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Caregiving identity emergence in parents of hospitalized handicapped children

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CAREGIVING IDENTITY EMERGENCE IN THE PARENTS OF HOSPITALIZED HANDICAPPED CHILDREN

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ABSTRACT

CAREGIVING IDENTITY EMERGENCE IN PARENTS OF HOSPITALIZED HANDICAPPED CHILDREN

by

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University of California, San Francisco, 1988

The number of parents rearing children with disabling conditions at home has grown over the last decade and, therefore, increased the number of handicapped children in the community. The vulnerable condition of many handicapped children predisposes them to diseases and accidents resulting in frequent hospitalizations. The frequency and the experience of hospitalization are anxiety-producing for these children as well as their parents (Knox & Hayes, 1983; Robinson, 1984). Nonetheless, little has been written about the effects that repeated hospitalizations of handicapped children have on the parent caregiver.

In this qualitative study, the caregiver meaning for parents of handicapped children was examined within the context of the situational condition of hospitalization. Intensive, in-depth interviews were performed on 23 parents of hospitalized or recently hospitalized children, 2-13 years of age, with cognitive impairments and a variety of disabling conditions. The children's primary diagnoses included meningomyelocele, cerebral palsy, congenital heart defect, retinoblastoma, congenital kidney disorder, and uncontrolled seizure disorders.

Findings in this study are demonstrative of a developmental and evolutionary process in managing the role as parent caregiver. Occurring simultaneously is an inadvertent identity emergence. Emerging as the child's "central person" was identified as the integrative theme in the substantive theory that describes how a specific parent/guardian caregiver gradually forms an identity as "protection agent", over time makes the transition to "survival agent" and later evolves as the deeply committed, strongly attached, highly informed and involved "central person".

The substantive theory, caregiving identity emergence, addresses a major nursing practice issue; dealing with psychosocial consequences of caring for a handicapped child. Evaluation and intervention measures can be formulated based on the phase identity trajectory to assist nurses to meet the needs of parent caregivers of handicapped children. Further investigations exploring the identity emergence theory in terms of intra-family supports, factors that facilitate the emergence process and the impact of intermittent, peripheral assistance on parent caregivers are suggested.

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CHAPTER 1

INTRODUCTION

Advances in medical technology and changes in legislated policies have resulted in many children with chronic illnesses and disabling conditions being cared for in the home. With more parents caring for their disabled children at home and the increased life expectancy of impaired infants and children, health care providers have become increasingly concerned with the needs of these children and their parents. For instance, the vulnerable condition of disabled children predisposes them to illnesses and accidents which often result in repeated hospitalizations. Their frequent and recurrent hospitalizations are demanding challenges for them, their parents and their network of health care professionals.

Because hospitalizations are challenging and recurring events for these families, existing studies that have examined this event and its effects on the family have concentrated primarily on parental concerns and stresses surrounding the event. Few studies have focused, however, on how parents of hospitalized handicapped children manage their caregiving in the setting, despite the fact that many parents continue aspects of caregiving during their child's hospitalization.

The focus of this study was to examine the caregiving experiences of parents of hospitalized children with long-term cognitive and physical limitations. The purpose was to develop substantive theory which describes how parents of hospitalized handicapped children deal with caregiving. Data from interviews with parents of hospitalized handicapped children provided the basis for this theory. Actual words used by respondents to describe their experiences are employed to convey their meaning most accurately. The theory explains how these parents take on the responsibilities of caring for a cognitively and physically impaired child and manage their caregiving in hospital settings.

Of the few investigators who have explored the experiences of parents of hospitalized chronically ill or handicapped infants and children, most have focused their attention on the parents of chronically ill children, leaving a scant few examining the experiences of hospitalized handicapped children and their parents. Those researchers exploring the needs of hospitalized chronically ill children and their parents have indicated that the event is not only stressful for the child but the entire family (Hymovich, 1976). Parents are confronted with the dual job of having to meet the hospitalized child's needs while maintaining the integrity of the family. Other salient sources of parental anxiety in the hospital are the ill-defined and undefined parenting role (Knox & Hayes, 1983; Young, 1984) or parents' lack of power in the hospital setting (Ferraro & Longo, 1985). Samples in these studies included either parents of congenitally impaired neonates in neonatal units (Young, 1984); parents of hospitalized chronically ill <u>and</u> long-term disabled children (Knox & Hayes, 1983) or a single case exemplar based on the investigators' observations (Ferraro & Longo, 1985).

Literature on hospitalized chronically ill children's abilities to cope with hospitalization and surgery and effects on their parents is far from being well-developed. Studies involving this population are limited in number and methodological sophistication but provide background information that is useful to research focusing on handicapped children.

Ofttimes, it is assumed that the chronic illness literature on the hospitalization event includes children with long-term physical disabilities because the term "chronic illnesses" refers to conditions that are associated with a protracted course which may be progressive, fatal, or disabling in physical or mental functioning (Mattsson, 1972). But many handicapped children are not included in most childhood chronic illness research samples. Samples for childhood chronic illness research are most often taken from populations of children with diseases such as cystic fibrosis, asthma, diabetes and cardiac problems (Hymovich & Baker, 1985; Lewandowski, 1980; McCubbin et al., 1983; Venters, 1985). When handicapped children are included in these samples, few studies include children with cognitive limitations, although these children and their parents have just as many if not more experiences in the hospital setting (Horner, 1987; Rutter, 1970).

The wealth of research on the impact of hospitalization on children centers on normal children's responses to hospitalization and their parents' adjustments to such an event (Shapiro, 1983). Current studies (LaMontagne, 1984; Thompson, 1985) related to the hospitalization of these children supports older reports that anxious and unprepared parents can transfer their anxieties to their children (Groslin, 1978; Hymovich, 1976; Wolfer & Visintainer, 1975). Such research stimulated the acknowledgement that parents play an important part in assisting the adaptation of their child to the hospitalization experience (Chinn, 1974; Hargrove, 1975; Smitherman, 1979), and encouraged the utilization of a plan of care that takes into account the effects of hospitalization and separation on children and parents (Ferraro & Longo, 1985; Henningsen, 1981).

Inasmuch as it can be assumed that hospitalized handicapped children and their parents have similar experiences as non-handicapped hospitalized children and their parents, one must be sensitive to the fact that there are many factors which make the experiences of parents of hospitalized handicapped children different. The predisposition of handicapped children to frequent bouts with illnesses and accidents result in many episodic hospitalizations (Irey, 1981). These events compel parents to deal with the demands of the health care system repeatedly. During these episodes, parents amass many experiences in dealing with this system. Consequently, health care professionals in turn, encounter a more experienced consumer, and one who has accumulated health care concerns about the child and the family. This is a challenging situation for both parties.

The health care professionals are faced with the challenge of providing care for a child and his family with complex needs, needs that the parents, on a day-to-day basis as the primary providers of health care for this child, have developed competence in meeting. This is an atypical client for the health care provider; a child-client who comes with a personal "expert" caregiver and a client with both an acute and long-term problem. The lack of knowledge about personal experiences of parents of hospitalized children with cognitive and physical limitations may significantly affect the quality of care received by the hospitalized child. Therefore this study has focused on the caregiver experiences of hospitalized handicapped children.

In this study, the terms, disability and handicap are used interchangeably to denote a mental or physical dysfunction beginning in fetal life or early childhood that disrupts normal physical, intellectual, emotional and/or social development.

The following additional definitions of terms are also used:

Perception represents one's personal meaning of a situation.

Role is defined by Turner (1968) as "a pattern of consistent behaviors composed of clusters of values and interpretations that guide in a specific social setting."

Role expectations are position-related norms that identify the attitudes, behaviors, and cognitions that are required and anticipated for a role occupant (Roberts, 1983).

"Role associates are people who interact with a person in a specific role" (Roberts, 1983, p. 72).

Interaction is the name given to the set of processes taking place between individuals. It denotes the social behavior involved when two or more persons interstimulate each other by any means of communication and hence modify each other's behavior (Schvaneveldt, 1981).

Parent refers to biologic or adoptive mother, father or guardian with whom the disabled child lives.

Functional care needs are those requirements that are necessary for the promotion of physiological, psychological, and sociological growth and development.

Problem Statement

The phenomenon addressed in this study is caregiving experiences of parents of hospitalized handicapped children. The research focus is specifically on the parent who takes on the responsibility of providing care for the hospitalized child while in the hospital, and includes influences of persons significant to them, such as nurses, physicians and family members. The research method selected for this study, grounded theory methodology, was specifically selected to allow exploration of personal experiences and perceptions of these parents regarding caregiving challenges and adjustments in the hospital.

Although there is an extensive list of interesting questions surrounding the caregiving experiences of parents of hospitalized handicapped children, the following questions were identified for study:

1) What do parents of hospitalized handicapped children perceive as their role in the hospital care of their child?
2) Do parents of handicapped children have preconceived expectations of the type and quality of tasks that should be performed by themselves and other professionals in the hospital?
3) Does a negotiation of tasks occur between parents and professionals in the hospital, and if so who initiates it, what triggers it, and what are the steps involved in the process?
4) What are processes and strategies used by parents in the care of their hospitalized disabled child?

As is customary in inquiry using grounded theory methodology, these questions were first addressed in a general manner, and as data were collected and analyzed, other more focused questions were pinpointed, such as: What is the personal construction of the caregiver role in the hospital as perceived by parents of handicapped children? Under what conditions do parents employ strategies to advance the work of caregiver in the hospital? What are the consequences of strategic implementations for parents and their hospitalized child?

Purposes of the Study

The purposes of this study were: 1) to explore the phenomenon of parent caregiver for hospitalized disabled children and 2) to discover and conceptualize a relevant description of the multiple interrelationships, interactions, and patterns inherent in their caregiving experiences. The study has resulted in findings which explain how parents manage the interactive process embodied in constructing their meaning of "caregiver" for handicapped children. This process involves a complex interplay between the parents and the socio-cultural environment of the hospital and befits meaningful explanation of the caregiver experience. Ultimately a substantive grounded theory was systematically generated which provides an explanation and aids in understanding this phenomenon. This theory is presented in Chapter 4.

The events and interactions surrounding parents of young handicapped children in the hospital setting are complicated. There are a multitude of factors that intervene and affect the perceptions and behaviors of all actors involved in this situation. The range of factors is extensive and examples include: historical experiences, cumulative knowledge, cultural-social background of the actors, and the structural organization and treatment philosophy of the establishment in which the experiences occur. To capture this complex interplay and the complexity of the parent role experiences in the hospital, a complete investigation of the phenomenon was necessary.

Although an ill-defined parenting role in the hospital setting has been suggested in a recent study as anxiety-producing in parents of hospitalized chronically ill children (Knox & Hayes, 1983), there was not enough evidence to explore the caregiving experiences of parents of hospitalized handicapped children in this light only. Thus, this research was not limited to investigating whether or not parents' roles are defined nor was it assumed that the experience was anxiety-producing.

Significance of Research of the Parent Caregiving Role for Nursing

Over the past 20 years, advances in medical science have resulted in high-risk infants who previously succumbed during the neonatal period surviving and living longer (Kramer, 1985; Newacheck, 1984). Some 4.2 percent of all children under the age of 21, in the United States have chronic limitations (National Center for Health Statistics, 1981). Gliedman and Roth (1980) present another perspective on the incidence of handicapping disorders in childhood by pointing out that one of every ten children has a handicap. In addition, approximately 250,000 infants are born with congenital defects each year in the United States (March of Dimes Foundation, 1981). The National Health Interview Survey data indicate that between 1960 and 1980, the proportion of children with any level of limitation of activity increased 111% while the proportion with severe limitations increased 122% (Newacheck, 1984). Although the rate of survival of disabled children is increasing, the number of institutions to care for them has decreased, with only an estimated 2.3% of all these children living in long-term residential facilities (U.S. Bureau of Census, 1978). This shift in the care of disabled children from institutions to the home and the increased survival rate have introduced multiple challenges to the family and its supportive network.

The hospitalization of the disabled child is an acute situational stressor that parents of handicapped children face frequently. Children with mental and physical disabilities are hospitalized more frequently than non-handicapped children (Irey, 1981). The vulnerability of handicapped children to serious illnesses and accidents is one of the primary reasons why their incidence of hospitalizations is higher. In addition, those children with physical impairments must be hospitalized often for corrective interventions or restorative surgeries. In 1981, over half of the children 0-5 years of age with activity limitations required one or more overnight hospitalizations, while, only a fifth of children the same age reporting no limitations required one or more overnight hospitalizations that year (National Health Interview Survey, 1981). In a survey by Rutter (1970), it was reported that mentally retarded children experienced convulsions, recurrent bronchitis, major diseases, and admissions to hospitals more often than the intellectually normal child. Thus, there is a close association between severity of handicap and number and duration of hospital admissions of these children, notwithstanding the fact that the diagnostic process probably required many hospital admissions and contacts with a variety of medical professionals.

This tendency of handicapped children to be hospitalized repeatedly, although considered a strain on parents, may create just as much of a strain on the professionals. The disabled child usually has multiple and complicated nursing care needs. Additionally, if the handicapped child is extremely debilitated, and has severe cognitive impairments, more difficulties in nursing care could occur. The disabled child with his conglomerate of complex needs makes it difficult for professionals to meet the current health care mandates for resource management. Inasmuch as this patient brings along a personal caregiver, this does not mean that the professional can or should totally relinquish professional duties to the caregiver. Although current trends toward "care-by-parent" have been fostered in many hospitals, is this the most feasible approach in a situation where the parent has been totally responsible for the functional activities of this child 24 hours of the day from the birth or diagnosis of this child?

Traditionally, in the hospital, it is accepted that the nurse is the professional who decides how much parents participate in the care of their hospitalized child. The nurse is responsible for coordinating the child's care and has duties that encompass those of the parents at home. Although the day-to-day management of the hospital care for the disabled child is regarded as the nurse's responsibility, there are limits to the options available to the nurse in making the best decisions concerning care management protocol. The nurse is performing her duties within the hospital structure with its set of rules and therefore may be constrained by the philosophic emphasis of the organization. With the current concern for cost-effective care, the parent will be encouraged to stay with the child and "encouraged" to participate in the child's care in whatever manner feasible. Due to the overlap of nursing and parental duties, and a nonspecific description of parental participation, subjective distress and adversarial relationships are prone to develop between the professional and the parent.

This potential for the development of adversarial relationships or negative feelings toward a professional in a situation where ongoing positive feelings are essential, necessitates investigations that will elucidate the specific interactions and parents' perceptions of this event. Through such investigations, the components of the interactions will be identified and knowledge will be discovered to sensitize health professionals to parental needs. This knowledge can be used to assist parents and nurses in collaboration to establish role functions which can be accepted by all parties. In addition, such information could fill the void of substantive knowledge that exists in current literature about the role experiences of parents of young hospitalized handicapped children and provide a stimulus for additional research in this area. With more scientific bases for nursing care practices for these children and their parents, guidelines for interventions that are specific to the expressed needs of parents can be formulated to assist them in adapting to their hospital role.

Summary

Scientific and technological advances have resulted in increased life expectancies for children with disabling conditions. In addition, public laws have enabled more parents to care for these children at home and have increased community services for them. With the number of parents rearing children with disabling conditions at home growing over the last decade, an increased number of handicapped children are now present in the community. These factors have placed enormous responsibilities on the family and the network of community services.

Parents in their efforts to rear a disabled child must frequently deal with disability-related stressors of the child, such as severe illnesses, accidents, and restorative or corrective surgeries. The vulnerable condition of many handicapped children predisposes them to diseases and accidents resulting in frequent hospitalizations. Through repeated exposure to the hospital system, parents accumulate experiences which may or may not assist them in subsequent hospitalization encounters. In addition these parents come to the hospitalization experience with a special expertise in communicating and caring for this child.

The combination of parental expertise and the experienced knowledge as a result of the recurrent encounters with the hospital professional precipitate challenges and strains for both the parents and the professionals. Although the basis for the challenges and strains may be different for the parties involved, their presence could significantly affect the quality of care given the disabled child. This fact and the lack of substantive knowledge on this issue support the need for research in this area.

CHAPTER TWO

LITERATURE REVIEW

This chapter presents a literature review focusing on elements that may affect parent role enactment when a young handicapped child is hospitalized. The review is organized into three major segments. The first section contains a summary of literature that addresses the experiences of parents of chronically ill or handicapped children with the health care system. The purpose of this section is to illustrate the importance of the health care system to these parents and to demonstrate the scope of the challenge in maintaining positive relationships between the parent caregiver and health care providers.

The second segment presents a discussion of the construct of role within the sociopsychological framework of interactionism. This content is included to illustrate the interactive relationships of these parents in the hospital with a primary role associate the nurse, and to provide a conceptual understanding of the broad range of variables embodied in this interaction.

The third and final segment presents a summary and critique of research that addresses parental experiences during the hospitalizations of their disabled children. To obtain a comprehensive overview, the term "disabled children" was broadly defined to include those with childhood chronic illnesses and handicapping conditions with the exception of mental illness. Inclusion of the section is necessary to furnish a background of previous work that focuses on parental hospitalization experiences.

Health Care System and the Handicapped Child's Parent

A review of the literature reveals a limited number of writings, research and narrative, on parents of disabled children and their experiences within the health care system, although it is recognized by professionals that access to quality medical care is a major need for these families (Kramer, 1985; Martin, 1985; McCubbin, et al., 1983; Sassaman, 1983). Though there is a growing body of anecdotal and narrative literature written by parents of handicapped children, and this review summarizes that literature which is published in professional books and journals.

Three basic thoughts are dominate in the existing literature and are summarized as follows:

1. The health care system is one of the most necessary support systems for these parents.
2. Parental exposure to the multitude of professionals create demands and anxiety.
3. The parental responsibility of maintaining the child's health is challenging.

The disabled child's condition necessitates the involvement of parents with the health care system. Hymovich (1985) conducted an exploratory study to determine perceptions that parents of children with cystic fibrosis have of the impact of their child's condition on family functioning. In the convenience sample of 100 parents, 92% of the parents mentioned the coping strategy of asking physicians and 88% mentioned asking the nurse for information regarding the child's development, care, and condition. The convenience sample included a range of family structures and developmental stages, with the majority of families (85%) having children who had been diagnosed more than a year.

Parents' initial encounters with this system usually begins with the diagnosis of the disorder (Mullins, 1987). A relationship thus begins and continues throughout the child's lifetime, a lifetime beset with intermittent requirements for medical attention. The required medical attention comes from a network of professionals, such as physicians, nurses, social workers, physical therapists, and psychologists who offer an array of services. These services may be helpful and supportive, but may simultaneously create additional demands and expectations. This exposure of the parents to various professionals or "experts" leaves them open to critical inspection and scrutiny.

Gallagher and Gallagher (1985), who are educators and parents of a handicapped child, shared their feelings about their exposure to assorted professionals in their chapter of the book, Parents Speak Out. According to the Gallaghers, the threats of scrutiny and the experience of having been criticized, deter and delay parents from utilizing needed services (Gallagher & Gallagher, 1985). Prior negative experiences are valid reasons for parents' reluctant use of certain health care services. If the disability was not an obvious one prior to the initial diagnostic procedures, parents possibly had to expend exorbitant amounts of time, energy, and finances convincing the clinician that an actual problem existed. Even after the diagnosis is made, professionals have made parents feel as if they are overreacting to the condition of the child (Gallagher & Gallagher, 1985).

The awareness of parents that they are considered as contributors to their child's condition often made them reluctant to seek immediate medical help on the grounds that they might be overreacting (Gallagher & Gallagher, 1985). Ofttimes when medical attention is sought and the child's condition results in hospitalization, parents may be made to feel guilty that they did not seek help earlier.

The feelings reported by the Gallaghers were a component of consistent themes in a literary study by Mullins (1987). Mullins conducted a literary analysis of sixty books written by parents with disabled children from which four common themes emerged: 1) realistic appraisal of the disability, 2) extraordinary demands on family, 3) extraordinary emotional stress, and 4) resolution. The importance of and the quality of professional relationships was a component of the theme involving extraordinary demands on the family.

Fortunately, changes are occurring where professionals are beginning to see that the child's handicap and situations related to the child's disorder cause parenting problems and parental stress (Gallagher & Gallagher, 1985). Professionals also realize that parents gain insightful knowledge with each professional encounter, and the manner in which this knowledge is gained makes lasting impressions and influences perceptions and behaviors in later situations (Kramer, 1985; Sassaman, 1983). However, because the ultimate responsibility for managing the child's long-term disability is the parents', the focus of the child's health care must include the expressed needs of the parents, and not the "perceived needs of the parents by the professional" (Horner, Rawlins, & Giles, 1987, p. 40).

Parental Responsibility and the Handicapped Child's Health

The Parent Role

The family member position of parent is a persistent role. Parental responsibilities and strains extend across the entire life cycle (Pearlin, 1983) and into every situation involving the child. The task of parenting, that is the act of rearing any child, is an intense and long-term endeavor. This is particularly true when the child is disabled. Parents of a disabled child work continuously to balance family needs, the demands of managing the child, the restrictions imposed by the disability, and their specific goals for normalization (Robinson, 1985). Robinson (1984) states that parents of chronically ill children attempt to minimize the restrictions imposed by their child's illness and management regimen to foster the child's growth and development within as normal a lifestyle as possible. As the pivotal organizers of the family, these parents have the enormous responsibility of buffering the disabled child's impact on individual family members in efforts to decrease the overall impact on the entire family unit (Robinson, 1985).

When a child has a disabling condition, parents must master many tasks which are not considered to be usual parenting tasks. In addition to fostering the socialization and development of a child with aberrant cognitive and physical abilities, parents have the tremendous responsibility of employing medical interventions for which they have no formal training. These parents are the daily primary health care providers (Ferraro & Longo, 1985; Robinson, 1986). They develop individualized methods for implementing these medical care procedures.

Specific procedures such as gavage, gastrostomy or stimulated oral feedings, tracheostomy care, catheterizations and the administration of medications and other treatments are now performed by parents in the home. These procedures at one time required professional expertise in specialized settings (Whaley & Wong, 1982).

But regardless of how successful parents are in decreasing the overall impact of the handicapped child on the family, and performing specialized procedures in the home, conditions that require long-term adjustments, such as the disability of a child, can be extremely taxing. Even if the family learns to function adequately in the presence of such prolonged hardships, any acute problem, for example the acute illness of the disabled child, will challenge the family's pre-existing functional patterns and tax an already overworked family unit. For example, McCubbin and Patterson (1981) summarized the hardships of families with a chronically ill child as:

1. Strained family relationships,
2. Modification in family activities and goals,
3. The burden of increased tasks and time commitments,
4. Increased financial burden,
5. Need for housing adaptation,
6. Social isolation,
7. Medical concerns,
8. Differences in school experiences, and
9. Grieving (Patterson & McCubbin, 1983, pp. 25-26).

Five of the nine hardships listed: tense family relationships, financial strains, modifications in family activities and goals, increased tasks and time commitments, and social isolation, could be intensified when a disabled child is hospitalized.

When a handicapped child is hospitalized, often one parent stays in the hospital with the child. This results in the relinquishing of that parent's ongoing responsibilities and duties to someone else. Because of this responsibility shifting, modifications in family activities occur. In addition, there will be added expenses for food and accommodations for the parent who stays with the child. Both the alteration of activities and additional financial requirements could produce tense family relationships. Since the hospital is one of the few systems that the family of the disabled child must use and the nurse most often interface with these parents in this setting, then a discussion of the psycho-social process and variables of the interaction is warranted. Therefore in the next section the construct role is presented within the framework of interactionism.

Nurse-Parent Role Interaction

When a person interacts with another person in a specific role, they are considered role associates (Roberts, 1983), as are the parents and the nursing staff in the hospital. Each role associate comes to this situation with individual feelings, beliefs, history, values, and attitudes about the ways in which each should behave (Burr, 1979). During their interactions, the parents and nurses improvise, explore, and judge what is appropriate on the basis of the situation and the responses of each other at the moment. This is a dynamic process wherein the parents and nurses engage each other by any means of communication thereby modifying each other's behavior (Schvaneveldt, 1981). From my own experiences in nursing practice and education, the modification of behaviors may or may not be pleasing to either or both role associates.

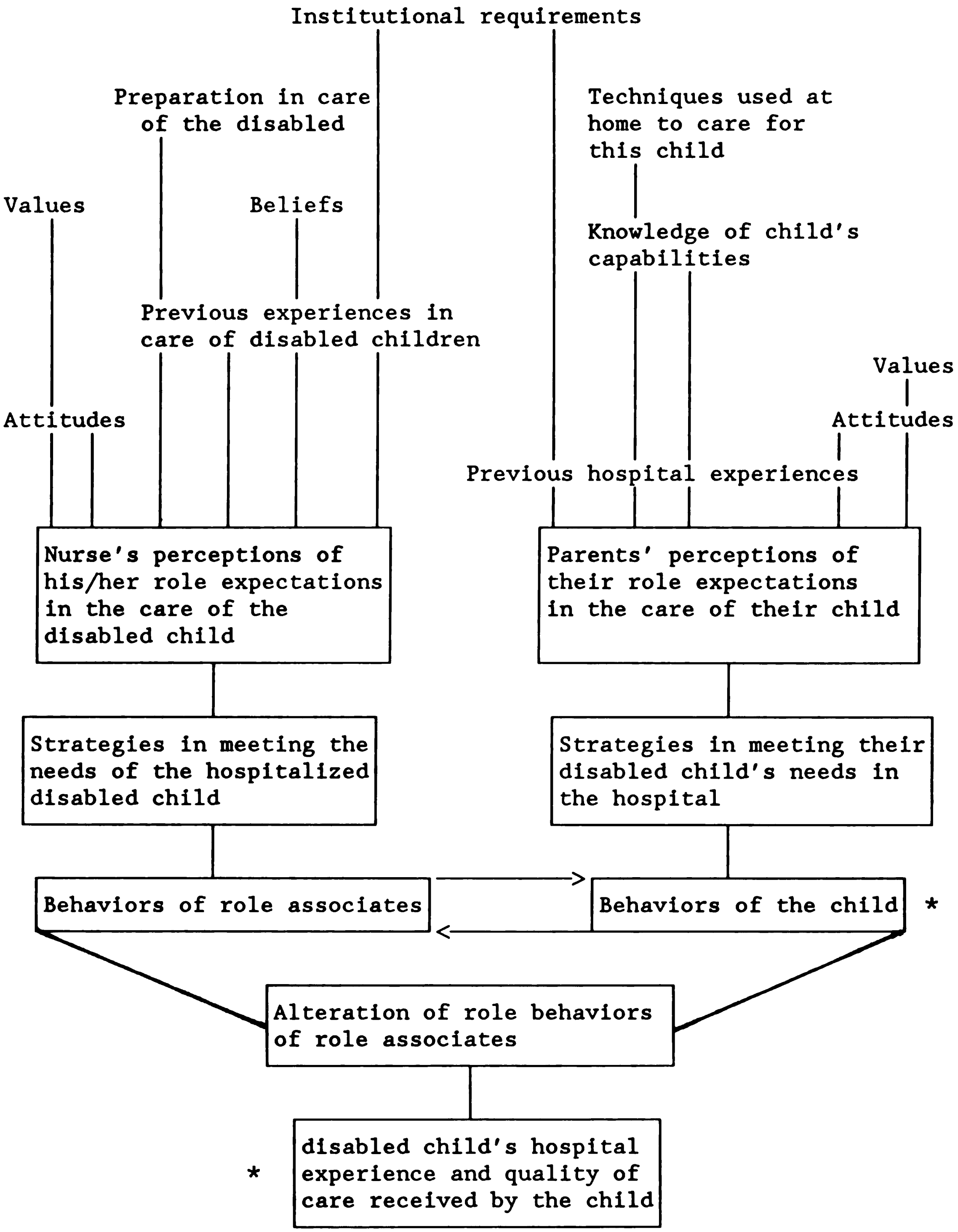
Three dyads, parent-child, nurse-child, and parent-nurse, actually interact among each other and modify the behavior of each member when the disabled child is hospitalized. When a disabled child is cognitively impaired and has limited capacity to communicate, it is often impossible to understand the feelings of the child. There are certain behavior changes of the child that are cues and may indicate his response to the experience. However, these behavioral cues may be detectable only by parents. Parents may see it as their responsibility to interpret these cues and explain them to the nurse.

Ideally, the nurse and the parents of disabled children as role associates in the hospital should clearly define their individual role expectations to each other in order to obtain a positive role relationship. Once each role associate's expectations are defined, it can then be determined if expectations are congruent.

An incongruency of perceptions between the nurses and parents can adversely affect role performances of all associates (Knox & Hayes, 1983). According to Knox and Hayes (1983) without role clarity, parents became anxious and nonparticipative in the care of their child or carried out procedures in manners contrary to those of the nurses. On the other hand, nurses may approach caregiving in a manner which is unfamiliar or frightening to the child or expect different parent implementation of tasks. As a result of the nurse's actions, the child may demonstrate behaviors which may contribute to parental stress and affect the parents' performances of their role. The reactions may lead to a decline in the quality of care given to the child.

Inasmuch as the role expectations of role associates co-act (Burr, 1979), a description of the parents' role expectations can lead to a clear definition of the role behaviors involved in the care of the disabled child. But, it is an infrequent occurrence when the nurse and the parent verbalize their specific expectations. Unless there is an obvious disagreement, both the nurse and the parent will carry out their role according to their personal specifications or attempt to adjust role behaviors based on nonverbal cues from each other.

The complex nature of a social experience deters the easy isolation of factors which may influence role enactment. However, to illustrate this interactional process involved between the parents of hospitalized disabled children and nurses, this author constructed a model representing this interaction. Figure 1 depicts the personal role dynamics of the role associates; the father and mother or guardian of the disabled child and the nurse(s) who provides care for the child and the relationship of these sets of role perceptions to the care of the hospitalized disabled child. Starting at the left of the model, the nurse's perceptions of his/her role in the care of the hospitalized disabled child which is a product of his/her attitudes, values, beliefs, etc., influence the nurse's perceptions of the parents' roles and the nurse's strategies used in meeting the needs of the disabled child. On the right of the model, the parents' perceptions of their role in the care of their child which is a product of their attitudes, past experiences, values, etc., influence their perceptions of the nurse's role in the care of their child and the strategies used by them to meet their child's needs in the hospital. It follows that if all the persons associated with a role hold their individual expectations, discrepancies in expectations may occur (Roberts, 1983).



*Beyond the scope of this paper
(Perkins, 1986)

Figure 1. Interactional relationship of the roles involved in meeting the needs of the hospitalized disabled child and the variables that affect role perceptions

This model also illustrates that the disabled child's behaviors can affect and alter the behaviors of the role associates, and that all behaviors influence the quality of care received by the child. This is a significant fact to keep in mind; however, the complex issues involved in the child's hospital experience are beyond the scope of this research.

Research on the Experiences of Parents during the Hospitalization of Their Disabled Children

Several investigators have studied the needs of hospitalized chronically ill children, but few have investigated the needs of parents during the hospitalization of these children. Six studies have been reviewed, five will be presented in this section, as they pertain to parental hospital experiences. One study, although the specific focus was not on the hospital experience, reported remarkable statistics on the health care professional-parent relationship. This information was presented in the earlier section of this chapter on the health care system and the disabled child's parent.

Of the five remaining studies, they all are varied in design and methodology. Three of the five use only interview data; one uses observational and interview data; another is an intervention study and cites a single case exemplar; and the fifth study uses self-reported data from questionnaires and scales. These studies are introduced and critiqued in this section relative to their content and are not presented in the above order.

The admission of children with handicaps to the hospital and the hospitalization experience have been identified by parents of these children as anxiety intensifying (Goodell, 1979; Robinson, 1984; Knox & Hayes, 1983). A salient source of parental anxiety identified by the few investigators who have explored this event, is the ill-defined parenting role in the hospital setting (Knox & Hayes, 1983; Young, 1984). In a grounded theory study of two groups of parents, Knox & Hayes (1983) disclosed several variables for potential parental stress for parents of hospitalized chronically ill children. The groups included; one group consisting of 10 mothers, three fathers, and one grandmother of 11 children hospitalized with long-term disabilities, excluding cancer, and another group of 24 mothers and four fathers of 24 children with cancer. Parents in this study were able to describe their own stress--its cause, effects on themselves and the family; and its management. The purpose of this study was to explore parent perceptions of the hospitalization experience and not to test a hypothesis. However, there are several limitations such as small sample size, variations of disorders and failure to specify age of the children readily identifiable in this study. The comparison of perceptions of parents of children with unspecified long-term disabilities with the perceptions of parents of children with cancer; a potentially terminal illness, will definitely uncover differing views between the two groups in relation to the significance of that particular hospitalization to the child's prognosis. The authors did not specify the number of parents who verbalized certain views nor did they state to which group these parents belonged. Nonetheless, their use of a grounded theory method diminishes the effects of such limitations. By using this qualitative method the researcher extracted common themes in a comparative analysis from the interview scripts of parents of children with a variety of diagnoses. This validated the universal existence of the identified themes. Thus the implications regarding stress related to the parental role in the hospital, can be regarded as significant because of the consistency in which these themes were reported.

Wells and Schwebel (1987) employed six measures at three intervals to assess the effects of parental stress and parent-child involvement on the chronically ill child's ability to cope with hospitalization and surgery on 40 mothers of handicapped children. The three intervals were: 1) 2 to 3 weeks prior to hospitalization, 2) during hospitalization, 3) 1 week after discharge. The pre-hospitalization measures were the Parenting Stress Index and The Family Relationship Scale (FRS). The in-hospital measures were the Observational Ratings of Child and Mother Upset and Cooperation and Mother and Child Retrospective Rating of Anxiety. The post-discharge measures were the Global Ratings by Nursing Staff upon Discharge (developed by the investigators) and the Post-Hospitalization Questionnaire (PHQ). In the convenience sample of 40 mothers of handicapped children, the children's diagnoses were varied. Twenty-seven percent of the children were cerebral palsied, 22% had a congenital hip deformity, 16% had myelomenigocele, 16% had club feet and the remaining 19% had a variety of other congenital anomalies. Forty-seven percent of the children (for whom scores were available) were found to be developmentally delayed. The children also had a wide range of prior experience with hospitalization and surgery, with the mean number of previous encounters being 2.4. T-tests were used to compare the obtained scores with published norms of families with normal children. The results indicated that the mothers of children in the developmentally delayed group reported significantly ($F = 3.80$, $p < 0.05$) more anxiety (mean = 32.3) during the hospitalization than mother of normal children. However, children with developmental delays, when compared with children in the normal developmental group, were not more vulnerable to the stress of hospitalization and surgery. The investigators attributed this discrepancy between the children and the mothers to beliefs among mothers of developmentally delayed children that their child is at greater risk due to relatively deficient cognitive-developmental skills and consequently more anxious. Pearson correlation coefficients were obtained between the number of previous surgeries and the dependent variables; mother coping and mother anxiety. The findings indicated that 1) mothers of children with fewer previous surgeries were rated as more anxious ($r = -0.48$, $p < 0.005$) and less cooperative ($r = 0.37$, $p < 0.05$) during the anesthetization procedure and reported greater levels of anxiety during the hospital stay than mothers of children who had more previous surgeries ($r = -0.43$, $p < 0.005$). This supported the commonly held belief that the greater the preparation, the less anxiety, and that more exposures to the experience usually increase knowledge in that area. Although this study contributes significantly to the research in this area in that it is the only theory-testing study published to date, the investigators themselves caution against overly broad interpretation of their findings. The study should be replicated with matched groups of normal and chronically ill children in order for the findings to be accepted as creditable. In addition a larger sample size could make the findings more generalizable.

Robinson (1984) interviewed nine parents from six families of hospitalized children with chronic illnesses such as muscular dystrophy, meningomyelocele and toxoplasmosis. Through interviews, it was found that in the hospital setting, parents often find themselves in complex, contradictory situations. Discrepant orientation to sickness, discrepant therapeutic goals, discrepant expectations about hospitalization and discrepant perspectives about family involvement attributed to the difficulties parents experienced with care in the hospital. Robinson (1987) described the discrepancies as "roadblocks" to family centered care and, although there was evidence in her study of parental skills and strategies to cope with the difficulties, very few were presented. However, the findings of this study are worthy of further discussion and will be presented in subsequent paragraphs.

A few methodological flaws were evident in this study. In qualitative research multiple interviews of 9 informants who are considered "expert witnesses" can suffice as an adequate sample, however the investigator did not state what number of interviews was considered to be "multiple" nor how intensive the interviews were. It is also stated that the length of time that the respondents had been caregivers ranged from 3 months to 21 years. Three months is a short length of time to be considered an "expert" caregiver unless the investigators used additional criteria which were unpublished, to determine this quality. Even though the investigator stated that the parents were especially knowledgeable about the experience of having a child repeatedly hospitalized, criterion for "knowledgeable" and "repeated" were not given nor discussed.

In findings of Robinson's study (1984) several core themes which are components of the core categories on discrepancies were presented. A predominant theme in the parents' accounts related to their need to normalize the experiences of their child's repeated hospitalizations. To combat the disrupting force of hospitalization, parents incorporated the event as an anticipated aspect of the trajectory in order to reduce its negative impact on the family.

Another theme that emerged is that parents perceive their therapeutic perspectives to be different from those of involved health care providers, a finding which was also demonstrated in the study by Knox and Hayes (1983). Parents of disabled children enter the hospital with preconceived expectations about themselves as parents (Knox & Hayes, 1983; Robinson, 1985) and about the needs of their child. They have established patterns of managing the child's care at home. Within the hospital setting, however, parents encounter many differences between their preconceived role expectations and the professional staff's role expectations for parents (Robinson, 1987). Anxiety experienced by these parents is due, in part, to the undefined parental role in the hospital, the discrepant therapeutic goals and a lack of communication of role expectations between themselves and the health care professionals (Knox & Hayes, 1983; Robinson, 1987). Robinson (1987) concludes that unacknowledged discrepancies lead to unfulfilled expectations and parental dissatisfaction with care.

Data in Robinson's study (1984) also indicated that parents will often relinquish the medical and treatment activities which they have been performing at home to health care providers because they believe that the providers <u>should</u> have more expertise. Even if parents prefer not to relinquish their duties, the child's hospitalization places parents in a position where they must share or relinquish their previous duties and responsibilities of the child's care (Robinson, 1987).

In addition to adjusting to the shared-role experience during the hospitalization of their disabled child, parents must execute duties in an environment which is very different from the home which contributes to their feelings of incompetency (Robinson, 1984). Not only is the set-up structurally different but the objectives and priorities between parent and professional may differ as well (Robinson, 1985). During the hospitalization experience, parents must attempt to carry out the primary parental activities of interpreting the child's behavior, teaching the child new skills, and providing support during new and frightening experiences in unfamiliar surroundings. According to Knox and Hayes (1983), parents, like their children, are faced with strange and frightening experiences. They describe themselves as feeling incapable of appropriately performing their duties in this situation.

Further magnification of parental feelings of incompetence occurs when the parents' interactions within the hospital setting are less than desirable (Robinson, 1984). With the exception of the initial hospitalization of their child for diagnostic tests, parents enter the setting with established expertise regarding the management of the child's disability and the child's responses to the treatment regimen. The parents who have been sole providers of care at home enter the hospital expecting complementary relationships. However, the philosophies of most hospitals are predicated on the care and cure of acute and episodic illnesses. Therefore, when a disabled child is hospitalized, parents with their expertise must interact and perform their roles within an external social system with a philosophically different, and ofttimes, uncongenial organization.

The philosophies of the parents of the disabled child and the staff of the hospital may be mutually exclusive and offer broad potential for conflict (Robinson, 1985). The hospital staff have segmented concerns for the disabled child. Each staff member has an individual, specialized interest in the care of this child and is fulfilling his/her duties within established and inflexible protocol of the hospital. The staff is oriented toward management of acute illnesses of the client and most often is not concerned with the ongoing problems related to the disability (Robinson, 1987).

The parents, on the other hand, have broader objectives and see the disabled child as a whole being with an acute problem which may affect his long-term status. The parents have informal rules but routinized approaches to the care of this child. They are more concerned with the needs of the child as a person. Parents in Knox and Hayes' (1983) and Robinson's (1984) studies found it difficult to confront the incongruences, for fear they may alienate the staff. However one can not determine the actual existence of incongruences because only the parents' perceptions were ascertained in both Knox and Hayes' and Robinson's studies.

The different ideologies of both parties may result in subtle messages from the staff to the parents of the disabled child (Robinson, 1985). Parents may be told by the staff that they are a significant part of the team, but given messages to indicate that they are insignificant. Examples of such behaviors can be cited from the author's own professional experiences and include: asking for information about the child's functional status that is disregarded; ignoring parents' suggestions regarding treatment procedures; and ignoring parents' observations of signs and symptoms related to the medical or surgical problem for which the child is hospitalized.

The health care professional primarily determines how, when, and if parents participate in the care of their child. Most of the time the exact participation expected is not described. Subjects in Knox's study (1983) indicated that "parenting a child in the hospital can be like having a job without a job description."

Young (1984), in conversation with parents of congenitally impaired infants in Sweden and Britain, supported the parents' perceptions reported in Knox's study (1983). In an anecdotal report, Young states that parents expressed feelings of intimidation toward the "foreign" hospital staff, and would not verbalize feelings to the staff for fear of being labeled "emotional" or "difficult". It was also noted from conversations with these parents, that they possessed limited knowledge on their legal rights and duties, the policies and procedures governing the hospital, and their roles in the parent-professional relationship (Young, 1984).

Hospitalization changes the amount and kind of parent-child contact and parental control (Ferraro and Longo, 1983). Parents who were in control of their child's care at home, enter the hospital setting expecting a co-managerial relationship with the staff (Robinson, 1985). Instead, they become entangled in a system that tends to disregard the dynamic nature of their experiences and emits subtle messages that they are insignificant to the process of providing care for their child. This mishandling of parents generates frustration in parents who may retaliate by mishandling professionals (Roos, 1985). A vicious cycle thus develops as parental mishandling of professionals reinforces the professional's negative view of parents which foster the mishandling of parents.

The ideal parent-professional interactions are intended to be supportive. It is expected that supportive interpersonal relationships that promote security, nurturance, self-worth, social integration, and guidance are facilitated by the nurse (Brandt, 1984). Ferraro and Longo (1985) indicated that many nurses and other health care professionals assume that dysfunction is a normative pattern in families with disabled and chronically ill children. Thus Ferraro and Longo (1985) explored an alternative framework for assessing families who are coping with a child who has a chronic condition and an acute medical problem. An assessment model based on Miller's patient power resources framework (1983) was developed to focus on families' response to long-term childhood health problems and successful adaptation. The model was applied to a clinical case of a family with a severely retarded, epileptic child with an acute head injury. This exemplar demonstrates that when the disabled child is hospitalized and family functioning problems are expected when none actually exists, counterproductive nursing actions may be implemented and that tension between the family and health care providers can be diminished over time if the nursing staff include in its goals the promotion of continued family self-care (Ferraro & Longo, 1985). However, the nurse should properly assess and evaluate the needs of this family because some parents may view the hospitalization of their child as a respite. The parents may need a respite from the demanding caregiver role and see the hospitalization of the child as an opportunity to have some time for themselves and if their needs are improperly assessed showing that the continuation of family self care is required, they may feel obligated to remain with the child constantly.

To summarize, the preceding literature suggests that the hospitalization of a disabled child is a stressful time for parents. Several elements have been indicated as contributors to the stressful nature of the event, such as ill-defined parent role, parents' lack of control, mutually exclusive philosophies of caregivers, structural and philosophical differences of the agency and/or a cycle of parent-professional-parent mishandling.

Although examples in the literature convey the potential for conflict between parents and hospital staff, very little substantive evidence has been presented to support the actual existence of such a dilemma. No published research to date has unraveled the intricate details of interactions and consequences involved in the caregiver experiences of the parents of hospitalized handicapped children as they are perceived by these parents.

Because of the complexity of such real-life situations as that of the parent caregiver, it may not be possible to make known a full explanation of the event (Connally, 1980), however, examinations of the lived experiences of these parents can disclose personal meanings and interpretations that could schematically depict their construction and understanding of this phenomenon. Several investigators have isolated certain factors that seem to influence parental role adjustment in the hospital. Therefore, the remainder of this chapter includes a discussion of these factors.

Factors Influencing Parental Role Adjustment

Internal (personal) and external (environmental) factors influence parental role adjustments in the hospital. Comprehension, perception, and coping strategies are significant internal factors which influence parental abilities to adapt their role performance in the hospital (Mattsson, 1979). Mishel (1983) proposed parental perceptions of their child's hospitalization as a vital variable which affects their coping responses in this situation. This proposition is supported by Lazarus and Launier (1979) in the statement that: "cognitive factors are central in determining the impact of stressful events and the ways individuals interpret or appraise a situation affect coping and the emotional, physiological, and behavioral reactions to stressful experience" (Cohen & Lazarus, 1979, p. 218).

There are also several external factors that are instrumental in facilitating parental role adjustments in the hospital. Certain qualities of the health care providers such as, trustworthiness, empathy, honesty, competence, and reliability have been identified as affecting parental adjustments (Knox, 1983). Increased exposure to the hospitalization situation, for example, length and frequency of the child's hospitalizations, was reported as an additional factor affecting parental adaptation. Elements influencing parents' self-esteem and sense of mastery such as increasing knowledge and empathic personnel were indicated as easing the stress of role adjustment (Knox & Hayes, 1983).

An important element influencing parental adjustment to the hospitalization of their child is the parents' perceptions of the trustworthiness of the health care providers (Knox & Hayes, 1983). Parents will entrust their child's care to someone whom they believe is confident, competent, and honest. They tend to seek out one person they believe is reliable, will share factual information, and will acknowledge both the child's and parents' needs.

Although parents in Knox's study did not specifically identify self-esteem and sense of mastery as factors which facilitated role adjustment, components of these constructs were described. "Self-esteem refers to the positiveness of one's attitude toward oneself" (Pearlin, 1983, p. 5). Mastery concerns the extent to which one regards that life situations are under one's control (Pearlin, 1983). Lack of knowledge was a key factor identified by parents as anxiety-intensifying (Knox, 1983). The amount of information that parents received about hospital protocol and policies also affected the adaptive process. Information decreased uncertainty of the situation and allowed the parents to assign meanings to events thereby leading to a feeling of control which fosters a positive attitude about the fulfillment of their parental role.

The more lengthy the child's hospitalization, the more opportunities were provided to parents to gain useful knowledge. Parents in Knox's study (1983) stated that as they spent more time in the hospital with their children, they felt more comfortable and less fearful. Time afforded parents the opportunity to become familiar with the physical environment, routines, and staff. Over time, parents developed an ability to predict future occurrences in this setting, thereby making them feel more confident in their ability to perform appropriately.

Previous hospital experiences affect parental role adjustments. Although their child may not have been hospitalized in the same agency each time, parents transferred information from past experiences to current situations. More rapid adjustment was attributed to this transferring of knowledge (Knox, 1983).

In sum, several factors that parents perceived as helpful in diminishing the stress of the event of hospitalization of their chronically ill child is delineated in the literature. These factors include frequency of hospitalizations, acquisition of knowledge and personal qualities of the staff.

Summary

The hospital as a member of the community network of services must provide services for a child and family with multiple and complex needs. Hospital professionals must also interact with the parent care provider. When the parents of the disabled child meet professionals on their territory in the hospital, the potential for conflict exists. The hospital organization and its staff function under philosophical guidelines that are different from those of the parents. Thus parents must perform duties in philosophically and structurally different environments and among professionals who may or may not share their child care goals or acknowledge the parents' expertise. However, they attempt to adjust their behavior and caregiving strategies and function within this environment because they know that they must depend on this system to provide frequent, necessary care for their children.

The potential for clashes between parents of handicapped children and professionals in the hospital exists. Most often, clashes may occur because the hospitalization of the disabled child brings together two factions with differing ideologies regarding the manner in which care should be given to this child. Because there is a complicated interplay of factors contributing to the functioning of all parties involved in the care of this child, the differences may not be easily resolved.

Another potential area of conflict between hospital professionals and parents of disabled children is their expertise. The child care "experts", the parents, and the professional "experts" in the hospital are forced to "collaboratively" meet the needs of the child. However, collaboration may not take place. Professionals, although they may verbalize the significance of these parents, can transmit subtle cues of their insignificance and how they actually want the parents to behave.

Several authors have made attempts to describe the stressful nature of parents' experiences when their chronically ill child is hospitalized (Knox, 1983; Ferraro, 1985). Parents expend much physical and psychological energies in managing the care of their hospitalized handicapped child but an adequate depiction representing the personally relevant context of the phenomenon has yet to be extracted and documented.

Although it has been hypothesized that this hospital experience is extremely stressful for parents of hospitalized chronically ill children (Knox & Hayes, 1983), an extensive review of medical and nursing literature revealed one study and few writings that explore the hospitalization experiences of parents of children with cognitive and physical limitations. Yet it seems that systematic research of this phenomenon is needed to provide the required knowledge base for designing effective collaborative nursing practices for this type client situation. This review of the literature reveals the scarcity of research on the social-psychological experiences of parents of hospitalized disabled children and strongly points to the need for research in this area.

CHAPTER 3

METHODOLOGY AND THEORETICAL PERSPECTIVE

This chapter presents the process of inquiry used in this study, grounded theory methodology. This research mode provided an avenue for assessment and analysis of the parent caregiver role when a young handicapped child is hospitalized. A description of the grounded theory method, the sensitizing theoretical perspective underlying the method and the perspective appropriate to this research question are presented. The strategies of inquiry and analysis procedures of grounded theory such as, interview, comparative analysis, dimensional analysis, and theoretical sampling are discussed. The research design, criteria for sample selection, specific inquiry and analysis procedures of grounded theory utilized to derive the conceptual schemata and subsequent theory of this study are delineated and described. In the final section of this chapter, an overview of the strengths and limitations of this method in exploring the psycho-social phenomenon of caregiving for a hospitalized handicapped child is presented.

Grounded Theory

Description and Theoretical Underpinning of Grounded Theory

Grounded theory, a retroductive approach to theory generation is a method of exploring complex social problems and generating conceptualizations and theories from respondents' data (Corbin, 1986; Glaser & Strauss, 1967; Schatzman & Strauss, 1973). The retroductive approach to research means that the investigator identifies a general question that provides focus for the investigation, derives theoretical concepts inductively from the data and verifies them deductively by theoretical sampling, constant comparative and dimensional analyses. That is, the investigation begins with general questions and eventually becomes more focused and deductive as patterns, discontinuities and gaps in the data are identified. Unrestricted by prior assumptions but guided by sensitizing definitions, the researcher attempts to understand the multiple interrelationships in naturally occurring phenomena in their naturally occurring states (Patton, 1980). The purpose of the investigation is to obtain a meaningful description of the phenomenon as defined by respondents experiencing it rather than to test previously formulated hypotheses.

Grounded theory is most appropriately applied in areas where little research has been done; however, its utility is not limited to unexplored or undiscovered territories. According to Strauss (1967) social reality or the meaning of a situation as created by people is so complicated and complex that different perspectives of prior theory often exist; thus, different perspectives of received theory can be explored using this method.

This method can also be utilized as an alternate or supplementary approach for quantitative modes of research, and can be employed when the problem area and/or data do not lend themselves to quantification (Corbin, 1986). It may be used when a particular universe is unknown or undescribed and therefore is impossible to obtain random stratified samples (Schatzman & Strauss, 1973). When the universe is unknown, grounded theory is utilized "to identify the core variable or the process that describe the characteristics of a particular social world" (Artinian, 1986, p. 17). The researcher's aim, in this case, is to answer the general question of what is going on and how (Artinian, 1986).

Anselm Strauss and Barney Glaser developed this approach during the 1960's as a form of naturalistic inquiry which come under the umbrella of field research (Schatzman & Strauss, 1973). This form of research has its roots in the field of sociology (Strauss,1967) and is based upon symbolic interactionism (Artinian, 1986). Symbolic interaction is a theory about human actions, interactions and emergent patterns of conduct, and can be used as a framework for exploring and studying human behavior (Turner, 1982). According to Blumer (1969), the symbolic interactionists use exploration and inspection in performing a direct naturalistic examination of the empirical social world.

Overview of Symbolic Interaction Theory and the Grounded Theory Methodology

Symbolic interactionism emphasizes relationships among individuals and society. The interactionist teachings of George Simmel, Max Weber and George H. Mead, which focus on interactional and interpersonal processes and actions, are just a few of the precursors of the evolution of symbolic interactionism. However, Mead's postulates are most often cited when discussing the history of this theoretical view.

Mead proposed that society could be viewed as a phenomenon constructed by human beings attaching meaning to objects, interpreting interactions with one another and arising out of their adjustive interactions. The uniqueness of the human ability to use symbols to designate objects in the environment, and to construct and communicate meaning to the social world is the basic tenet of symbolic interactionism. This tenet is the basis for the term `symbolic interactionism' (Turner, 1982).

There are two major "schools" within symbolic interactionism; the "Iowa school" and "Chicago school" (Turner, 1982). Manford Kuhn who had a positivistic orientation presented a view of symbolic interactionism known as the "Iowa school" (State University of Iowa). Kuhn (1964) believes that a central core self limits the alteration of meaning and process in social interaction. He takes a more deterministic view of symbolic interactionism. Kuhn supports however, that such meanings are derived from interpersonal processes (Turner, 1982).

A student of George Mead, Herbert Blumer is credited with the development of the "Chicago school" of thought, an alternative view of symbolic interactionism. In contrast to Kuhn, Blumer holds a more indeterminate, dynamic view of symbolic interactionism and believes that meanings and interactions are in constant flux, changing in differing social contexts (Blumer, 1969; Turner, 1982). The grounded theory approach to research is an outgrowth of Blumer's interpretations. This investigator subscribes to Blumer's view of symbolic interactionism and therefore, the remainder of this section will focus on the Blumer's formulation of symbolic interactionism.

Blumer, following the premises of Mead, considers mind, self, and society the central processes in his interactional perspective. Blumer suggests that individuals can redefine situations and share social meanings (Turner, 1982). The mind enables the human to analyze situations and to choose to attend selectively to one stimulus out of several. Through the process of thinking, the mind can actively construct a response to a stimulus.

Self is derived from experience and activity in social situations. According to Mead (1934), the development of a conception of self occurs through and in the process of interaction with others. This development affords the human being with a means of responding to objects by defining and constructing actions, rather than through mechanical or automatic response actions. Blumer views the self in terms of possibilities of interactions within the context of the experience as it is lived. He illustrates these beliefs in his statement on inductive theory development: "No theorizing, however, ingenious, and no observance of scientific protocol, however meticulous, are ever substitutes for developing familiarity with what is actually going on in the sphere of life under study" (Blumer, 1962).

Society is viewed as an ongoing, dynamic and ever-changing process constructed by groups of interacting individuals. Society represents the social world as well as the conditions under which interaction occurs. In summary, mind permits an individual to interact selectively with others, out of which self emerges and develops through further interactions and self analyses. All interactions occur within a social context and through interactions, human construct meanings for objects that are symbolically designated. These premises are considered significant in the following section on the appropriateness of symbolic interactionism as a perspective in exploring the parent caregiver experience for hospitalized handicapped children.

Theoretical Perspective Appropriate to this Study

This study uses grounded theory methodology to explore the parent caregiver experience during the hospitalization of their handicapped child. According to the symbolic interactionist perspective (Blumer, 1969) the meaning of a phenomenon (in this study, caregiving for a child with a long-term cognitive and physical disabilities) to an individual (the parent) will be influenced by the way that individual internalizes the definition of the situation. Hospitalization of the disabled child is one such situation whereby the process of internalizing occurs. During this process, the parent incorporates within the self as conscious or subconscious what s/he believes others expect of him/her.

To understand how parents perceive their caregiving for their handicapped child in hospital settings, this phenomenon was investigated in the hospital environment. Given this context, parents were likely to identify and discuss readily that which is personally meaningful to them. These conditions were suitable to obtain a beginning explanation and a temporal understanding of the phenomenon.

The applicability of symbolic interactionism as a perspective to guide the study of parent caregiving as an interactional phenomenon is illustrated in three of Blumer's central premises. These premises are as follows:

1. Human beings act toward phenomena on the basis of the meanings that they have for them.
2. The meaning of such phenomena is derived from or arises out of, the social interaction that one has with one's fellows and with self.

3. These meanings are handled in, and modified through, an interpretive process used by the person in dealing with the phenomena encountered.

Each premise and its applicability is discussed in the following paragraphs.

Blumer's first premise supports the acknowledgement that individual and personal meanings are attached to the caregiving phenomenon. As a sensitizing perspective for inquiry, it focuses the investigator on how they act in relation to these meanings, that their meanings are derived from a combination of social, cultural and family influences, and that these affect the actions of the respondents toward the phenomenon. With this in mind, the investigator openly explores as many conditions and factors as possible to access the respondents' definition of a phenomenon, or its meaning in their lives.

Blumer's second premise captures the influence that social interaction has on meaning. It reinforces that family members as well as those outside of the family play essential roles in the formulation of the meaning attached to caregiving by parents of handicapped children. In this case, those outside of the family not only include the friends or extended family, but all person encountered in daily transactions. For the parent of a handicapped child, these persons can include school, clinic, social agency, support groups, medical and hospital personnel. For example, the parent caregiver of a handicapped child has frequent contacts with professionals who emit various feelings about the quality of caregiving demonstrated by the parent. Depending on the value the parent places on the professional's opinions, the parent may incorporate these opinions into their personal conception of their caregiving abilities.

An emphasis is placed on the nonstatic and process-oriented nature of symbolic interactionism in Blumer's third premise. He reinforced this premise in his contentions that meanings "dictate" actions and behaviors. Thus, one constructs and attaches a meaning to a symbol but may revise such in the process of interaction. This idea as applied to the study of the parent caregiver phenomenon indicates that parents' interpretations of caregiving are modified and may change over time with various interactions.

Given the variety of conditions under which the handicapped child is hospitalized, parents may handle or modify their meaning of caregiving. For example, modifications and handling of their caregiving meaning can vary if their child is hospitalized for a major or minor problem or on an elective or emergency nature. These variations will be identified in the data but the selected methodology provides strategies to explore variations until the central explanation is identified. As stated by Benoliel, grounded theory provides a means "of conceptualizing the interacting influences of personal characteristics, social processes, and cultural circumstances as they bear on the adaptation of individuals and groups to crises and change" (Benoliel, 1983, p. 184). The following section describes the methods of inquiry and analysis of grounded theory research.

Grounded Theory: Methods of Inquiry and Analysis

Grounded theory methodology as a means of generating conceptual interpretations and theories involves a rigorous set of data collection and analyses strategies. The data collection and analyses strategies are performed in an interconnected manner. Data were analyzed using systematic interwoven and virtually simultaneous procedures of data collection and analysis. The data analysis guides the direction of further sampling and data collection. These processes are complementary and are aimed at the discovery of common thematic patterns based on systematically obtained data. Emerson (1983) states that in field research, "The collection, coding, and analysis of data are inextricably bound up with each other, a feature of field methods that maximizes flexible pursuit of theoretical leads discovered in the field" (p. 94). The process actually involves a "double fitting" of fact to theory and theory to fact (Emerson, 1983). This characteristic aids the researcher in meeting three significant responsibilities: "1) genuinely checking or qualifying the original data, 2) interacting deeply with his or her own data, 3) developing new theory on the basis of a true transaction between the previous and newly evolving theory" (Strauss, 1987, p. 14). This "qualitative analysis of data is termed grounded theory because of its emphasis on the generation of <u>theory</u> and the <u>data</u> in which that theory is grounded" (Strauss, 1986).

Procedures for Data Collection

Data are collected on behaviors and private concerns of individuals in natural settings. The emphasis is to capture the whole phenomenon in question not delimited by previously formulated hypothesis, prior theory or the use of specific quantitative measures, such as scales and other instruments. However, some theoretical perspective or framework is necessary to gain "conceptual entry" (Schatzman & Strauss, 1973) into the subject area and to formulate appropriate questions. Glaser (1978) coined the term "theoretical sensitivity" to denote the investigator's background knowledge that is utilized to conceptualize and formulate a theory as it emerges from the data. The sensitivity may come from professional knowledge, experiences, and/or reading the literature on the subject (Corbin, 1986).

Although the formulation of explicit hypotheses is not prerequisite to initiating inquiry, hypotheses may be posed at various points throughout the research. Such formulations emerge, as almost every observation and personal concern of the respondents causes the the researcher to question his own thinking (Schatzman, 1973). As the discovery work proceeds "new data are conceptualized, new problems and hypotheses . . . emerge" (Schatzman & Strauss, 1973, p. 13) which are incorporated into the research schema.

The primary data collection methods used in the grounded theory research approach are interviews and participant observations. The purpose of the interview is to obtain detailed verbal accounts or descriptions about the phenomenon in question in the respondents' own words (Lofland, 1971). An aim of qualitative interviewing is to "construct records of action-in-process from a variety of people who have likely performed these actions time and time again" (Lofland, 1976, pp. 8-9).

The unstructured or intensive interview is the type of interview most commonly used in collecting qualitative data (Swanson, 1986). This type of interview may consist of an interview guide or topical outline utilized to clarify general points about the subject area. Significant questions are formulated based upon the guide. However, the guide is not rigidly adhered to as it is the respondents concerns or viewpoints which are of primary importance. It is also advantageous, although not necessary, that the respondents' viewpoints be obtained within the settings in which the phenomenon is experienced. By so doing, the investigator is able to elicit, with the setting as a natural context, the respondents' meanings and perceptions of the situation in a more accurate manner (Davis, 1986).

It is a basic postulate in the social sciences that peoples' meanings of objects cannot be separated from the setting in which the object is experienced. Therefore, to gain an understanding of persons and accurate accounts of the nature of particular situations, the investigator must study them in their natural settings. Participant observation, a second data collection method, affords the investigator opportunity to observe how the situation is experienced as it is experienced. The investigator spends much time establishing a trusting relationship with respondents which allows him to enter their lives and obtain representative and comprehensive accounts of the respondents' experiences. The investigator listens closely and observes behaviors in the natural setting. In addition, the observer is able to observe the social context of the experience, such as interactions, organizational structuring, social and cultural features. By observing persons in natural settings, one obtains data which not only supplement data obtained from the interview, but tend to validate and enrich the other. Inasmuch as there is connection between the environment in which an occurrence takes place and how it is perceived and experienced, observation of properties or conditions within the social environment, may indicate the specific consequences or effects they have on the phenomena under study.

Although interviews and participant observations may be used independently, most often these two forms of data collection are used together to increase the validity of the data. Chenitz states that the "use of interviewing with participant observation increases validity since it assures that the truth in the observations is checked with active questioning of the interview situation and vice versa" (1986, p. 88). Generally, observations are used as the primary data with the supplement of interview information to extricate the observational data (Chenitz, 1986).

Analysis of Data

Data analysis in grounded theory method is not done in isolation from data collection. Rather, data analysis begins with data collection, and there is constant interchange and communication between the data collection and data analysis processes. As data are collected, the field notes and interview transcripts are systematically analyzed, often sentence by sentence or phrase by phrase (Strauss, 1986). There is a constant comparison of data points to identify properties and dimensions of conditions, consequences, actions, interactions and recurring processes or patterns within the data. The consequences of actions and patterns that occur within the identified conditions are coded and developed into categories. These categories guide further data collection as the analyst generates questions about the data related to each category. When the properties of the categories are identified, the researcher searches for verification, saturation and relevance of categories (Glaser, 1978). Linkages are made between categories to order the accumulated data and to establish relationships

(Corbin, 1986; Schatzman & Strauss, 1973). To verify the proposed categories, category links and relationships, additional data are collected.

As the researcher moves through interactive process between data collection and analysis, categories are built and organized using "theoretical codes" (Glaser, 1978). These codes are utilized by the researcher to clarify how the categories are related. Related categories are linked, and hypothetical relationships are formulated into hypotheses.

Additional interviews and observations are obtained from a select sample of informants, that is, a purposive sample that may or may not be comprised of respondents queried earlier. The additional data is used to check the informants' stories and the researcher's interpretations. The researcher's sampling becomes "selective along the lines of his focus on the central issues of his emerging theory" (Glaser, 1978, p. 46).

Verification of the proposed relationships and hypotheses can be accomplished through a careful review of field notes or by re-entering the field (Corbin, 1986). This procedure results in elimination of unsubstantiated hypotheses. Corbin states that "the analyst can . . . feel confident that the field has been thoroughly explored when no further categories emerge from the data, the categories are dense and well developed, the same patterns are seen repeatedly, and there is variation" (1986, p. 93).

In efforts to pull together the final categories into a central statement explaining the phenomenon under study, closer scrutiny of the data is necessary. A core or central category is identified by collapsing other categories or fitting other categories around the core category. The theory is built around this core category. This theory which is grounded in the data, "explains the major action in the situation under study. . . . It should be flexible and general enough to be applicable to diverse situations" (Corbin, 1986, p. 101). The generated theory is described as a grounded or substantive theory because it is based in the data and it "describes and in some cases predicts events or processes in a given social setting" (May, 1980 p. 180). The following section describes the design, inquiry and analysis procedures utilized in this study.

The Study Design

Using the theoretical perspective described in earlier sections of this chapter as background, this exploratory study was conducted employing a grounded theory approach. Since there is limited knowledge on management behaviors of parent caregivers of hospitalized handicapped children, the primary purpose of this study was to identify relevant patterns of behavior and thereby promote an understanding of the processes involved in parental management of caregiving for a handicapped child within a specific context, the hospital.

Sample Selection Criteria

The criteria for selecting the sample for this study were formulated in order to obtain a varied representation of parents. A specified age range of the children was not selected because the sample selection was based on the functional status of the child, and a representation of parents of children with a wide variety of disabilities was necessary.

An additional criterion for sample selection was that the diagnosis of the child's disability had to be established by the age of 2. No subjects were selected whose children were in the process of having a diagnosis established nor those who had been diagnosed less than 2 years prior to the onset of this study. The rationale for this criteria was that an established caregiver role was expected to have evolved by this time and it was expected that these parents have experienced the hospitalization event several times. Time was allocated for the parents to adjust family functioning, to incorporate a child with a long-term disability, and to establish caregiving skills. These criteria are based on the investigators' experience because the review of literature regarding parent role adjustments indicated no discrete time limits for these adjustments. In the next section, the specific collection and analysis procedures of this study are described, using examples from the study to demonstrated the interconnection between data collection and analysis.

Data Collection and Analysis Procedures

Data were collected using semi-structured interviews of approximately 3/4 hour to 1 and 1/2 hours in length. Personal interviews (Appendix A) were conducted using two different groups of parents who were recruited from the medical and surgical units of the University of California, Long Hospital. After reading the chart data of the children to ascertain if sampling criteria were met, parents were approached and the purpose of the study was explained. All parents approached consented to participate in the study.

Each subject was asked to read and sign a consent form in accordance with the committee on Human Research requirements. Copies of the consent forms are included in Appendix A. After the consent forms were signed, each subject was asked to decide on the time and location of their interview. The interview was begun informally, with open-ended questions, such as "Tell me about your caregiving experiences during the hospitalization of your child?" A semi-structured guide of questions was utilized to maintain a flow of questions; however, the majority of questions were formulated during the interview. These additional questions were generated in response to the parent's explanations which enabled thorough exploration of the respondents' perspectives. The guide used for the initial interviews is found in Appendix B. The second interview for the initial informants and the first interview of subsequent informants were more specific and focused as patterns began to emerge. An example of a second interview question is as follows;

> While analyzing your previous interview, several questions occurred. In order to obtain an understanding of your feelings as a parent caregiver, I need answers to these questions. What events or behaviors of other persons make you, as the parent caregiver, feel confident in performing medical/ technical tasks in the hospital?

An example of a question asked informants interviewed as patterns began to emerge is;

> Some parents describe themselves as their child's "central person", does this term mean anything to you? Describe what a "central person" does at home? In the hospital? What are the feelings of a "central person"?

Additional examples of questions for both the follow-up interviews are included in Appendix C. The "pattern checking" interview question examples are included in Appendix D.

Data were comprised of the parents' accounts of their experiences as reported in 31 interviews from a sample total of 23 informants. The sample size was determined as the data analysis progressed. When no further discontinuities or additional patterns emerged from the data and the same patterns were repeated, then the researcher/analyst was cued that additional sampling was not necessary for further theory development.

The interviewing of parents in group one and the subset of parents from group one took place in different locations. The first group was interviewed once in the hospital during the child's hospital stay. A select set of parents from this group was interviewed a second time by telephone two to four weeks after the child was discharged from the hospital to validate the researcher's interpretations of the first interview data. The selection of this group participants was based on the ease and clarity by which these respondents verbalized their perspectives. These respondents were asked to confirm or contrast their own accounts and those of other respondents in the first group. The interviews of approximately 45 minutes to one hour and 30 minutes were audiotaped and transcribed verbatim.

Upon the conclusion of each interview, transcribing was done immediately and prior to conducting any other interviews. Field notes and interview transcripts were reviewed, and sentence by sentence and phrase by phrase (Strauss, 1986) analyses were performed. Comparisons of data within the initial interview were done to discover and isolate codes and categories of like data sets and codes.

As each interview was analyzed throughout the data collection phase, major themes and relationships were discovered. The data from each interview were examined to provide focus for subsequent interviews and to learn more about what these parents viewed as valuable or helpful in this situation. Selective coding was used to sort data bits into emerging categories. Comparative concurrent analyses were performed between and across transcribed data of subject groups to dimensional categories, that is to identify properties of conditions, consequences and actions within the data. The extraction of data points and constant memoing aided this comparative analysis which continued until no more unique categories were identified in the data. Themes were identified, categorized, and conceptualizations regarding the parent caregiving experience were made. The categories were linked forming relationships and organized into a conceptual framework. To capture the essence of the meanings shared by group one respondents, as well as to clarify interrelationships and validate the researcher's interpretations, subsequent interviews were obtained from a theoretical sample.

The theoretical sample of a second group of parents was selected and interviewed in a private setting, away from the hospital. The children of these parents met the same criteria of the first group and had been hospitalized within the two to four weeks prior to the interview. Findings from preliminary work of this investigator were the rationale for the second sample; a preliminary study of this investigator noted that some parents had difficulty discussing their hospital role experiences while in that setting. Thus, a group of parents was interviewed either in person or by telephone outside the potentially threatening environment. This sampling strategy provided a variety of people who have experienced the event repeatedly and could give detailed verbal accounts or descriptions about the phenomenon in question in their own words. Data collection and analysis continued until theoretical saturation was achieved.

Amplifications of shared aspects of the experience occurred as common themes were identified and cross validated. Throughout the analytic process, codes and categories were renamed, reorganized and collapsed to achieve density and parsimony in the developing theory. Revisions of the conceptual map were made constantly as the data gained more richness. After data collection was completed, the data was analyzed time and time again to substantiate the conceptual schemata and validate the emergent theory. Themes relevant to certain phases and to variables within a phase were explored with members of respondents from both groups and additional parents who met the sample criteria. This process is congruent with that described by Strauss (1987) and Schatzman (forthcoming).

The selection of the appropriate method for this study involved a careful scrutiny of its strengths and limitations and its "fit" with the phenomenon in question. Accordingly, the next section of this paper presents an overview of the strengths and limitations of the grounded theory approach in exploring the hospital experience of parents of hospitalized young handicapped children as assessed prior to the study. An evaluation of the strengths and limitations of the completed study is included in Chapter Four.

Strengths and Limitations of Grounded Theory Approach for Exploring the Experiences of the Parent Caregiver of Hospitalized Handicapped Children

Perceptions and behaviors are social and psychological in nature. Social-psychological processes as well as different kinds of clinical contexts account for interactional behavioral variations in human experiences. The parent caregiver role is constructed through a myriad of parent experiences and interactions. The variations and complexity of interactions between and among parties involved in the care of the hospitalized handicapped child lend themselves to a mode of inquiry, at least initially, if only to discover the variety of interactions and conditions in various naturalistic settings.

A qualitative mode of inquiry, such as grounded theory, is an appropriate method of educing the personal meaning of caregiver as assigned by parents of hospitalized handicapped children. This method is suitable for discovering and illuminating the specific interactions and the components of the interactions as perceived by parents, and conceptualizing the social reality of parents handicapped children in the hospital. Furthermore, to date, the concepts and variables embodied in this phenomenon have yet to be adequately and systematically isolated or defined.

Strengths

The real meaning of the parent caregiver role of young handicapped children to parents in the hospital setting is entrenched in a complicated web of factors. Many factors affect the perceptions and behaviors of all actors involved in this situation. The range of factors is extensive and examples include: historical experiences, cumulative knowledge, cultural-social background of the actors and the philosophic-structural organization of the establishment in which the experiences occur. This complex interplay is the primary reason why grounded theory is the method suited to investigate this phenomenon.

The grounded theory approach provides an avenue for capturing the complexity of the parent role, of parental experiences and their history of interactions. This approach affords the researcher an opportunity to perform a thorough investigation of the phenomenon within the environment in which it occurs. In using the strategies of the grounded theory approach, the researcher enters the "world" of the respondents, and is able to perceive and describe the relationships, systems, and patterns as the respondents perceive them. The researcher develops meaningful understandings by being in the situations and obtaining verbal accounts of respondents' experiences. S/he simultaneously observes interactions and validates these observations with explanations from the respondents. S/he is able to watch and also listen to the sounds that characterize the respondents' world.

Dialogue with the respondents in the natural setting will disclose shades of meaning from which the respondents' perspectives and definitions are constructed (Schatzman & Strauss, 1973). The researcher basically acquires an understanding of the respondents' perceptions of meanings attributed to their world. Thus the researcher's interpretation of the data remains consistent with respondents' definitions.

Meaning construction based on understanding the situation from the respondents is a logical mode of acquiring insight into parents' perceptions of circumstances involved in their role performance when their handicapped child is hospitalized. The many fears, concerns and emotions of parents in these situations cannot be captured by quantitative or traditional measures, unless or until the measures are grounded in at least similar, if not identical, situations. The traditional measures are constructed so that "meaningful understanding" is not required to interpret the data. Quantitative methods employ objective and "uninvolved" data collection and analysis techniques which impede the discovery of subjective data.

The open-ended quality of the grounded theory methodology which allows the researcher opportunity to establish rapport with respondents and encourages the obtaining of subjective or personal data. When rapport is established between the respondents and the researcher, the respondents share their thoughts in an uninhibited manner. The respondents may even voice concerns which they would not have had opportunities to express if they have been assessed by traditional measures.

A final potential strength of the grounded theory approach for the examination of the phenomenon in question is that it allows the capturing of a dynamic or active process. Parents' hospital role experiences involve continuously changing and fluctuating social relationships. Situations are constantly evolving and their experiences are not static. Nonstatic processes are best comprehended when observed "on the spot--in the natural, ongoing environment" (Schatzman & Strauss, 1973, p. ix) where the action take place. When traditional data collection techniques are used, one obtains a recalled account of the situations and the respondents may not be able to remember all facts accurately.

In summary, the grounded theory approach allowed enough flexibility that the hospital experiences of parents of hospitalized handicapped children was explored in great depth. It afforded the opportunity to seek answers to questions about these experiences in the actual environment in which they occur. This approach provided a meaningful route to obtain information about this phenomenon because the researcher was able to utilize personal abilities to observe and interpret what was seen. The researcher was able to obtain data that provided evidence from the perspectives of the respondents. Through this research approach, a theory emerged that is substantiated by the data, and explains and describes the activities of the parents and their counterparts in terms that are meaningful to both the respondents and the researcher.

Limitations

No matter how well matched the research approach is to the phenomenon to be studied, limitations must always be considered. Several concerns about this methodology include: 1) maintenance of researcher's objectivity, 2) researcher influence on respondents' actions, and 3) nurse-researcher role ambiguity. The intimate and often close relationship which is developed over time during the grounded theory research process will certainly cause many questions regarding this issue. One will wonder how much the respondents will influence the researcher's perceptions of interactions observed and how the researcher protects himself from becoming too empathetic to the respondents' views. These are very common concerns addressed throughout field research literature. Advocates of this approach warn that this method of inquiry is not independent of such human influences. The operational procedures of the grounded theory method, if adhered to appropriately, will safeguard biased interpretations, since there is a systematic checking and rechecking of emerging relationships, hypotheses, and theory against incoming data. An example of one such checking strategy that was employed to counter the problem of investigator bias is triangulation.

Triangulation is a data collection approach wherein information is collected from a variety of sources such as the nurses, physicians or other family members to confirm interpretations (Odom and Shuster, 1986). In this study, selective samples of various informants such as spouses and nurses were taken to collect additional data that confirmed or discredited previous interpretations. Similarly, there was also the possibility that the researcher may influence the respondents' actions or perceptions. Again, such strategic methods as triangulation and purposive sampling are employed as checks and balances (Chenitz, 1986; Glaser, 1978; Schatzman & Strauss, 1973).

As a nurse-researcher, the naturalistic or qualitative approach to exploring phenomena will present problems if the phenomenon in question is investigated in an agency where the duties of the profession are performed. Confusion can exist in the respondents' mind regarding the actual role of the investigator such as, nurse or researcher. Even if the nurse-researcher clearly states her intentions, the respondents may cast the researcher in the role of clinician because of the socially ascribed role description attributed to the professional title of "nurse". This, of course can affect the type of data obtained. This nurse investigator handled this problem by wearing civilian clothes and a name badge. A lab coat or uniform was not worn to decrease the possibility of respondents ascribing the role of clinician to the investigator.

Swanson (1986) suggests one solution to decreasing the nurse-researcher role ambiguity problem. She recommends that if the nurse-researcher is too familiar with the setting such as, has been employed in a setting several years, that other settings should be obtained to explore the problem. This allows the nurse-researcher to examine the phenomenon and perceptual expressions from a fresh perspective without the bias of previous experiences and without the researcher exhibiting nurse behaviors. This researcher was not, nor had been employed in the setting where the research took place. In addition, theoretical sampling stimulated more interviews of a different group of parent caregivers who had experienced the event of their child's hospitalization within a recent span of time.

Practical Concerns

Two pragmatic concerns arose for consideration of grounded theory as a method of inquiry. These concerns are related to time and funds. The grounded theory approach, while conceptually appealing from a research perspective, is time-consuming. The inquiry process produced a voluminous data set which was laboriously analyzed. Although it was not absolutely necessary, it was beneficial for the investigator to transcribe the majority of the taped interview. Transcribing the first several interviews provided a familiarization which significantly facilitated data analysis.

Additionally, frequent re-entries into the field were required until theoretical saturation occurred. These procedures could deter any researcher from using this approach especially if quick and easy answers are desired. However, when the objectives were discovery and explanations of phenomena as they exist for the respondents, the quick route was not considered the best one.

The final pragmatic concern about the grounded theory approach deals with funding. In order to receive funds to support the research, the researcher must describe for funding agencies, the study's significance and must project a sample size. The sample size is not predetermined in theory-generating research as it is in theory-testing research. The qualitative researcher may encounter difficulty predicting the significance of the study because the focus of the research is developed and modified as the research progresses (Archbold, 1986). The sample size in qualitative research is evolutionary and aggrandizes as dictated by the data analysis. A thorough description of the component procedures for data analysis and collection will serve to counter both of these problems. With a recent increase in the acceptance of this method as creditable, this investigator did not encounter much difficulty convincing funding agencies of the validity of the method. But as with any research, the focus of the study was not considered a priority for some agencies.

Summary

The grounded theory research approach provides an alternative to quantitative research methods. It involves a systematic set of rigorous and detailed procedures for exploring complex social phenomena which may or may not have been previously described. There is an interweaving of data collection and data analysis procedures that results in interpretations of the data from which a theory is generated.

The grounded theory mode of inquiry is an excellent method for exploring human experiences as they are occurring. As a nurse-researcher, this approach is suitable for gaining understandings of the concerns and behaviors of clients within hospital settings. This approach creates opportunities for acquiring insights which are often overlooked or untapped by traditional measures (Chenitz, 1986; Odom & Shuster, 1986).

The grounded theory approach provided a dynamic avenue through which insightful parent data was obtained in the natural setting. Clarity of individualistic variations and the interactional process involved in parent role performance in the hospital setting was obtained through the use of this approach. By using the grounded theory approach, detailed investigations specifically focusing on parents' perceptions of their role and their role enactment in the hospital was performed. From these investigations, common patterns about this specific phenomenon were detected and a theory was generated. The resultant discoveries and theory provides useful knowledge which can be applied in current nursing practices. The findings and resultant theory of this study are discussed in Chapter Four.

CHAPTER FOUR

FINDINGS

In this chapter the sample, and study findings are described. Following description of the sample, the findings of the study are presented in an identity emergence framework. Passages from interview transcripts are interspersed for the purpose of illustration. A conceptual diagram of categorical data is introduced to show how analysis of data resulted in the development of the substantive theory which describes the process through which parents of handicapped children take on and manage the role of caregiver.

Sample

The sample of 23 parents and guardians of hospitalized children with cognitive and physical disabilities, was drawn from the pediatric medical and surgical units of the University of California, San Francisco Children's Medical Center. The hospital is a large regional referral center within a university setting. Primary diagnoses included cerebral palsy, spina bifida, post meningitis sequelae, dysplastic kidneys, congenital cardiac defects and retinoblastoma with resultant cognitive and physical disabilities. The resultant cognitive impairments ranged from developmental delay to profound retardation. Physical limitations varied from slight mobility difficulties to total immobility. The types of acute illnesses or surgical interventions varied as well, from seizure and respiratory disorders to orthopedic correctional surgery. A summary of the fundamental diagnoses, long-term disabilities and the reason(s) for the current hospitalization is presented in Table 1.

Table 1

Characteristics of the Handicapped Children of the Sample

Subject's Number	Child's Age/Sex	Fundamental Diagnosis	Disability	Reason for Current Hospital Admission
01	9 yrs/ Female	Spina Bifida Developmental delays	Paraplegia, Mild	Ureteral Implantations and colostomy
02	7 yrs/ Female	Post Cerebral Anoxic Syndrome	Cerebral Palsy, Severe mental retardation, Quadriplegia	Intractable seizures
03	11 yrs/ Male	Cerebral Palsy	Progressive Femoral Antiversion, Moderate Delays	Corrective orthopedic surgery
04	5 yrs/	Macrocephaly	Mild developmental delays Slight Activity Limitations	Head injury
05	12 yrs/ Male	Unknown Etiology	Severe retardation, Quadriplegia	Seizure Disorder
06	10 yrs/ Male	Post Meningitis Sequelae	Severe retardation, Quadraplegia	Feeding Disorder
07	10 yrs/ Female	Seizure Disorder	Moderate delays, Mod. activity limitations	Seizure Disorder

Table 1 (continued)

Subject's Number	Child's Age/Sex	Fundamental Diagnosis	Disability	Reason for Current Hospital Admission
08	3 yrs/ Female	Spina Bifida	Severe retardation. Paraplegia	Removal of Harrington Rods
09	12 yrs/ Male	Spina Bifida	Mild development delays, Paraplegia	Surgical repair of tethered cord
10	5 yrs/ Female	Hydrocephalus Dandy Walker Syndrome	Cerebral Palsy, Severe Mental Retardation	Seizure Activity
11	9 yrs/ Female	Cerebral Palsy, etiology unknown	Spastic Quadriplegia, Severe Mental Retardation	Repair of diaphragmatic hernia
12	3 yrs/	Bilateral Retinoblastomas	Moderate language, motor and growth delays	Radioactive plaquing
13	8 yrs/ Female	Hydrocephalus Spina bifida	Mild developmental delays	Laminectomy, Release of tethered cord
201	3 yrs/ Male	Neurodegenerative brain disorder	Severe mental retardation Quadriplegia	Fever, Intractable seizures
202	2 yrs/ Female	Congenital Heart defect (Cyanotic)	Mild developmental delays	Nissen procedure
203	3 yrs/ Female	Dysplastic Kidneys	Moderate language, motor, and growth delays	Chronic Renal Failure

Table 1 (continued)

Subject's Number	Child's Age/Sex	Fundamental Diagnosis	Disability	Reason for Current Hospital Admission
204	7 yrs/ Male	Not determined	Severe developmental delays, Quadriplegia	Seizure disorder
205	8 yrs/ Male	Degenerative brain disorder	Severe developmental delays, Quadriplegia	Feeding and breathing, tonsillectomy and gastrostomy

The children were living and being cared for in the homes of their parents or guardians and had resided with at least one of the parents since the primary diagnosis was made. Nine of the children were hospitalized at the time of their parent's interview and five had been hospitalized 2-4 weeks prior to the interview. The ages of the children ranged from 2 years to 13 years. The specific age and sex of the children are listed also in Table 1. The number of additional children in the family ranged from zero to five. Five subjects had only the one handicapped child. One couple who were adoptive/foster parents had 2 other disabled children in addition to their 3 normal biological children.

The sample of 23 parents were interviewed as two separate groups. Parents in group one were interviewed during their child's hospitalization, and parents in group two were interviewed 2-4 weeks after their child's hospitalization. There were 18 subjects in group one and 5 in group two. The group consisted of 5 couples (including one couple of adoptive parents), 12 mothers, and 1 paternal grandmother. A total of

31 interviews were conducted. Couples were interviewed conjointly. Eight mothers of group one were interviewed twice. Ten mothers were interviewed once, five mothers in group one and five in group two.

Ages of the subjects ranged from 22-63; with about 1/3 (n=7) in their thirties and 1/3 (n=6) in their twenties. All but one subject had at least a high school education. All male subjects were employed. Their jobs included banker, sales representative, business executive, business owner, and truck driver. Only four of the eighteen mothers were employed outside the home, two part time and two full time. Jobs of the mothers included teacher, registered nurse and sales representative. Seventeen of the women interviewed were the biological mothers of the handicapped child whereas only one of the five males interviewed was the biological father.

In the next section of this chapter, the study findings are described. An identity emergence framework is used to present the substantive theory which describes the process through which parents of handicapped children take on and manage the role of caregiver. Cognitive and behavioral characteristics are described within the three identity phases; protection agent, survival agent and central person.

Findings

The Process of Taking on the Role of Parent Caregiver and the Gradual Identity Formation of Central Person for the Handicapped Child

In this study, the caregiver meaning for parents of handicapped children was examined within the context of the situational condition of hospitalization. Respondents' reports, however, described a theme which transcends the variety of situations involving the handicapped child. Before presenting this integrative theme, it is important to note that the population of parent caregivers of handicapped children included in this study represents only a portion of those who might be included in the overall population of parents dealing with this phenomenon. Parent caregivers in this study are "experienced" and have "worked" on the aspects of their identities which involved caregiving and parenting a handicapped child with delayed development. The findings in this study describe where these parents are in the "work process" and what was involved in getting to this point.

Emerging as central person for the child was identified as the integrative theme. The substantive theory describes how a specific parent/guardian caregiver as a result of nurturing and protecting their child, gradually forms an identity as "survival agent". Over time the same parent evolves as the deeply committed, strongly attached, highly informed and involved "central person" organizer and manager of life situations on behalf of the handicapped child. This process through which the parent caregiver acquires the characteristics of central person entails behavioral and cognitive changes.

Findings suggest that there are three developmental levels in which gradual changes in commitment, involvement and knowledge occur. "Agent work" is the organizing scheme in which three identity phases are described; protection, survival and central person. The <u>protection agent</u> phase is preliminary and involves a vast amount of learning and discovering. The primary goal of the parent during this phase is to foster the growth and development of their child by providing sustenance, housing and love. The parents in this phase learns basic information about themselves as parents and caregivers, as they are exposed to many strange and unfamiliar circumstances. Their caregiving and parenting skills are limited but through daily encounters involving their disabled child, they learn to explore and seek out resources. As a result of their explorations of resources and the learning involved during this process, the identity of survival agent emerges. Parents have learned how to make it through various adverse situations on behalf of their child. Parents during this phase are committed to the continued existence and functioning of their disabled child in spite of adverse developments. They are more definitive in their accessing of resources and are developing caution in the acceptance of assistance. Their skills are growing in sophistication as an integration of parenting and clinical knowledge occurs. Consequentially, as this parent tests her abilities, acquires new skills and knowledge and reaffirms existing knowledge and skills, the identity of central person evolves. The parent who is in the central person phase is confident and assertive. S/he maintains the goal of assuring an optimal quality of life for her disabled child. S/he utilizes specialized filtering, negotiating, and monitoring techniques for maintaining the well-being of her child. S/he realizes his/ her capabilities, the child's capabilities and the necessary supplements for his/her own deficits and those of the child. S/he can articulate in words what matters, what needs to be done and what is significant for the child's well-being. Primarily, the central person is the ultimate integrator and translator of the expanding library of life data from the child's and his/her own experiences in the different arenas. The phases of the social psychological process are schematically depicted in Figure 2.

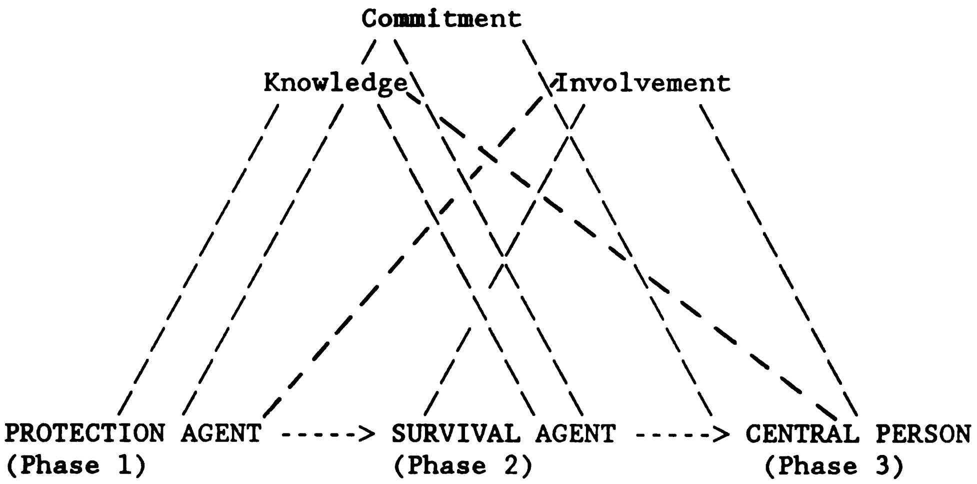


Figure 2. Conceptual diagram: Caregiving identity emergence in parents of hospitalized disabled children

Note: Figures 3, 4, and 5 list the major characteristics of commitment, knowledge and involvement for each of the three phases of identity emergence.

Within each agent phase, behavioral and cognitive transitions of commitment, involvement and knowledge occur. Commitment is a state of being obligated and emotionally compelled to provide for the daily needs of the child. Involvement is the actual performance of parenting/ caregiving activities and the active participating in decision making. Through the performance of what initially appears to be basic caring tasks, parents become enmeshed in the complex requirements of the child which necessitates intricate modes of negotiation and advanced knowledge. Knowledge applies to facts or ideas acquired through observations, study, investigation, and/or experiences as parent of a handicapped child. As knowledge increases so does involvement. Figures 3, 4, and 5 summarize the major characteristics of knowledge, commitment and involvement, according to identity phase.

PROTECTION AGENT ----->	SURVIVAL AGENT ----->	CENTRAL PERSON
Assents to rear and care for disabled child ---->	Pledges self to maintain the well-being of the child ----->	Bonds self to child emotionally
Develops attachment to child ---->	Parental concerns with emotional and cognitive states of the child increases ---->	Integrates child's response system and behavioral states with own
Fosters child's growth and development by providing food, medical care, and love ---->	Entrusts self to child's survival ---->	Internalizes child's identity in own

Figure 3. Commitment

PROTECTION AGENT ----->	SURVIVAL AGENT ----->	CENTRAL PERSON
Acquires preliminary parenting and caregiving knowledge and skills ------->	Merges and improves acquired clinical/ parenting skills and knowledge ------>	Masters specialized clinical knowledge and skills
Acquires intimate child knowledge and apprenticeship clinical information --->	Appraises child's limitations and learns how to supplement them ------->	Is well versed on how to supplement own knowledge deficits
Becomes aware of the child's communication deficits ----->	Establishes symbolic communication patterns between parent and child ------->	Can translate child's signs to others and vice versa

Figure 4. Knowledge

PROTECTION AGENT ----->	SURVIVAL AGENT ----->	CENTRAL PERSON
Most clinical -----> and caregiving situations are unfamiliar	Understands ------> a select number of clinical and caregiving techniques	Utilizes existing clinical knowledge to learn new skills
Medical terms ------> and techniques are new	Uses some ------> medical terms in conversation	Utilizes medical terms routinely and with ease

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Figure 4. Knowledge (continued)

PROTECTION AGENT ----->	SURVIVAL AGENT ----->	CENTRAL PERSON
Uncertainties ------> about self and child limits involvement	Direct efforts ---> toward keeping the child alive, normalizing the child's life	Complete focus on well-being of the child
In hospital -------> situations is an onlooker, assists staff when requested	Participant ------> observer, assist staff by carrying out usual home care tasks	Performs most caring tasks in the hospital, staff assist her
Explores and ------> seeks out services of others	Selectively ------> assists and accepts the services of others	Negotiates and monitors services of others
Indiscriminate -----> use of information received from others	Filters -----> information and researches answers to questions	Skilled in investigative skills

Figure 5. Involvement

PROTECTION AGENT ----->	SURVIVAL AGENT ----->	CENTRAL PERSON
Passive -------> involvement, primarily performs supportive, parenting tasks	Selective -------> involvement, supports the child by performing clinical tasks using personalized techniques	Directs the involvement of others
Remains with ------> child when hospitalized for emotional support	Purposes of ------> remaining with child are expanded from mere emotional support to a vigil	Coordinates and evaluates the performances of health care professionals
Provides -------> limited assistance in performing technical tasks	Begins a team ----> relationship with health care professionals	Alternates leadership duties with professionals

Figure 5. Involvement (continued)

There is no evidence which pinpoints the exact time involved in moving from one agent phase to another. Apparently, the transition is so gradual that respondents are unaware of the time factor. The accumulation of experiences and knowledge which aids the movement from the preliminary agent work of "protective agent" to the more advanced level of "central person" is individual. That is, depending upon the child's disabling condition and response to threats to his/her well-being, one parent may experience repeated exposures to assorted incidents within a short period of time, whereas a year or two may lapse before another parent has similar exposures. An example of the variation in occurrences of hospitalizations is presented in the following interview excerpt:

> I can (only) remember how many surgeries he's had. One year, he was hospitalized over thirty times. You know in a couple of days, out a couple of days. One stay was two months long. I mean we've just been back and forth so fast, that I never kept track of (it) specifically. But before that year, there were no hospital stays except for one for some different tests.

It is the parents' perceptions and evaluations of repeated hospital experiences on themselves and their child which facilitate parents to embark on the identity emergence process. The protection agent phase begins this process as parents attempt to diminish uncertainties of the hospitalization event by becoming more knowledgeable in their dealings with professionals.

Protection Agent

Commitment. During the post-diagnostic period, the parent recognizes and assents to total responsibility for care of a child with a disabling condition. A commitment to nurture the child is declared as the condition of the child is recognized as a deterrent to normal development. One mother of a ten-year-old severely disabled son describes the responsibility she felt following the incident that led to her son's disability in this statement: "After the incident, they recommended that we place him in a home but we refused to do that. This is our little boy and he should be at home with his family". Another mother of an eight-year-old, moderately disabled child recounts her acknowledging that the child's condition is different from what had been expected: ". . . its kind of just made me a more rounded person because I'd never looked at this before (having a child with special needs). I always figured that I'd have kids in patent leather shoes, with bows in their hair and real frilly dresses and you know, life just isn't like that."

Increased commitment develops as the parent proceeds through various child-related experiences with social organizations. The parents are learning to safeguard the child in various social situations as experiences "teach" them that these actions are necessary. The same mother of the eight-year-old shared a hospital experience that precipitated her protective behaviors toward her child and simultaneously enlightened her about professionals:

> I think that part of my own nervousness, at least maybe it's my own overprotectiveness. And I think I am kind of overprotective with her in this kind of setting. It's just that her problem was initiated after birth because of a mistake . . . she was given an IV and there was air in the tubing and she arrested. It was very eye opening to the fact that health care professionals are just human beings and there are mistakes made.

The mother gave her reason for taking on the "protection" identity; ". . . you can get easily overprotective about a kid that's so dependent on you because they need you."

The "protection" work of surveillance moves from noting one particular incident to several as the experiences accumulate. The same mother explains: " I've like come a long way (since then when) I was like watching the IV tubing for every second of the day when (ever) she was hospitalized after birth." The father comments: "I think that there has been a development of (my wife's) commitment because . . . there has been mistakes with her medicine, and we've talked about this several times, even at (another hospital) with her medications. Her medicine is something that we are just religious about". The mother adds: "There has been a lot of errors with her medications, so her medicines, I've really had to stay on top of." The parent is personally committed to protecting this child from unnecessary harm. But in order to forecast and prevent such harm from occurring, the parent who is in this protection agent phase must acquire a substantial amount of knowledge about various aspects of the child's disability and its requirements.

Knowledge. Through engagements with health professionals and very natural engagements with the child, generalized knowledge about the disabled child's care and upkeep is acquired. This knowledge can be categorized as parenting knowledge, clinical knowledge and intimate knowledge. Parenting knowledge is the information learned in ordinary parenting functions of raising a child who just happens to have a disability. Parents learn to carry out tasks of providing food, shelter and clothing to facilitate the growth and development of this child. In addition, they learn to provide for physiological necessities which initially may be envisioned as routine but is soon recognized by the parent to be energy and time consuming. As vividly described by the mother of a twelve-year-old in the following statement;

> He needs assistance with his colostomy care, his diapers because he is incontinent, he needs help transferring, his bathroom care. . . . He has difficulty with overexertion so either my assistance or that of a family member is needed to make sure that he doesn't overextend, overexert himself.

As the child grows, the providing of physiological necessities for the child becomes more complicated. The parent learns that the child requires "customized" performances of activities of daily living and as with any child the requirements are variable. However in this case, the variation depends on the child's condition. Parents of an eight-year-old describe the variations in the following interview excerpt:

> She has seizures which depending upon how severe they are, that dictates what kind of care she's going to get that day too. If she has a real good day, you may need to help hold her to sit up, and help feed her and everything, and just make sure that she's not in a position where she will bump her head.

In the beginning the parent has very little knowledge about parenting this child, the disabling condition and its precipitating effects. But during the process of caring for this child daily, for many months, the caregiver is "coming to terms" with the child's abilities and condition. One mother commented: "When J. is dressed up, he looks normal, except he has to be pushed around in a wheelchair and he can't respond to people. I tell you, it's very hard to accept that he's like this." The parent begins to question and wonder if maybe the cause of the disability is found, then more can be done for the child. As one mother remarked: "I think they are doing just about all they can for her. There's not much that anybody can do for her until we know exactly what the cause is."

During this "protection agent" phase, the parent develops a growing awareness of the child's capabilities. As care is provided, the parent gains "intimate knowledge" of the child's signs or signals and a developing awareness that this child may not be able to convert his own signs into appropriate communication to relate to others. Gradually, the parent begins to develop symbolic communication with the child. The initial step in developing communication is exemplified in the following excerpt: "I try to understand what she wants because she's delayed in language. Like when she tells me something I try to figure out what she wants. I have to show her all kinds of different things to make sure she tells me what she wants."

Personal peculiarities are also being learned; "He has had 2 surgeries and a lot of stitches because he's so clumsy, well not so clumsy as unlucky. Really, he just seems to be the one who always fell the half of an inch so his head happens to hit the table or something."

The parent is beginning to "read" the child; the gestures, posturing and verbal utterances and to develop a conception of the child's whole response system. A parent of a thirteen-year-old describes this conception in the following segment of an interview: "not with professional accuracy but I can look at him and tell if something's different than it would be at home, if he is in pain."

Concurrently, the caregiver acquires "clinical knowledge" about the disability, i.e., the care, the treatment, and the prognosis. Initially this knowledge is limited and is gained from observations as a nonparticipant. The mother of a five-year-old describes her introduction to a hospital: "her first hospitalization wasn't that bad but also everything was very new. I didn't know what to expect and I didn't talk as much. I kinda of sat back and watched."

The beginning clinical knowledge is basic, procedure specific and comes from instructions of professionals. Nurses attempt to introduce parents formally to the system by giving them a general orientation, explaining the operation of the call button, bed, television and where the bathrooms are located. Other formal information also may come from the nurses sometime prior to the child's discharge, if a "home care" procedure is required. Becoming familiar with the structure of the hospital is a task taken on by individual parents as the need arises. For example, if parents must take their child to another location of the hospital, then directions are given and the parent finds the desired location. Parents also intentionally "pick up" information about the social system of the hospital through the conversations of other parents.

Much information and socialization received by parents, however, is inadvertently obtained "just by being there." At the bedside of their child, the parent is learning about the social interactions in the hospital as nurses and doctors perform their routine duties. They "learn" how they can fit into this system and how to perform simple "clinical tasks" for the child by being available when the nurse is unable to accommodate the child immediately.

However, the information acquired from observations of all activities surrounding the care of the child is purely from a layman's perspective. Parents will take in <u>any</u> information which may have bearing on understanding the child's care and condition, but everything is very new to them. The mother of the thirteen-year-old describes that unfamiliarity in the following:

> They (parents) don't understand the blood work-up, they don't understand why they have to have it done so frequently, nobody knows when a person walks in for blood, he walks out another one walks in for blood and you wonder, why are they doing all these studies? Why don't they do them all at once? The child certainly doesn't understand.

Parents are also beginning to realize that knowledge is the key to decreasing some of their fear, and thus their approach to learning is very open. An example of their open attitude to learning is depicted in the following: "I'm always open to any suggestions for him . . . learning . . . you know every little bit always helps." Another parent shares her beliefs about knowledge as follows:

> When you first encounter a problem, its very important to have someone explain to you what they are doing, what's going on, where they are going to be going, and it calms everybody down, so what you don't have to worry about that or if you do, at least you've already seen it. I think that there's a lot of pluses in that.

This parent continues by describing the benefit this could have been for her when her son was younger:

> But when M. was little, to have had a little bit of knowledge and seeing all of those infants with all those IVs in them and all the other stuff . . . being a new parent coming in, it probably would have taken some anxiety away, to have things explained. Parents really need an education on a lot of this because a lot of parents are scared stiff.

Parents also realize, especially in medically related situations, that language barriers impede their understanding of what is going on with their child. The communication difference is seen as a barrier to establishing a much-needed relationship with professionals. One father states: ". . . that's real important to have that relationship, otherwise, its just really tough. And if communicating is a problem, a barrier is there, and it's not real comfortable."

Incorporating medical terms into their personal language shows the staff how informed and concerned parents are about their children. "It makes me feel," says one mother, "that I'm showing them that I know what I'm talking about. Also I feel like I'm not dumb. If I don't understand it, I feel stupid when I can't understand what they are saying." Another mother commented that the consequences of not learning the medical language may be the professionals' assumption that:

> they are dealing with a parent who does not care. We do care about our children and we're showing you by being able to grasp the language that you are talking, trying to work with you [professionals] at your level. Sure we don't understand all of it but it makes it easier to say it in their terms instead of taking 2 hours to get across something they could have said in 15 minutes.

Observing with a willingness to learn is the primary avenue by which parents in the protection agent phase acquires knowledge. However, the parent learns also that their knowledge is increased by participating in the child's care. Thus during the protection agent phase, parents demonstrate gradual increments of involvement in the hospital care of their child.

Involvement. By participating in their child's care during hospitalization, parents acquire practical experience, additional knowledge and personal confidence. Parents state that this expansion of knowledge makes them feel less anxious and more comfortable with themselves as a parent and a caregiver. As the parent of a nine-year-old severely disabled boy describes: "It's just that, I can get involved and it makes me feel more comfortable and then I am saying that when I take him home anyways, I'll have to do this stuff."

Learning takes place through ordinary "participant observation" as the parent caregiver moves from spectator to active involvement. In the hospital however, initial involvement, is limited to care tasks usually performed in the home or procedures that parents are comfortable in performing. Nurses usually must elicit the parent's help in performing these routine activities of daily living for the child.

Since the initial participation of parents involves the performance of those tasks usually performed at home, parents are very critical of their own performance and look to the staff for encouragement and validation of their "good" caregiving skills. They usually have to be "encouraged" to participate in nursing care activities as they don't want the nurses to "feel that you're taking over what they're doing." In talking about their involvement, parents make references to "being allowed to do" certain tasks or that the "staff trusts me to do certain things."

Parents in the "protection agent" phase delineate clearly parent duties from nursing duties as described by the mother of a four-year-old: "My main responsibility in the hospital has been to comfort him, when the nurses come in and take his temperature and do most of the other things. I have been a comfort to him more than anything and taken away a lot of the fear, just by my presence." Nurses, according to another mother, "do all the documenting, weighing of her diapers and managing the IV. Of course, I would turn on the light when the thing would go off. But her little bath, her Dad and I both gave that to her today." They "trust" the competency of most staff members. "I go by them," says the guardian of a seven-year-old severely disabled child. "They are the doctors or the nurses and I go by their word on how he is doing. Once he's in the hospital, they are there to take care of him and they aren't going to harm him or anything." "I'm not one for questioning nurses," a grandmother states. "I just know, I feel that they earn their degree for something, so use it." "After all," as another mother states, "that's what they've been trained for."

In sum, the "protection agent" phase is the apprenticeship phase for parents of handicapped children. This is the phase when these parents are exposed to numerous and varied new and unfamiliar experiences. During this phase, they acquire a wealth of knowledge; learning a variety of information about themselves as parents, as caregivers and about their child and the disabling condition of the child. Feelings of confidence arise from this acquisition of knowledge and motivate the parents to continue their pursuits for knowledge. Thus with an inquisitive mind, this parent proceeds to the survival agent phase.

Survival Agent

During the "survival agent" phase, parents have become more involved and knowledgeable, and they begin to feel better able to manage the life situations surrounding the family with a disabled child. They realize that negotiations are required to obtain the attention and resources necessary for the child's continued existence and to provide a sense of normality to the family. Realizing that they can't sit back and let things happen, they carefully design and orchestrate their actions. Although their actions may focus on solving immediate problems, they also include long-range goals. The primary long-term goal is to stabilize the child's and family's life.

Some time during the "protection agent" phase, the work of protecting the disabled child has placed excessive strains on the family unit. Evidence of such strains may be demonstrated by a dissolution of the union between the biological mother and father or the handicapped child and its family. Indications of the strain were evident in this study in that 50% of the sample were blended families with the biological mother retaining the handicapped child. For these parents, family reconstructions have begun with a focus of family survival with this child as a member. They realize at this point that having some control over as many child-related situations as possible will assist them in providing "stability" to this family. That is, a balancing of family life can occur when parents are able to effectively integrate the intermittent disability-related challenges into their family functioning.

This realization and goal commitment are what move this parent from a basic "protection agent" to "survival agent". The parent is working for the survival of the child as well as that of the family. The precise temporal point of this shift is specific to each parent, and although it cannot be pinpointed by respondents, the shift is reflected in respondents' remarks as a personal realization that they have become more adept in dealing with the experiences of rearing this disabled child.

Parents at this point have had a myriad of experiences related to the management and care of this child, with hospitalization and trips to clinics and doctors' offices consuming a large portion of the experiences. The parent can express many insights gained from their experiences, of particular importance, the insight that they have acquired a reasonable amount of control of these situations. They continue to focus their actions on accomplishing this goal of family and child stability.

Commitment. Prior to now, any parent or family member could have acted as the "protection agent". As a matter of fact, respondents have indicated that partners or family members alternate being the "agent" or share the responsibilities of this role. Findings indicate that gradually one of these members become more obligated to the child's care. Their explanations for this phenomenon are varied and include such comments as, being a maternal responsibility, being emotionally compelled, having less employable assets, having an innate attribute, and/ or being better able to handle the situation.

In any case, this parent realizes that he/she has the a greater capacity than all others involved with this child for initiating and mediating actions on behalf of the child. This parent exhibits a demeanor which differs from that of the "protection agent" as she is more educated in all aspects of the child's life. She can and does interpret, translate and educate (even while being educated) all others on behalf of the child.

During this phase, the "survival agent" is able to realistically envision the long-term requirements and the "potential" of this child. The child has grown and the signs of delay or limited cognitive development are more obvious. Additionally, the prognosis and definition of the child's disability have become clearer and as a result, this parent is more attuned to and pragmatically assesses the child's current status and future potential. The parent "comes to terms" with the child's condition and helps others to deal with it. This attitudinal adjustment is demonstrated in the following reports by parents: "When you have a child like this, you have to accept that your child will never be normal." Another mother in speaking of her attitude toward the longevity of her child's requirements states: "I do what I've always done, and take it one day at a time. And that's the attitude and that's actually the way I organize my schedule. Uhm, you just do as much as you can as long as you can."

The parent realizes that the commitment declared at this phase requires great personal involvement and vast expenditures of energy. As the mother of a 10-year-old severely disabled child stated: "Taking care of a child like J. requires a lot of strength and energy. It's your entire life's work."

Even so, with the recognition of the personal expense, a deeper commitment is established as a mutual relationship forms between this parent and the child. The parent is able to point out the lessons they have learned by being so involved with this child. He/she speaks of the benefits bestowed upon him/her as a result of having such a child and how this child has "enriched" the family life. As a result, the "survival agent" is more emotionally impelled to ensure that this child "makes it through" each adverse development. She gears her actions toward the child's continued level of functioning with hopes of her/him prospering to a better status, despite of the child's repeated exposures to threats to his/her well-being.

Each illness and hospitalization episode is seen as threatening to the child's well-being because of the vulnerability of this child. After enduring a variety of threats, the parent becomes immensely aware of the unpredictable nature of the child's problems. One parent states:

> Oh no, what if this wasn't it? What if his progress doesn't continue at the present good level that it is? What if we go back and have some of the same problems he had before? So there's always that . . . because he's had so many surprising things. I mean things that doctors who've seen it all are surprised to see. But I think that that's my main concern. It's what's Z.'s body going to do next would be my only concern."

It is these unpredictable struggles and the positive outcomes of most of these struggles that intensifies parental devotion and commitment for the continuation of this child's life. The parent views this child as a "fighter," of having survived to this point for unexplainable purposes and states that if this child, given the limitations he/she has, can endure the trials that he has had to this point, then it's their obligation to fight these battles along with him.

Because hospitalization is a constant threat, whenever the child is hospitalized, one of the biggest fears expressed by the parents who are in the survival agent phase is that of survival. The mother of a nine-year-old severely disabled boy described this fear in the following:

> Usually if you've had to struggle to get here (to this point), you had to put in enough effort that you know what's coming and you know what you're in for and you're ready for it. You know that you are going to reach the bottom of the pit emotionally because you are worried about your child. When they go through those operating room doors, you wonder if you are ever going to see them again. And in most cases, your child is critical enough, that there's always that chance. Or what if this isn't the last stay. Like what we have gone through. Or you know that this is going to be a problem taken care of but what's next? And so you know that you are not here to solve every problem that your child is ever going to have.

Up to this point, this parent has been through many child-related experiences with selected social organizations and has learned to solve multiple immediate problems involving this child. The complexity of problems incurred in protecting the existence of this child has taught her that assistance of others is needed to maintain this child at a certain functioning level. As one mother remarked, ". . . you need someone who understands this and can give you support when you need it."

The "field" in which encounters occur on behalf of the child enlarges as the child grows. The parent become involved with more social organizations such as schools, churches and social service agencies. They are learning how to access a variety of resources and are facing new challenges. "He goes to school five days a week and to respite care after school and for two weeks during the summer, which we pay for out of our pockets because state funds are unavailable to us," says the mother of a nine-year-old severely disabled child. "We've been fortunate enough to have good insurance. I think this is unfair," she continued, "we pay for his diapers, wheelchair and if we were state funded, we wouldn't have to worry."

The safeguarding and protective behaviors exhibited during the "protection agent" phase evolve into skilled vigilance and "measured intervention". The parent is more alert to the differing competencies and attitudes of professionals and now maintains a surveillance to employ those professional with the "appropriate" qualities. They are more prudent in their solicitation of assistance from professionals and they carefully interject opinions about the child's needs.

"Measured intervention" involves a mental analysis of situations resulting in carefully selected actions. This parent has now amassed enough empirical knowledge to calculate privately and strategically what should be done in particular situations. These decisions focus on who should be involved in order to get desired results. Informal analyses are done to determine her power and the importance of the issues. The parent weighs the outcome of the desired effects for the child against the consequences of speaking up to professionals and deciding what actions should be taken. Cautiously, assertive actions are performed based upon the outcome of the analyses. The parent has no intentions of showing professionals that she is a "know-it-all" but rather that she has considerable experience with this child and this particular child's reactions. The mother of an eight- year-old girl with spina bifida describes the analysis process in the following statement: "It depends on the outcome for my child. If its going to be . . . make it difficult for her, then I'll push. I learned from previous experiences because I was green when I came into this, I really hadn't had that much experience, but now . . . I know that they must know what I know." The same mother continued: "I think the parents think of what the consequences will be, the problems that may occur."

Each successful intervention acts as a reinforcement of this parent's personal confidence in her decision making skills. However, she does not allow herself to become overconfident because it is realized that "there's always a new twist to everything." They attempt to "keep their options open" because they don't want to miss out on anything that may benefit the child. These parents speak of using a "wait and see" approach when a professional attempt to convince her of the benefits of a particular procedure. Although, the parent may mentally question its effectiveness, she maintains the thought of its possible benefits. The mother of four-year-old describes: "I like listening to a lot of doctors and getting their opinions. A lot of times, I like to do what they say just to see if it works as long as it is not going to affect her or hurt her."

Knowledge. Knowledge broadens in the "survival agent" phase as the engagements with various professionals and with the child continue. The acquisitions of parenting knowledge, clinical knowledge and intimate knowledge are more focused and organized. Guided by past empirical knowledge, the parent directs her attention to specific problem areas while keeping in mind the "wholeness" of the child and the long-term consequences for the child and the family. The intent is to learn as much as possible to facilitate the optimal development of this child. "We're always trying to find a better treatment regiment or read things or take her to new doctors or try to do anything we can to make her life more normal," says the parents of an eight-year-old severely disabled girl.

Knowledge attainment occurs with increasing rapidity as learning opportunities are frequent. With the rate at which this child becomes ill and/or needs medical or surgical attention, coupled with changes in the child's growth and development, this parent lives a "practicum" of learning experiences. The parent now has more parenting and caregiving knowledge. The parent is able to identify her personal growth in knowledge as illustrated in the statement of the mother of a thirteen year boy with spina bifida: "I've been with him so long and gone through all the difficult times with him." As the child grows and develops in manners which differ from textbook growth and development patterns, the parent, using her child as her yardstick, establishes guidelines by which she measures her child's developmental achievements. As one parent states: "When you expect more out of the child than he's capable of doing, you will not get a lot of joy out of the little things he does accomplish."

"Intimate knowledge" has expanded and is continuing to expand. This parent now has established patterns of communicating with this child and is now aware of the need to exert control over this child's behavior as they focus on the future with this child. As one mother stated: "Some people feel sorry for him and they don't want to make him do what he has to do. He is too big. If I let him get away with things now, how am I going to handle him when he gets older? And we want to keep him at home so we <u>have</u> to make him mind."

The symbolic communication with the child is more advanced as the parent is now able to convert the child's signs of communication into meaningful symbols and relate those meanings to others. The needs of this child can now be anticipated and shared with others. The following interview excerpt demonstrates this skill as well as this parent's realization of her advancing knowledge:

> I can tell things like that . . . before I would not have thought that, if a nurse would have told me that he was not in pain. I would have said, oh, okay. And now I say, Yes, he <u>is</u> in pain and you need to pay attention to that, or look at that, please.

Another mother states: "I had to show the nurses what responses to look for from J. to tell if he liked something or didn't like something. I mean he's aware of his surroundings but he can't talk, so you have to be able to read his expressions."

Through the constant testing of her knowledge and the validations from successful outcomes of some of her actions, she gains more confidence in her abilities and she begins to communicate her knowledge to others who are involved in the child's life. This parent can now make assessments about the child's progress or lack of progress and share this assessment. Family members and professionals begin to recognize that this particular parent has specialized knowledge. Feedback is given about the quality of parenting and caring that is being given to this child. Comments acknowledging the positive outcomes of long-term care such as the absence of skin breakdown or contractures also reinforce this parent's confidence. These acknowledgements of the caregiver's spiraling progression of knowledge and skill acquisitions by associates provide the confidence to master future endeavors and lead to feelings of being empowered.

This parent feels in more control of most aspects of the child's life with each passing engagement. She speaks in terms of "knowing her rights" as a parent and an advocate for a child with disabilities. "I couldn't even get the people at the regional center to suggest names of respite workers or experienced sitters," says one mother, "until I told them that I knew that I was entitled to advice. Then they suggested one."

"Clinical knowledge" is more sophisticated and is obtained with more precision. With the rapidity in which knowledge is accumulated, the "survival agent" realizes that certain illness/hospitalization data must be managed. Some time later in the development of this phase, the "agent" begins to organize and store data in some written form. The written data is managed in a variety of ways such as in journals, on large index cards and on calendars or appointment books. The purpose of the information management strategies is to facilitate immediate and accurate retrieval of this data because the "agent" is often required to retrieve certain data. They are also well aware of the possibilities of forgetting pertinent information and its consequences to the child. Such consequences include; the unnecessary repetition of testing that results in additional traumatic experiences and medical expenses, or the administration of an allergic medication. The mother of a two-year-old girl with congenital heart problems states, "Yeah, it saves in terms of pokes (needle sticks), and trauma. You know all this stuff has already been done once, and you've got the results in front of you, why do it again?"

Previous clinical knowledge obtained during the "protection agent" phase is continually enhanced. Skills acquired during the beginner's phase have been individualized by the parents to suit the needs of the child. Parents have learned how to improvise as needed because many times the necessary resources and materials outside the hospital environment are not easily accessible. The "survival agent" is now looking for and has devised ways to decrease energy, time and financial requirements. As stated by the mother of the eight-year-old severely disabled boy: "I know, I'm always looking for different ways of doing things, that's going to save time. I mean if you're going to come up with something that's going to save me ten minutes, well that's ten minutes I can use in some other place, doing something else."

Likewise, new clinical skills are acquired in more depth. The parent has more insight and absorbs as much information as possible about the child's disability and the hazards relative to the disability, such as predisposing acute illnesses and associated long-term disturbances. She is prepared to learn whatever it takes to provide the necessary care for the child. This mode of thinking is represented in the following statement by the mother of an eight-year-old girl with an uncontrolled seizure disorder: "All of my nursing/medical knowledge I learned through my child. It's real ironic because before I had her, I was afraid of the sight of blood and tonight we're going to learn how to give her a shot. We're going to take some medicine home so if she has some breathing problems, we're going to give her a shot. I really don't think about it now at all."

Another characteristic of the "survival agent" that is indicative of the level of knowledge attained is her capacity to describe the "work" in caring for this child. "The work is very involved in the care of a chronically ill child and one must keep on top of it," states the mother of a severely disabled five-year-old. "Because she can't tell you," she continues, "you have to take on the responsibility of knowing when certain things happen." Experience has taught the "agent" the consequences of not adequately performing the work. "Such as knowing when she has a B.M. because if she gets constipated it takes days of her being uncomfortable for you to get her regular again."

The "survival" work of observing is more skilled and quasi-clinical. In contrast to the "protection" phase, the parent in the "survival agent" phase can describe her observational perspective and purposes. "I'm watching to see if they're doing something differently than I do that is better than what I do. You know it's an educational watching," says the mother of an eight-year-old severely disabled boy. There is not merely an acquiring of any information but specific knowledge is being sought. "So I try to watch as much as possible to make sure she doesn't get any shots, any more than necessary. For instance, I didn't think that one was necessary when they had something in liquid form that they could have given her."

The parents ask more specific and medically discerning questions and exchange their ideas with professionals with more ease. Their approach to learning continues to be open because they realize that there is much more to be learned about this child's care. The "agent" has learned not to anticipate what might happen, but armed with knowledge from previous experiences, they come to recognize they should be able to get through yet another new learning situation. As described in this excerpt: "I don't expect, I let things happen and I have knowledge and I try to prevent certain things that I know causes certain situations. But then I just wait, because I didn't expect him to be throwing up and he was."

During this phase the "agent" also begins to question the accuracy of information disseminated. However, she reluctantly presents her opinions and will accept a professional's opinion over her own, again in the mode of "measured" intervention. An example of such an exchange is depicted in the following, note that with the undesirable outcome, that there is an attitudinal change;

> They gave her what was called the DPT cocktail. And I asked then not to because I heard that it was a very powerful drug. And it knocked her out for 14 hours. But there wasn't anything that I could say about it because that's what her doctor ordered. . . . So I'm really enforcing that now, nobody is going to use that drug on my daughter, because there's no reason for knocking her out that length of time.

The increased knowledge of parents who are in the "survival agent" phase precipitates assertive behaviors. Parents are assertively involving themselves in the care of their child.

Involvement. During the "survival agent" phase, parents recognize that some requirements for the child will necessitate creative parental involvement and they learn how to meet these demand. The mother of a nine-year-old severely disabled boy describes the "agent's" viewpoint on hospitalization;

> In any hospital, even if it's someplace where you're going to have to do battle to see that you child is properly cared for, you have to get as involved and as knowledgeable about what you child's medical needs are as possible. If that means doing research on your own, if that means seeing a number of doctors and asking them questions and making lists of questions, anything that comes up into your mind, write it down and ask it. Or look it up yourself but go in prepared because you don't know what you're going to get into the first time you're going into a hospital. If it's an emergency situation, and you haven't got any time to prepare, try and set aside your anxiety and after you're there and the initial care is given, do some research, write down those questions and carry a list with you. And even if you are considered obnoxious, ask the questions, get the answers.

The "survival agent" takes a more assertive role in resource accessing and managing. She is more aware that her active participation is necessary in order to meet the individual child's needs in their entirety. It is apparent that of all the persons who are involved in providing essentials for this child, she is the only person who has a "whole child" perspective. The mother of an eight-year-old girl states: "They treat these children with spina bifida in kinda of a clinic approach where all the specialists decide what's best for the child by one treating this part and one treating another part, and then the parent has to treat the child as one whole person."

Since the hospital has become one of this parent's most frequently accessed resources, then her involvement can best be observed and described within this context. In the hospital, "educational" observing has developed into a round-the-clock monitoring of the child's care and filtering out traumatic experiences. From a combined parental and quasi-clinical perspective, the "agent" parent checks the state of the child and his/her responses to the treatment regimen using limited physiological knowledge. She uses the professional to confirm her quasi-clinical interpretations while simultaneously evaluating their caregiving abilities. She is equipped with data from previous encounters with professionals and, as she observes in the current situation, she picks up on the competencies or incompetencies of staff.

Her vigil of monitoring the work of others, is personally perceived as necessary "because someone must be with her [the child] at all times to take care of her needs." The vigil is justified not just because she sees it as her responsibility but because she has assessed that staffing is such that one nurse cannot be with the child all the time. The parent is able to relate from past results of the benefits of her vigil. She states that as a result of her presence the child can receive attention when needed, at a more concentrated level and at a better quality because the "agent" is there to focus the nurse in specific directions. Also, since these children cannot verbalize their needs or their reactions may be masked by cognitive or physical impairments, the "agent" must interpret the child's behaviors and translate the child's feelings to the staff. Likewise, the parent is also present to interpret the staff's actions for the child.

The parent in the "survival agent" phase becomes more independently involved in the care of the child. Being actively involved is important to the "survival agent" for several reasons. Involvement makes the agent feel more in control of the situation in addition to providing "hands on" learning opportunities. However, there is some hesitation in performing procedures requiring specialized skills different from those performed by the "agent" at home. But it takes only a few instructions for this parent to learn to perform those new procedures since parental caregiving activities are gradually overlapping with the specialized caring activities of many professionals.

The caring activities have become more medically-oriented particularly if the child's condition has warranted specialized home care procedures. The "agent" speaks of the importance of her performing these procedures because her individualized techniques are less traumatic and not as time consuming. As stated by the mother of a thirteen-year-old boy with spina bifida: "Basically, its a one, two, three procedure for me. It's easier for me, knowing what to do, it takes me two minutes to do it whereas a nurse coming in or someone who's not familiar with that procedure would just take them a little longer." Acquired "intimate" knowledge regarding what has worked for this child, the goal of maintaining current progress and the future consequences are the key reasons why her techniques are preferable over the nurse's.

Although the "survival agent" is skilled now in certain technical procedures, she views the professional as more skilled. Even if she does have more knowledge about certain facets of this child's care, she does not speak of herself as an "expert". She looks to the professional nurse in the hospital to provide the leadership in the hospital care of her child.

The parent who is in the "survival agent" phase describes herself as an "aide" to the staff. Relatives and friends reinforce this perception as presented in the following statement of a husband: "L. [the `survival agent'] is here constantly. She does this as an aide to the nurses. We don't think that R. (the child) would get the treatment that she gets without her being here. She makes sure that she get the medicines she needs and its just that she's personally involved."

She is knowledgeable about most hospital operations, but continues to profess that her primary purpose as a team member is providing emotional support for her child. However, she now expects to contribute more in planning and providing the child's care. She appreciates and asks for constructive feedback from the nurse about the child's care while she diplomatically interjects her opinions about care administered by others. She expects to have a mutually trusting relationship with professionals and attempts to establish one if it does appear to be present. Needless to say, although the parent may feel the need for such a relationship, it may not always be considered a priority of the professional involved in the relationship.

The nurse's trust is especially important in the hospital as the "agent" looks to the nurse for encouragement in performing selected acquired skills as well as new technical procedures. The parent feels that trust and perceptions of the "agent's" performance is necessary to provide the agent with confidence. As described by this mother, ". . . the nurses get the medications together and bring it to me and I give it to her. And that's fine. I'm use to giving it to her. They trust me giving it to her and she trusts me."

Nurses, as do other professionals, gain the respect and trust of the parents by passing the competency "tests" and by meeting the "agent's" criteria of professionalism. The parent has observed how staff handle themselves in various situations in the hospital and have formulated standards of professional behavior. Because she now can accept the fact that professionals are human, she appreciates and trusts a professional who can admit to their shortcomings but shows a desire to learn.

Besides being competent, professionals are expected to carry out their duties in a caring manner. This is particularly expected of nurses as the parent now is associating her role more with that of the nurse. She knows now that she can perform certain duties which she at one time thought that only the nurse could do. With each proficient performance she adds to her formulated standard by which she measures the quality of care given her child and the competency of those providing it. She is aware, however, that there are technical aspects of care that she is unable to evaluate thoroughly, but, she knows that it's just a matter of time for her to gain the required knowledge for a more inclusive evaluation. For with each hospital situation, she, the "survival agent," is reinforcing, testing and increasing her caregiving abilities and knowledge.

In general, the arrival at the "survival agent" phase is the culmination of a long and difficult journey. The parent has personally matured and amassed more knowledge than could be imagined when she assented initially to the care of this disabled child in the "protection agent" phase. In this phase of "survival agent", although unforeseen by the parent, groundwork was being laid for becoming a highly skilled and medically literate caregiver; the child's "central person".

Central Person

As in the previous identity phase of "survival agent", the transition to the complex "central person" identity is also a gradual development. Again, with the accumulation of empirical knowledge from the encounters with various social systems, the "parent-agent" becomes most learned in all facets of this child's being. She now possesses clinically explicit and detailed intimate knowledge of her child and her pledge of self to this child's welfare has become more solemn. The identity of being the child's "central person" emerges as a culmination of deep personal commitment, strong affective attachment and advanced specialized knowledge in all aspects of the child's being. The identity evolved from the dynamic personal growth in confidence and competencies and an empowerment from others which did not exist previously. What characterizes the "central person" identity is described by a parent in the following illustration: "there are so many variables of complications with him . . . . I am his central person. I'm the one that really KNOWS what's really going on with him. Everyone else sees him for an hour or two and then goes and does something else but I have been with him through all the difficult times, that I feel I'm knowledged . . . on his individual care."

The "central person" identity phase is the most complicated and involved of all the other identity phases. The behaviors exhibited as the child's "central person" are distinct and are indicative of advanced levels of commitment and knowledge. Both characteristics facilitate complete involvement in this child's life. Essentially, this parent or guardian has become the child's behavioral and communication system and is more than merely an "agent" of the child. As the child's "central person", the parent assumes the child's interactive being. That is, the parent acquires the "feelings" of the child and becomes the child's "sensor" for environmental stimuli.

The three areas, commitment, knowledge and involvement, that were quite distinguishable in earlier phases, are now intermingled and more interdependent. The boundaries of commitment and intimacy during this phase are nonexistent. The central person is profoundly devoted and dedicated to this child. In addition, knowledge and involvement are closely related, in that the more knowledgeable the central person is perceived to be by herself and others, the more involved she is. Since there is such an interrelationship of these features, the descriptive findings will be presented with this fact in mind. While commitment will be presented in a separate section, the reader must keep in mind the fact that this characteristic influences what additional knowledge is sought and acquired, and how existing knowledge is utilized in various situations. Likewise, the influence of commitment must be recognized in the sections on knowledge and involvement behaviors.

<u>Commitment</u>. The "central person" is engrossed in all aspects of this child's personage, that is, the child's identity has become internalized within this parent. This has taken place because of the parent's awareness of this child's inabilities to convey discernible messages to others. This parent, however has had repeated successes in interpreting and conveying these messages, and therefore has a total understanding of this child's being. The mother of a nine-year-old severely disabled boy describes this quality in the following: "Z. is me, in a lot of ways because he has to be. Not that I don't think he has a personality of his own, but I'm the one who has to read his

personality and say things to other people as if Z. was saying them." The mother of a ten-year-old boy also shared: "He's got a brain in there, it's just a matter of his brain not allowing him to say this. He's got feelings, he's got a personality and got things about him, its just that I need to share with people what I know he's going through." She has taken on the responsibilities of doing those things that the child can't do because of the disability limitations. Actually, she is supplementing the impaired functioning in the child with her abilities.

"Impairment supplementation" is enacted in every aspect of deficit in the child's functioning. For example, for a cognitively and language impaired child, the parent develops proficient abilities to interpret the child's emotions and behaviors. As the child's "central person", the parent has acquired the "feelings" of the child and has become the "voice" of the child. The mother of a nine-year-old severely disabled boy states:

> I'm his voice. What Z. can't say, what Z. is feeling that he can't convey. What has worked before that Z. can't tell them. I'm the voice and it is a very fine line. Sometimes its almost as if he is just an extension of my own body and its like explaining something that my own body is doing.

Another type of impairment supplementing done by the child's "central person" of the verbally and cognitively impaired child is that of sensory interpretation. This parent can determine what is pleasant or obnoxious to the child and translates for, from and to the child. Over time, she has organized a conception of the child's whole response system and has assumed the child's interactive being and "identity" but of course not the body. One mother shared the following incident that exemplifies the above trait:

> One instance the other night, Z. was just screaming and everyone thought he was in agony. And I came into the room and they said, `what's wrong, does he need some morphine? We've got to do something, what's going on?' And I said, `They've got the teddy bear wound up in the next bed.' And they said, `What?' And I said, `its the teddy bear, get rid of the teddy bear, turn it off.' And it was. I don't remember ever him doing that before, every time after that, we'd test it out. We'd turn on the teddy bear and Z. would absolutely go nuts. But I don't know why, but my brain was feeling what his was feeling.

The special connectedness between the child and "central person" is described by one mother in the following excerpt: "There's something that isn't physical, that never ends. There's something there that attaches you with that being and its almost like a physical attachment but there's nothing anybody can see. It's almost as if the blood is still going back and forth and that our brains are one." The intensive commitment is also illustrated in a continuation of her statement: "an extension of yourself that you are taking care of and when you're doing all of these things, it's not a job, it's as if your are taking care of an extension of your own body or your own being."

Whereas as the abilities of the "central person" to skillfully supplement the child's impairments are comforting to this parent, this quality carries awesome realizations. The parent expresses that knowing that she is the only person who has this capability is accompanied by a great deal of anxiety. "In a way", says one mother, "it makes me kind of afraid too because I know there's no back up. If I give out, who's going to do it?"

The idea of having no substitute for herself is supported by the acknowledgement that this responsibility must be continued throughout this child's lifetime, a lifetime which may or may not outlast her own. There is no resigning from the role of "central person" other than through death (of the child or the central person) or the onset of a debilitating illness of the central person. One parent who was hospitalized, shared how her hospital stay was abbreviated so she could be available when the child suddenly had to be hospitalized. Because of this realization, one of the objectives of this parent becomes that of educating possible substitutes. In so much as parents in this study spoke of the lack of substitute concern, they could not specify who in particular would take on their total "job" in the event they would be unable to do it.

In sum, the "central person's" commitment is profound and devoted. The feelings and attachment to this child have grown so deeply that the parent views her own emotions as inseparable from those of her child. The profound commitment demonstrated during the "central person" phase is sustained with extensive knowledge.

Knowledge. In this phase of the agent work trajectory, the parent or guardian, as "central person" holds knowledge from all branches of this child's life. She has a broad base of both clinical and intimate knowledge. Having the greater intimate knowledge of all other persons encountering the child, she now feels thoroughly capable of educating others on her child. She has lived the history of the child's growth, development and through all disability-related events. Most aspects of the child's life are centralized in her, and as her child's storehouse of knowledge, she is structurally at the intersection of "world-child" interactions. She is principally responsible for utilizing her stores of knowledge to strategically maneuver the child-affiliated actions of others.

The parents who have made the transition to being their child's "central person" refer to themselves as being "knowledged". According to respondents in this study, "knowledged" means possessing in-depth intimate knowledge on your child's feelings and particularities, in addition to having advanced facts and information in a specialized field of care for your disable child. Being knowledged also means being extremely familiar with the mechanical workings of most, if not all, social systems encountered on your child's behalf. "I've been exposed to the system, I know the program", says one mother when talking about being knowledgeable. "I kind of know what to expect, especially from the time when K. was hospitalized for one and a half months. I could tell the residents from the interns and how often they change, when they change. I figured out their routines and the best times to get certain things accomplished." In other words, she has developed creative strategies for getting the system to work for her and she is not intimidated by <u>any</u> system.

A component of "being knowledged" is being an "expert learner", according to the respondents in this study. One mother in describing herself as an "expert learner" commented:

> That's knowing your abilities and knowing you need to grow in them and can grow in them. That's the important thing because you are going to have to grow in your knowledge of them [your child] as well as your abilities to do these things and to learn more and more, more, more, more.

Therefore, being knowledged as the central person involves being able to evaluate yourself and maintain an openness to learning.

Respondents who are their child's "central person" also refer to themselves as an "information center" and a repository of an accumulated knowledge about this child's care. They view themselves as the essential element in tapping the assets of others to gain benefits for their child. She must interpret the history, capabilities, behaviors and reactions of the child to professionals. She essentially is the one person who has at her disposal all the pieces to the puzzle which must be put together in order for others to provide their assets proficiently. One mother states: "I'm the information center and I don't think they could care for Z. as well unless I was telling them all that Z. is and has been." However, sometimes this responsibility can be considered sobering, as demonstrated in the following comments of this same mother:

> Sometimes it's almost an oppressive responsibility, because everything the world has to know about your child, you have to be the one that makes the world aware of it. And it's hard, it's like not only having to know yourself, and that's difficult for most people, but knowing someone else that well too. Especially if the child is mildly retarded or not at all but simply can't respond. The responsibility is awesome, but you get so good at it sometimes you don't even have to think about it until somebody else has noticed.

Nonetheless, being able to take on such a responsibility is empowering, as those persons associated with the central person gives her credit for her abilities. Families, friends, and professionals in addition to making comments about how well her performance is, utilize her as a resource to update them on this child. Comments by family members make it quite clear that she is viewed as the principal agent for assuring that this child receives his/her entitlements. The following account shows empowering feedback given by others to the child's "central person":

> When M. go to the hospital, my family and friends tell me that I have to be there, they want me there. They want to rely on my knowledge and the experiences that I've had with M. Like there are so many variables with M., he's allergic to so many medicines, he reacts differently to many things when he is sick. So I am there to be their central knowledge and I am also there to give M. help in the process.

This particular parent's special expertise is also recognized by most professionals and their feedback add to this parent's feelings of empowerment. "In one way," commented a mother on the doctor's confidence in her as caregiver, "it's reassuring because the doctors know I can take care of Z. and we've done it under some pretty primitive conditions because we live so far out." About professionals' respecting her as a knowledgeable team member and thus enhancing her feelings of empowerment, the mother of an eight-year-old contributed the following comment. "I mean the doctors make you feel just as important as any other member in the team . . . just like one of the residents. They have made me feel real important. They've trusted my judgements. I've been able to make decisions about her medications including the dosages."

The feedback received from others validates for the "central person" what she has learned from the series of natural experiments in which she has been involved since the onset of this child's disability. With the success of most past "experiments" in caring for a disabled child, she learned how her feelings about herself and her goal to attain control in most aspects of the child's life can interfere with her actual control in various situations. She accepts the fact that certain aspects are uncontrollable and that, from time to time, variations in the degree of control which she may have will occur.

Yet with her present knowledge level of an accomplished parent and caregiver, she demonstrates "confident flexibility." She is confident that she is prepared to tackle each new endeavor and will do her best in any case. The central person has learned to remain flexible in her thinking because experience has taught her that the future will hold many new challenges. In addition, she realizes that it is impossible to be prepared for every happening in this child's life. Understanding this fact is the primary factor that has tempered the anxiety associated with the uncertainty of the future.

"Confident flexibility" as a manifestation of control is also demonstrated in the individual's treatment of increased self-confidence. The "central person" maintains a sense of control over her feelings of confidence in that she recognizes that being overconfident will interfere with the acquisition of future knowledge. She has learned from the previous phase to maintain an open attitude about knowledge for she knows that others can interpret her confident behaviors as cockiness or overconfidence. There is always the realization that there is a wide range of knowledge that she has yet to tap. The following exemplar is representative of the flexible but confident attitude of the "central person":

> . . . we don't want to be considered `know it alls' but we do know an awfully lot about K., her problems, her needs and specific quirks she has. And we know her developmentally. We're also open to suggestions. We like finding out things to help her. If we have questions we feel comfortable calling the doctors or the floor, we feel that this is our only link to information that can help her.

Note that inherent in the above statement is her realization that on top of the possession of significant in-depth knowledge, she has a capacity to learn whatever is necessary to give her child the best quality of life available. This is a distinct feature that separates this agent category from all the others.

As stated earlier, having an awareness that she is capable of complete control, does not necessarily mean that complete control at all times is absolutely a requisite for the "central person". She has enough knowledge to realize that she and the professional may alternate in the controlling position. In addition she is capable of making an formal and informed analysis of how much power she has as each situation present itself. She knows there are occasions where she must assert herself in the decision making process and other times when she must leave decisions to the doctors. This behavior, as the reader may recall is an extension of "measured intervention" strategy which began in the "survival agent" phase and continues into future operations. Her current level of knowledge makes the "central person" feel on a even level with the professional. She and the professional have specialized knowledge, which if exchanged will benefit both of them and the child as well. She knows that there can and must be an intelligent exchange and she now expects this type of exchange. However she is intolerant of the professional who is incompetent, impatient and unreliable and one who does nothing to rectify these deficiencies. The parent of a three-year-old with a congenital kidney disorder stated:

> I don't usually call our pediatrician because he hasn't done anything to get himself informed. We have shared articles with him and I don't think he has read one word. I feel that he's gone to med school and should have kept up to date on peritoneal dialysis for a child, like K. but he doesn't.

In terms of knowledge, the formal professional education is the only quality that sets the "central person" apart from the professional. She credits herself with an enormous capacity for learning and retaining specialized and advanced knowledge and past endeavors have proven her belief true. Bear in mind, that past experiences, particularly those during the "survival agent" phase, have taught her the worth of the tests of her knowledge. One way this parent tests her knowledge is by instructing the nurse on how she (the central person) takes care of specific problems. By instructing the nurse, she gains more insight into this as well as other caregiving techniques. One mother explains this exchange in the following:

> I can tell them what has worked for Z. before. And sometimes it's rather odd because it's not your normal scientific research program of care for a specific problem. Like my squirt bottle for washing out the insides of the syringes when gravity medications have been put through them. The nurses say they have never seen that before. Well they learn those kinds of things from me. But as far as how the body works and why they're doing certain procedures in a certain way, and why a certain kind of care is given to a certain problem, that's where I learn from them. And then I can decipher whether it's working or not. And I can always go back and say, is there another way of doing this? If it was changed what will happen? That's where being an expert learner comes in.

Unique techniques, such as that of the squirt bottle mentioned above, are acquired during the series of natural experiments that are routinely performed by the "central person" caregiver. The caregiver constantly performs experimental trials to test her knowledge and to develop more proficient techniques of care for her child. The more positive the outcome of these constant tests of her knowledge, the more certain she feels and the more validated she is by herself, family members and professionals.

In addition to acquiring knowledge through natural experimentations, knowledge is gained as a result of unplanned occurrences and near-mishaps. The following account is an example of learning from an unforeseen and potentially tragic incident, the outcome of which has lead to increased knowledge and a change in the behavior of the child's "central person". One mother described how she left her child's bedside to take a shower and during that time her child had a grand mal seizure. The seizuring was noticed and reported by a person who just happen to be passing by her child's room. This particular incident caused her to formulate a specific mode of action that she shared in the form of advice to other parents who might experience a similar situations. ". . . if the nursing staff was aware that they (parents) were going to be gone and that they specifically told them that they were going to be leaving, that the child would probably be watched and monitored, but I'd tell them not to just assume that they could leave and that the child would be watched."

Realizing that she is well equipped with an expansive body of knowledge, the "central person" has expanded the group of persons to which she disseminates information. No longer is her information sharing limited to just those involved in her child's life. Now she freely shares her knowledge with other parents. She can identify and describe the less informed parent and because she knows how it was when she did not have knowledge, she feels a responsibility for informing them. In describing why she shared information with other parents, one mother commented: "I guess other parents who have handled similar situations can relax you a little bit, from the panic time that professional people like to throw at you."

Another characteristic indicative of the specialized knowledge of the child's central person is her command of medical language. She communicates in a medically literate manner, in that, she has incorporated clinical terms and meanings in her vocabulary and she uses them with ease. She collaborates with professional in a highly intellectual way and prefers that the professional uses technical terms in explanations because sometimes they lose pertinent information when medical language is translated into lay terms. As a matter of fact, the language has become such a part of her ordinary vocabulary that she is unaware of this feature.

Also indicative of the level of knowledge possessed by the "central person" is her mastery of strategies for dealing with various annoying situations. One such incident involves her encyclopedia of intimate knowledge about this child and the professional's treatment of such knowledge. While this mother has gained and is continuing to acquire varying amounts of different types of clinical knowledge, the professionals, particularly doctors and nurses, have gained limited intimate knowledge of the child. She alone can integrate past experiences from different arenas with the child's present situation. Professionals knowing this utilize the parent's journal of knowledge throughout their engagements with the parent. But from the parent's perspective, this action is often utilized to excess as she may be asked to repeat all or most of this information numerous times within the course of her child's hospital stay. The professional's actions cause frustration for her, but she recognizes the risks involved if certain historical information is not utilized and often accommodate professionals by constantly repeating the child's history.

However, she has developed strategies for dealing with these situations. Two strategies utilized by her to decrease the number of repetitions of information are, first, having one professional share this information with the others in her presence, so that she can interject pertinent information from time to time. The second strategy is to request the primary physician to present her child in rounds so that all residents, interns, etc., are informed by the primary physician, simultaneously.

The child's "central person" is medically literate in the majority of areas involving her child. She has mastered a vast number of technical skills and is often more trusting of her own performance than that of others. She can state what her expertise entails and what specifically is lacking in her skills and knowledge. She is aware of where to go to obtain these lacking aspects and who is better equipped to give her what is needed. Therefore she will elicit the instruction of those selected staff whom she has identified as competent and empathetic to her needs.

In summary, the "central person" possesses a level of knowledge that is representative of competence and proficiency in performing as well as learning. Accompanying the advanced knowledge and skills is the responsibility of being the absolute coordinator and organizer for the child. This link along with a profound commitment dictates the level and type of involvement.

Involvement. The dynamic work of the "central person" is comprised of many actions and interactions. She is now at a level where she may be as involved as she wants to be as she is the essential link bringing together all others involved in this child's life. She has organized and is in control of a multiplicity of momentary actions designed to solve immediate and long-term problems. The past helped with learning, the future is vague but controls her present actions. Her actions are those of a highly skilled and knowledgeable caregiver. Degree of involvement should not be confused with degree of participation, for the "central person" may decide not to be a participant and still be totally involved in her child's care. For the purpose of continuity in this paper, involvement activities will be described within those categories identified in the "survival agent" phase; coordinating, intervening, monitoring and vigil. Emphasis will be placed however, on the skillful and professional accuracy of her performance.

Coordinating as done by the child's "central person" can be divided into an intimate and non-intimate component. The intimate component is that of connecting certain inner aspects of the child's life with his/ her external environment and vice versa. As the child's "central person", this parent acts as a translator or "bridge" between the environments of the child (both external and internal) to sustain and preserve the well-being of this child. One mother described herself as being her child's "bridge between the world and his inner self." She also described herself as her child's "sensor, like being his megaphone and there seems to be a very thin line between what he is feeling and what I feel. I can tell what is bothering him."

The non-intimate, professional component of coordinating involves all external endeavors on behalf of this child, such as accessing and utilizing professionals. The parent in the "central person" phase is independent in her decision making. She feels free to decide the degree to she will participate in various activities and will not hesitate to be totally responsible for the performance of her child's hospital care. Those tasks which she knows she have yet to learn will be "assigned" to the doctors or nurses.

Most often in the hospital, when a parent has attained this level of agency development, nurses and doctors are considered to be assisting the "central person" instead of the reverse as was demonstrated in the "survival agent" phase. In most cases, the "central person" is the primary performer of the child's care. Most parents in this phase, describe themselves as doing all the child's care with the nurse assisting them. The "central person" determines the need for assistance and when professional interventions are necessary. As one mother stated: "I do everything. . . . I do his skin care so he won't get breakdown. His skin is in real good condition and he's never had a breakdown. I know how to do his feedings [NG feedings] and I think he feel more comfortable with my doing it for him." In any case, joint efforts are expected in order to give the child the best possible care. Another mother verbalizes her feelings on this issue in the following manner: "So far the nurses that we've had working with K. has worked <u>with</u> us. None have tried to run the whole show. I feel that if we work with them and they work with us that the baby gets the best care."

The nurse's primary involvement when a parent reaches the "central person" phase entails the performance of selected highly technical procedures or the instructing of the "central person" in new procedures or new doctor's orders. As specifically stated by the mother of a three-year-old, "The nurse's responsibilities are to check her vital signs, watch the I.V. I don't know all there is to know about the I.V., so they have to watch that."

Teamwork takes on a different meaning in this phase as the "central person" views herself as a partner with alternating leadership in certain situations. "I think we should work together. But there have been times when I've wondered, if we were working together." But if conflicts arise in relations to teamwork, the "central person" has very few difficulties resolving them. Her experiences in the past have taught her how to manage staff members and maintain a working relationship. She does not allow conflicts to linger because she knows that a positive working relationship is important to get the most possible accomplished for her child. This strategy category of "measured intervention" began early in the "survival agent" phase and is now more refined.

The "central person" is a shrewd negotiator and is proficient in initiating and mediating the actions of others. She is described by herself and others as a facilitator of staff. In describing why their child's hospitalization was necessary since the mother does all the care for the child, one stepfather stated: "We brought her here because it's more of a controlled environment and we feel if something did go wrong or if there was a major, major problem, there'd be the equipment and we could facilitate the start of a procedure."

Parents state that as a "knowledged" caregiver that they have earned a place on the hospital team. They are not forceful or demanding in getting their place on the team but they demonstrate in their behavior that they deserve a place of significance on this team. She prefers that the nurse and/or her primary physician acknowledge her assets and welcome her as a formal member of the team. Nonetheless, this does not always occur, thus it becomes the "central person's" duty to demonstrate to staff members that her skill in caring for her child and her possession of intimate knowledge are necessary assets for the provision of her child's care needs.

The "central person" sees herself as providing additional services to the staff as a result of her being present and participating the child's care. Although in her provision of care for her child she is giving emotional support to the child, she is also supporting the staff. As her child's "central person", the mother possess knowledge about certain things that the staff does not know about, such as where the child's most sensitive areas are, or a special way to perform a task to reduce the traumatizing effects to the child.

During the "central person" phase when the handicapped child is hospitalized, she more often than not stays with her child 24 hours of the day. The vigil has more specific purposes now. Her monitoring is more skilled and informed. The "central person" can assess personalities, competency and intent of others quite readily so she does not have to go through experiences in order to evaluate the worth. She does what is termed by this investigator as "gatekeeping". Basically she checks out staff's credentials from questioning other staff members and other parents and predetermines the worth of staff members. She also watches their interactions with other patients and parents. These actions coupled with her broad experiential knowledge, provide her with the data to make her decisions on whether or not the staff members will have "entry" into her team of workers for caring for her child.

Another type of monitoring done by the child's "central person" is clinical. Although the parenting perspective is maintained, the child's central person is so knowledgeable that she clinically assesses and evaluates her child's physiological state. She is able to check most often with professional accuracy the physiological state of the child and his/her responses to the treatment regimen. She has a general working knowledge of her child's body and how it functions and can scrutinize its condition. She is able to recognize threats to this child's well-being and has the capacity of thwarting such threats. She critically analyze treatments and their effects on her child and she is not afraid to question their benefits and/or adverse effects.

Even when she is not present, she utilizes skillful investigative abilities to check on and evaluate care given in her absence by noting specific signs of care. One mother states: "You know when the nurses have been in the room, whether its just a blanket folded differently or he's holding a different toy. There may be some signs of a medication given. You know what's been done while you were gone." Not only does she recognize comforting signs but nursing measures as well. She observes and mentally records the mechanics for a vast number of treatments such as the level of fluids in intravenous containers, urinary output; the condition of the child's incisional area or dressings.

Generally, involvement during the "central person" phase is the aggregate of the advanced knowledge and total commitment attained during this and previous phases. Even though there are times when the child's "central person" may chose not to participate in certain caregiving tasks, there is never a time when this "agent" is not totally involved. The degree of participation depends on whether or not the child's "central person" feels that she is equipped with the proper knowledge for performing particular specialized tasks. It is significant that, although the "central person" phase was described by respondents to be the most learned of all other phases that growth does not cease at this level. Growth in knowledge and confidence continues through the caregiver and child's entire lives.

Summary

In this study of parent caregivers of hospitalized handicapped children, emerging as the child's "central person" was identified as the integrative theme of the substantive theory which describes the process of managing the work as a caregiver. In their efforts to manage their work as parent caregivers, an inadvertent developmental and evolutionary emergence of identity occurs. Three phases of agent work were identified and utilized as the central schema for describing the developmental process. The behavioral and cognitive characteristics of commitment, knowledge and involvement described in each agent category demonstrated the changes indicative of each phase. The parent caregiver proceeds from an inexperienced "agent" of protecting the child to "survival agent". Over time the same parent proceeds to the more advanced phase of "central person". At the onset of this dynamic process when the parent sets out to become the best parent possible for the disabled child and a skilled caregiver, she may not realize that she is moving toward becoming the child's "central person". However, as she progresses from one phase to the next she gains increasing knowledge, commitment and involvement.

CHAPTER FIVE

DISCUSSIONS

The discussion of the findings is organized in the following manner. The phase and temporal considerations of the substantive theory developed in the study are discussed initially. Second, speculative insights are shared regarding qualifiers influencing identity transitions such as caregiver's gender, child's disability status, and frequency of hospitalization experiences. Strengths and limitations of the research are discussed with implications for practice and future research concluding the chapter.

Substantive Theory Considerations

Identity Phase Considerations

Emerging as the child's "central person" applies to the parent caregiver who is rearing a child with cognitive and physical limitations. The theory developed in this study explains the identity patterning process which takes place as the parent of a handicapped child takes on and manages the caregiving of this child. This theory suggests a trajectory involving "identity" phases.

A requisite of a system wherein phases are identified, is clearly defined and unambiguous phase descriptions (Burr, 1979). Presented in this theory are three "phases" of parent caregiving identities: protection agent, survival agent and central person. Although distinctions are shown in the behavioral and cognitive indicators of commitment, knowledge and involvement, the behaviors are not without some ambiguity because of the overlapping nature of the identity emergence process. This difficulty is incurred often when a dynamic, interactive and cumulative process is depicted in writing.

The process in which the parent caregiver moves from one identity category to the next involves spiraling progressions and is connoted by cognitive and behavioral changes. Acquisition of knowledge is the facilitator of transition. However, the acquiring of knowledge in not straightforward and clearcut. Within the three phases, there are various intermittent peaks and valleys in the caregiver's learning and utilization of knowledge. Knowledge acquisition is permeated with the learning of; new information, different ways of performing previously learned skills and the adding on of new knowledge to prior knowledge. The unfamiliarity with new endeavors may be viewed by the parent caregiver as frustrating, however the acceptance of the fact that new endeavors will continually present themselves and must be dealt with, is what facilitates parents through the struggles of the process.

Another aid to identity transitions is the presence of supportive, responsive behaviors from others. Parent caregivers in this study tend to move more steadily toward becoming their child's "central person" when they perceive the presence of support, either from their significant others or professionals. Analogies from child development research on the socialization of children can be utilize to support these observations in this study. Rollins and Thomas (1979), in their review of child development research state that "man appears to grow physically, emotionally and socially in the presence of supportive relationships, while he encounters considerable problems in its absence"

(p. 351). However, the ability to perceive an environment or person as supportive, is dependent upon the individual's capacity to engage in the mental activity of imagining what is in the minds of others and to correctly "read" their behaviors. In this study, the parents who could accurately assess environmental supports were more adept as parent caregivers and defined themselves as "knowledged". These parents not only demonstrated their abilities to actively interact with adults, they verbalized very few difficulties learning to understand their child's verbal and nonverbal cues or responses. On the other hand, those parents who did not speak of themselves as "knowledged", demonstrated a lack of sophistication in problem solving skills, parenting inaptness and naive attitudes regarding the potentials of child caregiving challenges.

Identifying and reacting to the effects of a responsive environment also affect the development of a sense of competency (Rollins & Thomas, 1979). Those parents who identified themselves as their child's "central person", the most competent of all three identity phases, also referred to themselves as having attained a level of proficiency, in carrying out their caregiving duties and in assessing and evaluating the competencies of professionals. Rollins and Thomas (1979) extracted information from research and writings on the human infant to construct a view of man regarding competency and control. Based upon the work of Piaget (1954) on cognitive theory, Appleton (1975) on infant competency, and Shantz (1975) on social cognition, Rollins and Thomas (1979) declare that when man, from infant to functioning adult, is faced with a choice, he will make many of his choices according to which one allows him the greatest amount of control over his environment. The question of motivation is of concern, according to Rollins and Thomas (1979), only when one asks why one course of action is selected over another. The assumption is that a particular choice is selected over another, most often on the basis of choosing the course that gives the greatest potential for personal control, which results in the development of a sense of competence in the organism as an agent of change in his environment (Rollins & Thomas, 1979).

In applying the preceding assumptions to the transitions and phases in this study, the parent caregiver is motivated to acquire more knowledge and skills to change her competency level. Initially, it is the uneasy feelings of incompetence resulting from lack of knowledge, experience and skills which stimulate an active competency-based notion in the caregiver. Of course, as indicated in the explication of the substantive theory, these intentions may not be conscious at the onset, but in the striving to prevail over the difficult undertakings of caregiving, knowledge is acquired and accumulated. With the accumulation of knowledge and skills, comes increased self-confidence and the acknowledgement of a personal sense of control in most child caregiving endeavors. As depicted in the substantive theory, it is during the second identity phase; the survival agent phase, that conscious, active efforts are made to attain specific knowledge through active involvement. The eventual development of the strategy to purposefully acquire knowledge by parents facilitates transition from one phase to the next. The specific amount of time it takes to move from one identity phase to the next is an issue that warrants further discussion, therefore the next section discusses temporal considerations.

Temporal Considerations

Passage from one phase to the next is unrelated to years of experience in the caregiving role. It seems to be related to a combination of the personal attributes of the caregiver and the presence of a responsive, supportive environment. In addition, cumulative knowledge is obtained from frequent exposures to a variety of child-related endeavors. Basically, time-related criteria cannot be determined from the data in this study. That is, the study data can not be utilized to state, that after experiencing caregiving for a handicapped child for x number of years that a parent moves from "survival agent" to a "central person". There were, however, certain characteristics peculiar to the respondents in this study and are discussed as factors affecting transitions.

Qualifiers of Caregiving Identity Emergence Process

Characteristics that were peculiar to the respondents in this study and appear to influenced the emergence process are; caregiver's gender, child's disability status and frequency and type of child-related experiences; specifically hospitalizations of the child. The process was experienced primarily by female caregivers. Males interviewed in the study specified their female partner as the primary caregiver for the child. Reasons for the female assuming major caregiving responsibilities were varied. In some cases, it was a matter of employment; that is, the partner who was not employed outside of the home or who had the least income potential was the designated caregiver. In other cases, it was explained in terms of "gender-typing" (McGee and

Wells, 1984) that is, caregiving was defined as the mother's responsibility or as an innate quality of mothering.

The assumption of the caregiving responsibility was either automatic or legitimized. The biological mothers who were in original spousal relationships automatically assumed the duties, whether or not they were employed outside the home. Those divorced mothers who had remarried and retained the legal custody of their disabled child also described themselves as the primary caregiver.

The gender issue was examined in the caregiving literature. The gender-typing theory has been explored in literature involving adult partner caregiving (Graham, 1984; Oliver, 1983) and adult-child caregiving for aging or ill parents (Brody, 1981; Evers, 1985). Although the caregiving literature correlates normal parent-child relationships to adult caregiving situation, little research has focused on parent-child caregiving situation. Much of the adult caregiving literature suggests that women shoulder a greater share of the caregiving burden than men. In providing rationale for this occurrence, Graham (1984) suggests that women are symbolized as caregivers in society. Society expects mothers to provide basic health care for their infants and wives to maintain health promoting situations for the family, such as healthy diets and stress-reducing environments. Noddings, in her text Caring: A Feminine Approach to Ethics and Moral Education (1984), asserts that women develop a distinct ethic of care and define themselves in terms of their "capacity to care" (p. 40). Noddings describes the mother's caring as a response to her "natural relatedness" to the child (p. 43). Whereas this literature is rich with opinions that have explanatory potential for scrutinizing the female bias to caregiving, very little statistical data is presented. A flaw that suggests a need for further research in this area.

The second and third qualifiers are interrelated. The more complicated the disability of the child, the more opportunities the caregiver had to interface with hospital personnel and professionals. The caregiver of the most vulnerable child or the child requiring significant corrective interventions had more experiences with managing unpredictable child-related events and therefore more exposure to various types of information. The success of managing unpredictable events, influences the accumulation of knowledge and heightens the progress of the emergence process.

Another interesting observation surrounds the "central person" phase and the acquisition and utilization of intimate knowledge and its relationship to the severity of the child's disability. The caregiver of a child with severe cognitive deficits had difficulty defining the boundary between the child's response and communication systems and her own. Whereas the caregiver of child with mild to moderate delays could more accurately define those boundaries. This observation is explained relative to normal mother-child circumstances. In an ideal normal mother-infant relationship, the mother forms a "behavioral set" (Holaday, p. 47, 1982) in response to the infant's signals. She eventually learns to satisfy and meet the need requirements of the infant and to translate those signals to others. Gradually the normal child, increasingly represents himself; gives his own signs to others, which if read correctly, becomes symbols. Soon the mother cannot represent fully, the child. The normal child eventually becomes so complex, he alone must represent himself. The mother, then, gradually loses track as the child develops relationships with peers, teachers, etc. Her knowledge becomes increasingly segmented and confined to her own relations with her child. Independence for the child is an ability to convert his own signs into symbols appropriate to communication, to a social existence without the benefit of the mother.

Now, consider what happens in the mother-child circumstances when the child has cognitive limitations. The more cognitively disabled a child is, the more dependent the child is on the caregiver to read, translate, and communicate his signs to others. The caregiver works very hard to form the behavioral set as the cues of chronically ill infants lack consistency and fixed rules for evaluating them (Holaday, 1982). Overtime, this mother has established her own rules of evaluating and responding to her child's cues, primarily through trial and error (Holaday, 1982). With each successful maternal intervention, patterns are set and her skills are reinforced (Holaday, 1982). The mother of this child maintains a heightened state of vigilance in order to anticipate any signs of danger to this child's well-being. This continues as the child grows physically but in the situation of a severely impaired child, independence is never obtained as the mother refines her skills in interpreting the child's communicative and responsive system. The child with mild to moderate cognitive limitations achieve some emotional and responsive independence, such as in the case of some of the children in this study with spina bifida. Since these children possessed some communicative abilities, it was necessary only for their mothers to supplement limitations and to not assume the child's total interactive being.

Now, a final comment about the theory which emerged from this research study. During the initial stages of data collection and analysis, the data was approached using background knowledge from clinical experience and literature review. Based upon this knowledge, this researcher was curious as to if parents would convey perspectives demonstrative of conflicts between parents and hospital staff. Although such conflicts were well verbalized by some respondents, a more global meaning of caregiving emerged from the data. The data disclosed personal meanings and interpretations that schematically depicted the respondents' construction and understanding of the phenomenon of caregiving of handicapped children. Conflict and strategies of handling such conflicts were just components of the overall picture.

In the following section of this chapter, an evaluation of this study is presented. The specific strengths and limitations of the study are discussed.

Strengths and Limitations of the Study

Strengths

The strengths of naturalistic inquiries, such as this grounded theory study, are evaluated utilizing four criteria; credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985). Three of the four criteria, credibility, transferability and confirmability will be discussed in this section while the fourth criterion of dependability will be discussed in the limitations section.

Credibility is concerned with verification of the plausibility of the findings. The grounded theory methodology has mechanisms in which the plausibility of findings are verified. In this study four methods were utilized to ensure credible findings. Through theoretical sampling, this investigator "checked out" emergent concepts and their interrelationships with respondents. The investigator returned to the data frequently to gain additional insights and discussed the analysis as it progressed with respondents. Category links and central themes that emerged from early interviews were confirmed or denied by those respondents and checked out in later interviews. Consequently the verification was provided to ensure that the analysis was, in fact, representing a piece of the parent's perception of managing caregiving of their disabled child.

Prior to and after interviews, the investigator remained on the unit to observe the interactions and behaviors of parent caregivers. Persistent observational notes were made and compared with the interview transcripts. Respondents were queried about observational notes to ascertain their perspectives of the interactions and observed behaviors. Thus, the conceptualizations that emerged were verified and modified with both observational and interview data.

During the data collection-analysis period, scheduled conferences were held with a jury of peers. Portions of transcribed notes and open codes were presented in the initial meetings and discussion ensued which facilitated the coding and categorizing process. Additionally, a broad range of questions for exploration was suggested. The researcher's analytic proceedings were exposed to peers with substantial background in the grounded theory method. In addition to these meetings, periodic conferences were held from inception to completion of the study with two renown grounded theory methodologists. Also at periodic intervals throughout the study, portions of the raw data were shared with an expert in childhood chronic illnesses. Periodic dialoguing took place wherein thought-provoking questions were raised concerning the content area, the investigator's thinking, emerging concepts, patterns and themes. As a result of all sessions, the investigator was able to verify that the categories generated were indicated in the data and applied readily to the data. After the analysis was completed, several parent "experts", who were not a part of the study sample, read the findings chapter for content validity.

Triangulation was used as an additional credibility check. It was accomplished by comparing the emerging conceptualizations with lay articles by parents of handicapped children and literature on parents' experiences in the hospitalization of their chronically ill children.

Transferability refers to relevancy of the results (theory) to the social or practice world and the assurance that the theory is not context-bound. Glaser and Strauss (1967) ascribe the term "grab" to this definition. The sample included parents with children whose cognitive impairments ranged from mild to severe, and a variety of physically disabling conditions. Additionally, all parent respondents had at least two years of experience as a caregiver. Home and hospital interviews were performed. The different settings afforded the researcher a varied approach to parent's perspectives of caregiving. Therefore, the respondents, context and range of data were sufficient to provide significant variety to assess relevancy to related contexts.

Limitations

While this study provides a plausible explanation of how parents of handicapped children manage caregiving, it has limitations. The majority of the parents in this study were upper-middle class and caucasian. The inability to recruit more male and minority primary caregivers limits the generalizability of the findings to Anglo-white, female parent caregivers of handicapped children. In addition, the sample was recruited from a hospital which is a referral center and this in itself eliminated many clinic patients. Those parents who were not informed about referral centers and/or did not have funds to travel to the center were automatically excluded from the study.

This study is also limited in that the majority of parent caregivers were in the "central person" identity phase. These parents were more articulate and assertive than the inexperienced "protection agent" caregiver, and thus provide more verbal information. Although these differences assisted in delineation of the three phases, with most of the data coming from the more competent caregiver, a question of the dependability of their recall of their experiences during the first two phases is an issue. Dependability or "modifiability" (Glaser & Strauss, 1967) is the criterion of grounded theory which refers to the need to qualify a theory over time and adapt to changing social conditions. While there are limitations to obtaining data from the recall of respondents, the retrospective view of the experienced caregiver could serve as a check of dependability of the theory. The experienced caregivers' perspectives on their experiences in prior identity phases corresponded with the perspectives of parents currently experiencing those phases. The third identity phase, however, should be checked for its variance over time.

A final limitation has to deal with the sample and the possibility of the existence of an identity phase beyond the "central person".

Since the ages of the respondents' children ranged from 2 years to 13 years, parent caregiving for adult handicapped children was excluded. Thus, the identity emergent phases identified in this study could in fact extend beyond the third phase indicated in the study results, and research in this area is needed. Although there were limitations to this study, the results of this study have significant implications for nursing practice and are presented in the following section.

Implications for Nursing Practice

Nursing deals with people anticipating transitions, experiencing transitions or completing the act of transitions (Meleis, 1975). The substantive theory generated in this study propose phases of transition, with cognitive and behavioral changes. It suggests that parents of handicapped children incorporate new knowledge and alter their behaviors to manage the work of caregiving and rearing this child. The theory encompasses several transitions that fall within the domain of nursing. These transitions are: 1) from nonparental role to a parental role of rearing and providing care for a handicapped child, 2) from parental role of rearing a nonhandicapped child to that of rearing a handicapped child and finally the essence of the theory generated in this study, and 3) from inexperienced parent caregiver to a more competent parent caregiver. Each transition requires defining and reorganizing parental conceptions of their responsibilities to the handicapped child and the family. All of which affect the health status of the child, parents, and family.

The nurse is interested in articulating knowledge about transitions which affect health and in utilizing that knowledge to devise effective ways of meeting the client's health care needs (Meleis, 1983). The proposed substantive theory can be utilized by nurses in identifying parental needs during various phases of caregiving; from the most inexperienced to the competent caregiver. Since the findings suggest that acquisition of knowledge is a key factor in managing caregiving for a handicapped child, the hospitalization situation is a potentially fruitful time for parent education and support. Interventions should focus on fostering the individual parent's self-confidence by providing reassurances about parenting and instructions to introduce, reinforce, and/or enhance specialized care techniques.

The findings of this study also provides a positive message to parents of handicapped children, particularly those parents who are in the early identity emergence phase. The message conveyed by the findings is that while initially caregiving for a handicapped child appears to be an insurmountable task, the experience provides innumerable returns in the form of personal, emotional, educational and maturational assets. The findings will help parents assess themselves and to realize the benefits of their experiences.
Understanding where they have been and where they are, should decrease some of the inherent stress in managing the work as a parent caregiver.

An important implication of the results of this study that is significant not only to nursing practice but the general political arena as well, was verbalized by several respondents. Respondents expressed their concern regarding the diminishing financial support to families of handicapped children. One mother stated:

> It's really important to express to all professionals exactly what we parents of handicapped children are experiencing because I see a lot of the financial provisions for these kids being cut back. I've already seen it with Z. and if the importance of the parent as caregiver is seen then I think that the attitude of those who have the money to give is going to be different. It's not just that they are paying to keep a vegetable alive because Mommy would miss baby. It's not that at all. . . . Somebody needs some information about what really goes on with these kids.

This mother clearly describes the current situation in which funds and resources for handicapped children are being reevaluated and curtailed. She is also making a strong plea for involvement of all professionals. Professionals, specifically nurses, who work closely with these families are the most prepared to be proponents for improving resource distribution to these families. Nurses can contribute by providing information to parents and politicians. For the parents, nurses can seek out current resources and advise them of appropriate ways to gain access to them. Nurses can make politicians aware of the tremendous personal and material costs to the family, and to society when adequate support is not given to these families. Nurse can also lobby for the legislating of future service delivery to these children and their families.

The findings on caregiving identity emergence merits further research. The implications for further research are presented in the final segment of this chapter.

Implications for Research

The findings of this study are just the beginning step in a relatively new area of inquiry into the phenomenon of parent caregiving and therefore raise additional questions. Further inquiry is warranted on the identity phases of parent caregiving and whether or not the emergence theory holds true in other populations of parents with handicapped children or chronically ill children. What specifically causes parent caregivers to continue the caregiving process? This question points out the need for a study to identify the factors which differentiate parents who maintain their handicapped child at home for a short period of time from those who continue the childrearing through a lifetime. Another study is needed to determine the required supports and services that will facilitate parents to maintain the disabled child at home. Other questions are; why is it that some caregivers move more rapidly than others from one phase to the next? Or is it important for <u>every</u> parent to move through all the phases? Does every parent caregiver have to become their child's "central person"? Finally, are there phases beyond the "central person" phase such as in the situation of parent caregiving for an adult handicapped child? This question suggests research with an older population of subjects.

The identity emergence theory which was generated from the data in this study is a global description of the transitions relative to caregiving. However, two specific areas for further research were indicated. One indicator is expressed in the question, what is the nature of the partner's involvement in the care of a handicapped child who is maintained at home? A study is needed to determine the level of involvement of partners in the care of handicapped child. Such research could identify intra-family supports for the primary caregiver and determine ways to supplement their caregiving duties. Additionally, investigations concerning the impact of intermittent assistance from peripheral persons, that is, those persons who take on some of the duties of the caregiver periodically but never assume complete responsibility for all aspects of caregiving, e.g., nurses, friends, or doctors are needed. Such investigations would also provide a wealth of data from which interventions could be formulated.

The final question is relative to the repetitive hospitalization experiences of parent caregiver. In the theory described in this study, knowledge acquisitions significantly influenced identity emergence patterns of caregiving. Hospitalization exposes parents to a host of new and unpredictable situations with vast educational requirements. The isolation of cognitive, intellectual and environmental factors which facilitate knowledge acquisition in the hospital environment is a legitimate area for exploration.

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APPENDIX A

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
CONSENT TO BE A RESEARCH SUBJECT
GROUP ONE

Approval Number: 944013-01

PURPOSE AND BACKGROUND:

Dr. Sandra Ferketich, Assistant Professor of Family Health Care Nursing, and Mrs. Mary T. Perkins, doctoral candidate in the Department of Family Health Care Nursing are conducting a study to learn more about the caregiving experiences of parents of young hospitalized or recently hospitalized disabled children.

PROCEDURES:

If I agree to be in this study, my child will receive the care regularly provided by the hospital. I will be interviewed and observed after my first contact with Mrs. Perkins, which will take about 30 minutes. Mrs. Perkins will tape the interview and make written notations. The interview tape will be locked in a file cabinet until it is transcribed and then erased. During the interview session, Mrs. Perkins will observe the care provided my child by me and/or hospital personnel. She will also make notes about these observations.

The purpose of both the interview and the observation is to learn about my hospital experiences as a parent caregiver. Two to three weeks after the first interview, preferably after my child is discharged from the hospital, I will be contacted by telephone by Mrs. Perkins to discuss my hospital experience and the content of the initial interview. This conversation will take approximately 30 minutes. I may decide to complete the second interview at the time of her telephone call or I may decide to have her visit me in my home.

Mrs. Perkins may review my child's records for details of my child's hospitalization, past medical/surgical history, and family history.

RISKS/ DISCOMFORTS:

a) The observation and interviews could possibly create uneasiness as the questions asked may bring to mind some things I might not care to think about, however I am aware that I may decline to answer any questions at any time during the interview process or request that observations be terminated at any time.

b) Confidentiality of my responses to the interview questions, as well as information obtained from written records, will be protected as far as possible. While my individual responses will not be identifiable to anyone other than Mrs. Perkins and Dr. Ferketich, overall results of the study may be shared with other health care professionals and may be reported in scientific literature. My name or my child's name will not be associated with any reports.

CONSENT TO BE A RESEARCH SUBJECT (continued)
PARENT CAREGIVER/APPROVAL # 944013-01
GROUP ONE

BENEFITS:

I will receive no direct benefit from participation in the study. The research conducted by Dr. Ferketich and Mrs. Perkins may help nurses and other health care professionals to better understand and meet the needs of hospitalized disabled children.

PAYMENT:

I will not receive monetary compensation for participation in the study. However, I understand that results of the investigation will be made available to me upon completion of the study, if I so desire.

QUESTIONS:

I have talked with Mrs. Perkins and my questions have been answered. If I have any questions I may call:

Mrs. Mary Perkins
(415) 922-6368

CONSENT:

I have been given a copy of this form and the Experimental Subject's Bill of Rights to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY. I have the right to decline to participate or to withdraw at any point in this study without jeopardy to my child's medical/surgical care. If I wish to participate I should sign this form.

__________________ DATE

______________________________ SUBJECT'S SIGNATURE

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO
CONSENT TO BE A RESEARCH SUBJECT
GROUP TWO

Approval Number: 944013-01

PURPOSE AND BACKGROUND:

Dr. Sandra Ferketich, Assistant Professor of Family Health Care Nursing, and Mrs. Mary T. Perkins, doctoral candidate in the Department of Family Health Care Nursing are conducting a study to learn more about the caregiving experiences of parents of young hospitalized or recently hospitalized disabled children.

PROCEDURES:

If I agree to be in this study, Mrs. Perkins and I will set up an appointment for me to be interviewed 2-3 weeks after my child has been discharged from the hospital. The interview will take about 30 minutes. Mrs. Perkins will tape the interview and make written notations. The interview tape will be locked in a file cabinet until it is transcribed and then erased.

The purpose of the interview is to learn about my hospital experiences as a parent caregiver. I may decide to complete the interview by telephone or at my home.

Mrs. Perkins may review my child's records for details of my child's hospitalization, past medical/surgical history, and family history.

RISKS/ DISCOMFORTS:

a) The interview could possibly create uneasiness as the questions asked may bring to mind some things I might not care to think about, however I am aware that I may decline to answer any questions at any time during the interview process.

b) Confidentiality of my responses to the interview questions, as well as information obtained from written records, will be protected as far as possible. While my individual responses will not be identifiable to anyone other than Mrs. Perkins and Dr. Ferketich, overall results of the study may be shared with other health care professionals and may be reported in scientific literature. My name or my child's name will not be associated with any reports.

BENEFITS:

I will receive no direct benefit from participation in the study. The research conducted by Dr. Ferketich and Mrs. Perkins may help nurses and other health care professionals to better understand and meet the needs of hospitalized disabled children.

CONSENT TO BE A RESEARCH SUBJECT (continued)
PARENT CAREGIVER/APPROVAL # 944013-01
GROUP TWO

PAYMENT:

I will not receive monetary compensation for participation in the study. However, I understand that results of the investigation will be made available to me upon completion of the study, if I so desire.

QUESTIONS:

I have talked with Mrs. Perkins and my questions have been answered. If I have any questions I may call:

Mrs. Mary Perkins
(415) 922-6368

CONSENT:

I have been given a copy of this form and the Experimental Subject's Bill of Rights to keep.

PARTICIPATION IN RESEARCH IS VOLUNTARY. I have the right to decline to participate or to withdraw at any point in this study without jeopardy to my child's medical/surgical care. If I wish to participate I should sign this form.

DATE

SUBJECT'S SIGNATURE

APPENDIX B

INTERVIEW GUIDE/WORKSHEET

Interview # Date
Hospital Home

1986-87 DIMENSIONS TO EXPLORE IN CURRENT INTERVIEWS

BIOLOGICAL CONSTRUCTION OF CHILD'S DISABILITIES (RECORDS AND OBSERVATION)

*duration of disabilities

*severity

*type

*visibility of disability

*how and when diagnosis was made

PHILOSOPHICAL CONSTRUCTION OF PARENTAL WORK AND LIFE
Interview question: Tell me about your caregiving experiences as the parent/guardian of a child with multiple disabilities.

*cognitive analysis of work involved in the care of this child (categorized by the interviewer)

*At Home

*hospital

Interview question: What do you feel are your responsibilities for your child while he/she is hospitalized?

Interview question: How did you decide on these responsibilities, that is the role that you will take in his/her care?

Interview question: What part did previous hospitalizations influence your selection of duties?

Interview questions: What has this experience of the hospitalization of your child been like for you? Is it different from previous hospitalizations? If so how?(particularly relative to your role).

PARENT CAREGIVING VS NURSE CAREGIVING

Interview question: What do you expect the nurses to do for your child/you?

Interview question: How did you decide that these were their responsibilities?

Interview question: Did you and the nurses discuss expectations/ responsibilities?

Interview question: Do you feel that a discussion of this nature is necessary?

Interview question: What events/persons have contributed the most to your adjustment to the hospitalization of your child?

CALIBRATING OF EXPECTATIONS

Interview questions: Did you adjust your expectations of your duties? the nurse's duties?

*when?

*why?

Interview question: What is your opinion of yourself as a parent?

Interview question: Does your opinion of yourself as a parent change when your child is hospitalized?

Interview question: What events in the hospitalization experience of your child affect the way you feel about yourself as a parent?

Interview question: Do (DID) you expect to be able to continue the same parenting style used at home with your child in the hospital?

Interview question: Do (DID) you expect to use similar methods of care for your child here in the hospital as at home?

Interview question: Can (COULD) you anticipate your child's needs as you did at home,here in the hospital?

Interview question: What concerns (CONCERNED) you about your child's hospitalization?

Interview question: What is (WAS) your general impression of this hospital experience?

BACKGROUND DATA RE: PREVIOUS HOSPITALIZATION (Chart data)

# of times child has been hospitalized since birth

# of hospitals

Date of last hospitalization

CURRENT HOSPITALIZATION (Chart information)

Type of acute illness

Type of surgery

BACKGROUND DATA RE: FAMILY

Father's age	Mother's age
Educ.	Educ.
Occupation	Occup.

SES

Number of siblings

Any disabilities/chronic illnesses of siblings

Ages of siblings

(Perkins,1987)

SUBSTANTIVE THEMES INVOLVED IN OBSERVATIONS AND INTERVIEWS

I. Comparison of parental caregiving in the hospital and home.

II. Special techniques used to provide for the functional needs of the child.

III. Perceived expectations about the care of the child in the hospital.

IV. Purposes of the child's hospitalization.

V. Division of care for the hospitalized child between the parents and the nurse.

TENTATIVE INTERVIEW SCHEDULE

TELL ME ABOUT YOUR CAREGIVING EXPERIENCES AS THE PARENT/GUARDIAN OF A CHILD WITH MULTIPLE DISABILITIES.

Do you have a special way to feed your child? communicate to your child?

What are the techniques you use at home to feed your child? bathe your child? position him/her? Are there special techniques you use for maintaining other body functions, i.e, bowel and bladder functioning? mobility?

THE HOSPITAL EXPERIENCE

What do (did) you expect to do for your child during his/her hospital stay?

When did you make these decisions about your participation in your child's care?

Do (did) you feel comfortable caring for your child here (when he/she was hospitalized) in the hospital as you did for him/her at home?

Can (could) you anticipate your child's behavior while (when) he/she is hospitalized? Why or why not?

Do (did) you know exactly what is (was) expected of you in terms of providing care for your child while he/she is (was) in the hospital?

Is (was) it clear to you which staff member is (was) responsible for which parts of your child's care?

What do (did) you expect the nurses to do for your child during your child's hospital stay?

Has it been (was it) explained to you by the nurses, exactly what you should do to help your child while (when) he/she is (was) hospitalized?

What is/are/was the purpose(s) of your child's hospitalization?

APPENDIX C

EXAMPLES OF FOLLOW-UP INTERVIEW QUESTIONS

Introductory statement:

I am about to conclude a study with mothers who have had similar experiences with the hospitalization of a child with special needs and I need to check my interpretations of some of the information that I received from them. Would you consent to answer some questions about your caregiving experiences during the hospitalization of your child?

What does the term "parent caregiver" mean to you?

I know that you have specific duties as a parent caregiver, can you describe what they are?

Whenever your child is hospitalized do you stay with him 24 hours?

Describe to me what you do (did) as a parent caregiver in the hospital. Describe a 24 hour day in the hospital with your child.

Some parents have indicated various reasons they stay in the hospital, does any of the following reasons apply to you?

Being present to communicate my child's needs to the nurses/doctors

To relate the specialness of my child to the staff

Being here to know what happens to my child....
- to get information first hand
- to see how well my child eats
- to see how staff performs treatments and other procedures.
- to calm my child because of the frightening environment

Can you think of other reasons you stay with your child during hospitalization?

Can you put them in terms of importance? Which one(s) do you feel are the most important? Least important? Not at all important?

APPENDIX D

EXAMPLES OF "PATTERN CHECKING" QUESTIONS

CATEGORY: MEASURED INTERVENTION

Other parents have said that even though they know that certain things (procedures, treatments, drugs, etc) are effective for their child, they will allow the doctor or nurse to use another approach until they have seen that it is ineffective, do you find this true in your particular situation?

If so do you consider this to be a "wait and see" approach?

Or a way of keeping your options/avenues of care open?

When would you not use this approach?

CATEGORY: CENTRAL PERSON

Some parents/guardians describe themselves as their child's "central person". Can you define this term?

Describe what being your child's "central person means.

What does it take to be your child's "central person"?

CATEGORY: TEAMWORK

Parents have indicated to me that they feel that they and the health care professionals in the hospital must function as a team, do you feel that you and the staff should work as a team in providing your child's care?

Do you and the staff work as a team in providing your child's care?

Who is responsible for establishing and maintaining a team relationship?

Can you divide the responsibilities/duties of the team members?

What are your responsibilities/duties?
...... the health professionals' responsibilities?

CATEGORY: KNOWLEDGED CAREGIVERS

Some parents have called themselves knowledged caregivers, do you consider yourself to be knowledged?

Describe for me "a knowledged parent caregiver".

CATEGORY: KNOWLEDGE ACQUISITION/MANAGEMENT

How do you manage the medical information/history of your child?

How do you manage the information you get from each of your child's hospitalizations?

What is your purpose for using this specific management routine?

MTP/Oct. 20, 1987