who most often are the primary caregivers of the family unit.

In summary this Chapter gave an overview of the study and presented the conclusions. Implications for nursing practice, education, as well as recommendations for further research were also described.
REFERENCES


Dear parent/primary caregiver:

My name is Sola Gudmundsdottir and I am a pediatric nursing teacher from Iceland. I came to Canada to study in the Master of Science program in Nursing at the University of British Columbia. I am conducting a study to learn more about parents' experience of caring for their child at home following an acute surgical procedure. My Faculty Advisor is Connie Canam (phone: 822-7558).

There is very little information available on how parents manage at home with a child who has just had an operation. Information on parents' experiences could contribute to more effective discharge teaching for parents caring for a child at home following surgery.

This letter is to inquire if you are interested in participating in my study. Should you agree to participate, I will talk with you on two occasions in your home or in another place that you choose. The first interview will take place 6 - 8 days after you return home, and the second interview will be 2 - 3 weeks after your child's operation. Each meeting will be approximately one hour long and will be arranged at a time most convenient for you and your family. With your permission, the interviews will be tape recorded, transcribed (typed), and analyzed following my visits. These recordings are used so I don't have to take written notes while we talk. They are for my personal use and will only be shared with two of my advisors who are my thesis committee. I will assume all responsibility for the tape recordings and will personally destroy them when I have completed the project and any related publications (after one year).

During the interviews, I am interested in learning about your perceptions regarding the child's home care after discharge from the hospital. All of the information that you share with me will be kept strictly confidential and your identity will never be revealed in any way whatsoever.

Parents often find it helpful to talk about their child's home care with a nurse and if we (the nurses) learn more about your experiences, we could use the knowledge to better prepare parents for coping with a similar experience.

You are under no obligation to participate in this study. If you should decide to participate, you have the right to change your mind and withdraw at any time. You also have the right to refuse to answer any questions that I may ask or comment on any topic during the course of an interview. If you should decide not to participate, your refusal will not in any way affect your child's nursing or medical care. If you are willing to participate please sign below and I will contact you by phone to arrange a time to meet with you.

Thank you for your consideration.

Sincerely,

Sola Gudmundsdottir BSN (Phone: 222-4761)

Familyname:_________________________________________ PhoneNumber:__________________
Primary care giver's Consent Form

I ____________________________, do hereby give my consent to participate in the study on parents' experiences related to their child's home care after discharge from hospital following an acute surgical procedure. I understand that this study is being conducted by Sola Gudmundsdottir, a Masters candidate from the School of Nursing at the University of British Columbia.

I have been informed about the nature and purpose of this study. I also understand that:
- participation is entirely voluntary and refusal to participate will not in any way affect the future medical or nursing care that my child may receive;
- I can withdraw from the study at any time, or refuse to answer any questions or discuss any topic, with no effect on my child's future medical or nursing care;
- there will be a maximum of two interviews of approximately one hour in length each and will be tape recorded. I have the right to request erasure of any tape or portion of a tape at any time during the study. The tapes will be transcribed (typed), and analyzed (the tapes and transcriptions will be destroyed within one year);
- any information which may personally identify me as a participant in this study will be removed from the transcription;
- there are no known personal risks or discomforts for me or my family members;
- if I have any questions at any time during the study, I may contact the nurse researcher, Sola Gudmundsdottir (Phone: 222-4761) or her Faculty Advisor Connie Canam (822-7558).

I acknowledge receipt of a copy of this consent form.

Participant's Signature: ____________________________ Date: ____________________________

Witness Signature:

If you wish to receive a summary of the report when it is finished, please write your address:
APPENDIX C

Initial Interview Guide

1. What has it been like for you to care for your child after discharge from the hospital?

2. Have you any specific concerns about the child's care at present?

3. What has helped you to care for your child since discharge?

4. What would have been helpful for you?

5. What sorts of things make it more difficult for you to manage your child's care?

6. What do you find is the best way to receive information from nurses?
APPENDIX D

Demographic Data

This information will enhance the researcher’s understanding of your family’s experience. If you do not wish to answer any of these questions you are free to refuse.

Age of Child: __________ Female ( ) Male ( )

Diagnosis: __________________________

How many days in hospital: ________

How many days after discharge until s/he recovered (no symptoms)? __________

When was everything back to normal? __________________________

Household Composition:

Adults in the household: __________________________

Relationship to child: __________________________ Relationship to child: __________________________

Age: __________________________ Age: __________________________

Cultural Background: __________________________ Cultural Background: __________________________

Employed? Yes ( ) No ( )

Employed? Yes ( ) No ( )

Position: __________________________ Position: __________________________

Full time ( ) Part time ( )

Full time ( ) Part time ( )

What is the highest educational level attained? __________________________

What is the highest educational level attained? __________________________

Children in household: __________________________

Age: _______ (F) (M)

Age: _______ (F) (M)

Age: _______ (F) (M)

Age: _______ (F) (M)

What category does your yearly family income fall into?

≤ 20.000 ( )

21.000 - 49.999 ( )

greater than 50.000 ( )

Thank you very much for taking part in this study.