A Mother's Lived Experience During an Acute Episodic Hospitalization of a Child with a Chronic Condition

A Case Study

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by
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Dedication

I wish to dedicate this dissertation to my Beloved Husband Phil whose premature death denied him the opportunity of experiencing the realization of my final work.

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The completion of this dissertation would not have occurred without the guidance and invaluable input of my committee, and the unending support from my wonderful family, friends and colleagues.

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Finally, I would like to extend my thanks to Pam, the mother who so graciously allowed me to enter her home and heart. She willingly revealed her innermost thoughts and feelings that made this dissertation possible. It is hoped that her story will enlighten nurses and other health care professionals about what is requisite to enhance the interactions between mothers of children with chronic diseases/disabilities and health care providers.

ABSTRACT

Chronic conditions affect approximately 31% of children less than 18 years of age of which 2% have severe conditions. Advances in medical and surgical technologies have created and maintained this growing population of children. Many of these medically fragile children have an unknown life expectancy and face a future that is uncertain and unpredictable. Caring for such a child is a difficult and challenging job. Children with chronic conditions who become hospitalized with an acute episodic illness may stress the mother even more.

The purpose of this case study was to investigate a mother's perceptions of her experience during the acute episodic hospitalization of a 3-6 year old child who also had a chronic condition. The subject interviewed was a mother of a 6 year old boy who had multiple chronic problems and disabilities and who had an episodic hospitalization.

Using naturalistic inquiry, data were obtained through three interviews, an observation, and field notes. Analysis of data was done following the coding method suggested by Bogdan and Biklen. The data provide an emic perspective of the mother's relationship with nurses, other health care professionals, and family members, and the impact each one had as she experienced her child's hospitalization. A total of 15 themes that clustered within six primary categories emerged.

Overall, the data gleaned confirmed the lack of communication between the mother and health care professionals, the need to implement family centered care, the problems encountered during the transfer of the child from home to hospital and hospital to home, and the impact a child with a chronic condition\disabilities has on family members, especially the mother.

The results of the study are based on one mother's lived experience therefore the findings are not generalizable. However, it is hoped that the knowledge gleaned through this mother's perceptions will impact the practice of child health nurses, and lead to improved parent/professional partnerships and patient/family services.

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Parents have to be recognized as
special educators, the true experts
on their children, and professional
people, teachers, pediatricians,
psychologists, and others, have to
learn how to be consultants to parents.
(Hobbs, 1978, p. 497).

CHAPTER 1

THE PROBLEM

> A child's chronic illness engraves a family's life with worry. Variable in its daily effects yet ever a threat to the child's survival, a chronic illness is inescapable. For both child and family, it is a perpetual, demanding companion; a lifelong associate; a constant shadow. (Hobbs, Perrin & Ireys, 1985, p.62)

Caring for a well child is a difficult and challenging enough job. What is the experience when a mother* with a child who has a chronic condition is confronted with hospitalization of their child for an acute episodic illness?

*For purposes of this study mother will be substituted for parent and family throughout the text unless the use of the word mother changes the contextual meaning.

Need for the Study

Children with chronic conditions who become hospitalized with an acute episodic illness may stress the mothers more than usual. To date no studies were found that investigated mothers' perceptions of their experience during a 3-6 year old child's episodic hospitalization who also has a chronic condition. Much of the literature focuses on the cure of episodic conditions (Robinson, 1987; Thorne & Robinson, 1988) neglecting the child's chronic condition. Health care professionals tend to assume responsibility for the episodic problem neglecting to take into consideration the impact the child's chronic condition has on the total family constellation (Hobbs, 1975).

Most of the studies concerning children's hospitalizations and mothers' perceptions have been carried out in the hospital setting during the child's hospitalization rather than in an environment that might be less intimidating. Interviewing mothers after they have returned home with the child provides a less threatening atmosphere allowing for a more relaxed reflection on the hospital experience. Interpretation of the mother's experience that is not directly connected to the actual time of their child's hospitalization helped to elicit findings that can enhance the practice of child health nurses.

Establishing an open trusting relationship between the nurse and mother is of great importance to the provision of excellent nursing care to the hospitalized child. Asking mothers about their perceptions is of primary importance to the attainment of the insights necessary to establish a resilient working relationship. Recognition of mothers' ability to properly care for their child and the importance of being with their child is critical. The integration of both mothers' and health professionals' expertise can support and/or contribute to maintaining the continuity and emotional stability of the mother-child relationship.

Background of the Study

A chronic condition is a long term health condition that lasts three months or more within a year or requires at least 1 month of hospitalization, and leads to actual or potential interference with a system's level of functioning (Hymovich & Hagopian, 1992; Jackson & Vessey, 1992). Chronic conditions affect approximately 31% of children less than 18 years of age, almost 20 million nationwide (Newacheck & Taylor, 1992; Newacheck, Stoddard & McManus, 1993). According to Newacheck and Taylor (1992), "31% of US children with chronic conditions can be divided into three groups: 20% with mild conditions that result in little or no bother or activity limitations; 9% with conditions of moderate severity that result in some bother or limitation of activity, but not both; and 2% with severe conditions that cause frequent bother and limitation of activity" (p.370). Advances in medical and surgical technologies have created and maintained a growing population of children with chronic conditions. Many of these medically fragile children have an unknown life expectancy and face a future that is uncertain and unpredictable (Cohen, 1995; Hobbs, 1985).

Presently the health care system functions within an acute care framework. The chronic condition is basically ignored as the health care provider zeros in on "curing" the acute health care problem in a timely, cost efficient manner (Mundinger, 1994).

With the shift to managed care, pediatric patients are no longer hospitalized for long periods unless the child with a chronic condition has an acute exacerbation, or the severity of the illness warrants high technological surveillance, ie. pneumonia, seizures, septicemia, diarrhea with dehydration, or acute traumatic incidents (Rennick,1995). Pediatric patients who are presently hospitalized have severe and complicated conditions. A child with a chronic condition who suddenly develops an acute episodic problem irrespective of whether it is related to the chronic condition or an acute problem with the potential for a "curable" outcome is hospitalized for much shorter periods of time. Mothers have less time to deal with more increasingly difficult decisions and uncertainty of outcomes. Mothers do not have the luxury of time that could help them to become knowledgeable about their child's current acute health care needs. Mothers must quickly become comfortable with the changed modalities required to now care for their child. The mother should leave the hospital environment with the additional knowledge needed to care for the child at home (Perrin, Shane & Bloom, 1993), and be able to reflect on the hospital experience as a positive one.

Nurses need to view the mother as the child's advocate since the mother is the one that provides care for the child on a daily basis. The mothers' responsibilities for the child's health care at home have steadily increased as the length of hospitalizations has decreased. The needs of these mothers have been overlooked. A mother's understanding of the child's needs helps maintain the mother's sense of control and helps the mother provide a supportive and loving environment for the hospitalized child (Perrin et al., 1993).

Chronic conditions can challenge the stability of the family unit. Nurses who can refocus their energies toward a more harmonious mother/nurse relationship can play a critical role in helping mothers adapt to the impact of their child's chronic condition. According to Corbin and Strauss (1992) "of all the health professionals, only nurses have the skills, knowledge, and vision to organize and provide for comprehensive and technologically complex care that ill clients require" (p. 21).

The manner in which health care professionals help mothers cope with the complexities of their child's condition can have a positive or negative outcome. Nurses can play a primary role in helping mothers adjust and function at an optimal level that is both beneficial to the child and family members. "Problems faced by an ill child and the family very much depend on and must be dealt with in the context of a complex interaction between the illness, the family's responses, and the child's developmental status" (Stein & Jessop, 1984, p. 191).

The impact of the child's future in relation to other children the same age becomes excruciatingly visible as mothers become acutely aware of their child's present functioning and special care needs (Copeland & Clements, 1993; Stein & Jessop, 1984). All mothers feel the physical, social, emotional and financial strains. The degree of impact, however, tends to differ from one mother to another. A family's composition and its financial, social, and personal resources significantly influence the impact of the child's chronic condition on the family (Cooke, 1993; Stein, 1989; Stein & Jessop, 1984).

Significance of the Study

A child's chronic condition impacts on the family in many ways. "When chronic illness is viewed non categorically, it is possible to begin to learn about characteristics, attitudes and behaviors of the affected children in relation to the total population in given communities" (Stein & Jessop, 1982, p. 361). Labeling children with a diagnostic classification, ie. "Diabetic" can have devastating consequences both socially and emotionally. No two children or families are alike. Every child is an individual and should be treated as such. According to Stein and Jessop (1984) "all chronic illnesses in childhood are characterized by a potential to disrupt family life and the child's growth and development and as such share many common features" (p.192).

Commonalities exist amongst all children with a chronic condition regardless of the specific chronic illness (Perrin & MacLean, 1988; Stein & Jessop, 1984). Some of the commonalities that exist within the various chronic conditions are "implications of illness for normal growth and development; effects on parents, siblings, the children and family life; concerns about long-range consequences; and need to understand and make choices about treatment modalities" (Stein & Jessop, 1984, p.193). Therefore, it would be efficacious to focus on the dimensions that cross all disease categories rather than on a specific condition. The efficacy of this approach would provide nurses and other health care professionals with a broad base understanding of how any chronic condition impacts the child, mother, and family.

Children with chronic conditions often have episodic conditions that require hospitalization causing a potential disruption in family life and in the child's growth and development (Stein & Jessop, 1984). The mothers' perception of their child's condition and the mothers' coping mechanisms can be a major determinant of their adjustment (Copeland & Clements, 1993; Stein & Jessop, 1984). How the family interprets the condition and handles the problems is dependent on the health care provider's ability to attenuate existing stressors (Stein & Jessop, 1984).

As a child health nurse specialist, practitioner and faculty person for pediatric students, I have come in contact with many mothers of children who have chronic problems. As a visiting faculty person I can be more objective with my assessments of experiences on the pediatric units. I have interacted with numerous mothers who have a child with a chronic condition who have expressed dissatisfaction with the hospital experience, their encounters with child care nurses and other health care professionals.

Mothers' and nurses' perceptions of situations are often different. Invisible barriers exist, and health care personnel often send mixed messages. Although nurses expound on how they think mothers should be active participants, there is an underlying skepticism, maybe fear, that the mother will interfere with the therapeutic modalities that have been prescribed (Algren, 1985; Berman, 1991; Brown & Ritchie, 1990; Rennick, 1995). This may be related to the fact that each individual experiences the world through a different set of lenses from which each develops their own perspective on life events. Nurses and mothers assess a happening differently because they each have their own distinct worldview, therefore perceptions of mother professional relationships are often not analogous. Disputes often occur because the mother and professionals have different agendas (Algren, 1985; Berman, 1991; Brown and Ritchie, 1990; Rennick, 1995).

Nurses often think they know what is best for the mother and child and tend to take control of the situation. Nurses' interpretation of the mothers' needs are sometimes very different from the mothers'. This may be because nurses really do not understand the needs of these mothers. Some nurses have never been inculturated with the skills that enable them to pick up on mothers' cues (Rennick, 1995). The initial encounter with a mother is critical (Hobbs, 1976) and often leaves an indelible mark. Consequently, it is important to develop rapport with the mother so that a mother/professional partnership develops.

Family members need to become participants of the health care team providing care for the ill child. Maintaining perceived control of the parenting role is essential to a mother's self esteem and for establishing positive mother/nurse interactions. "The parent has the ultimate responsibility for the child's total care" (Hobbs, 1976, p. 159), therefore the mother should become the expert in the child's health care management. Team members must recognize how valuable each member is in the decision making process and that each member does not have total control of the situation. This can only occur if the health care professionals are willing to become consultants to the mother and share their expertise with the mother (Hobbs, 1975; 1976; Leff, Chan & Walizer, 1989).

It is essential that pediatric health care nurses recognize the importance of a solid family/professional relationship. According to Drotar, Crawford and Bush (1984) "the presence of a chronic illness inevitably poses extraordinary constraints because staff and family are locked into a treatment course in which neither can exit but where neither is completely comfortable" (p. 117). Encounters between mothers and health care professionals require honest and open communication. The quality of intrafamilial coping and a healthy enhancement of family life are critical components in the course of a child's health condition (Drotar, Crawford & Bush, 1984; Leff, Chan & Walizer, 1989). Honest and open communication between mothers and health care professionals can help establish solutions that maintain a quality of life acceptable to all involved (Drotar, Crawford & Bush, 1984).

Scholarly inquiry into a mother's lived experience during an acute episodic hospitalization of her child with a chronic condition can elucidate and explicate how she perceives her relationship with health care professionals. The knowledge gained through a mother's lived experience can make a difference in the way nurses relate to mothers while providing care for children with a chronic condition who are hospitalized for an acute episodic problem.

CHAPTER 2

REVIEW OF THE LITERATURE

Introduction

Hospitalization of a child with a chronic condition is a stressful event. The mother initially experiences a period of disequilibrium, increased anxiety levels and role shifting (Hobbs, Perrin, & Irreys, 1985; Mahon, 1992; Thomas, 1987; Wright & Leahy, 1987),and a level of uncertainty (Cohen, 1995).

> In order for the family to function optimally for the child, the well-being of the unit itself has to be taken into consideration. In chronic illness, the social context of the family and the psychological status and the history of its members have central importance in the way the family interprets the illness and handles the situation. (Jessop & Stein, 1989, p.72)

Every child and mother is unique, and so is the adaptation process (Erikson, 1963; Hobbs, Perrins & Irreys, 1985; Jackson & Vessey, 1992; Jessop & Stein, 1989; Stein, 1989). Mothers of a child with a chronic condition have similar if not the same concerns about their child's growth and development as mothers of a child without a chronic condition (Mahon, 1992). Most families who have a child with a chronic condition learn through adaptation to accept the uncertainty of their child's future (Thomas, 1990).

The process of adaptation "means the family is able to change patterns of daily life in order to 'fit in' better within the social and physical world" (Thomas, 1990, p.247). In order to survive the families adapt "by creating a new balance within the family and with the environment" (p.247). They develop the ability to change their life style in response to the family's changing needs (Thomas, 1987; Thomas, 1990).

In order to meet the multitude of challenges, these family members need individual as well as family and community resources. The development of coping strategies and adaptive patterns assist mothers to function in the role they have defined in relation to their child with a chronic condition (Corbin & Strauss, 1992; Danielson, Hamel-Bissell & Winstead-Fry, 1993; Thomas, 1987; Wright & Leahy, 1987).

The mother's response to the child's chronic condition and hospitalization will affect the child's response. A mother's fear and anxiety is easily communicated to the child who in turn demonstrates increased anxiety and fears. The mother's presence can be extremely beneficial to a hospitalized child, especially if the mother is not overly anxious and can provide supportive care for the child (Wolfer & Visintainer, 1975, 1979). "Parental encouragement, guidance and acceptance can have a profound effect in shaping the way a child adjusts and copes..." (Thomas, 1987, p.136). Children want and need their mothers to cuddle and hold them and never leave their sides (Servonsky & Opas, 1987). Children 3-6 years of age lack an understanding of why a mother is not always present and lack the proper coping mechanisms to withstand separation from the mother (Servonsky & Opas, 1987).

The importance of mothers' presence during a child's hospitalization became evident in the 1960's (Bowlby, 1973). Bowlby in his report for the World Health Organization stated "there is no room for doubt that prolonged deprivation of young children of maternal care may have grave and far reaching effects on his character and so on the whole of his future life" (cited in Johnson, 1990, p. 234). Bowlby observed severe physical and mental impairment in infants who experienced prolonged separation from their mothers (Bowlby, 1966). Subsequently hospitals began to slowly change their philosophy about mothers' visiting hours and participation of mothers in the care of the child (Berman, 1991; Peterson & Mori, 1988; Wolfer & Visintainer, 1975, 1979).

The Meaning of Hospitalization to a Pre-Schooler

Hospitalization holds different meanings for children at different developmental levels. Separation from their mothers is especially stressful for children of pre-school age (Erikson, 1963). Chronic conditions can result in various developmental disruptions throughout a child's developmental trajectory (Stein, 1989). All children traverse the various stages of growth and development, however children who have a chronic condition follow a more complex trajectory, causing ordinary life events to have a greater than normal impact especially when a child reaches critical developmental stages eg. walking, talking and birthdays (Stein & Jessop, 1984).

According to Piaget, children 2-7 years of age are in the preoperational stage of cognitive development. Children are unable to mentally conceive of another person's point of view and are unable to link the parts to make a whole. Their thinking is egocentrical and magical (Piaget, 1962; Pulaski, 1980). The child often regresses, withdraws and/or acts out in response to the hospitalization and the mother's absence (Bowlby, 1963; Servonsky & Opas, 1987; Schuster, 1986).

Self concept and feeling of independence become threatened in children aged 3-6 years who are hospitalized. Children of this age are unable to cognitively process events in a logical manner. They possess active imaginations, and it is difficult for them to differentiate between fantasy and reality leading to fears of the unknown, and fear of punishment for becoming ill. Children often feel supremely powerful and responsible for occurrence of events. They are vulnerable to feelings of shame, self doubt and guilt. The resultant effects depend on how the issues are handled by the mother and other individuals who are intimately involved with the child's care (Freiberg, 1987; Jessop & Stein, 1989; Piaget, 1962; Servonsky & Opas, 1987; Stein, 1989).

The home is generally the center of care for children with a chronic condition and the mother is generally the child's primary care taker (Ambert, 1992; Clements, Copeland & Loftus, 1990; Corbin & Strauss, 1992). When a child is hospitalized the mother and child need to acclimate to a strange environment where the mother has to entrust the care of her child to strangers, professionals who are unfamiliar with the family's values and ethnocultural background (Drotar, Crawford & Bush, 1984). To maintain as normal environment as possible when the child is admitted to the hospital it is important that the health care team help the mother and child adhere to previously established routines with as little disruption as possible (Corbin & Strauss, 1992; Robinson, 1987).

Recognition by nurses of the importance of working closely with mothers of hospitalized children is paramount. Nurses must focus on helping mothers adjust to the temporal and role disruption the chronic condition may be causing, so that mothers can learn how to manage the child's illness trajectory (Wright & Leahy, 1987).

Illness Trajectory

According to Corbin & Strauss (in Woog,1992) who developed the illness trajectory framework, chronic conditions follow a course that varies and changes over time. Management of the chronic condition impacts the direction and shape of the illness trajectory. "Not all illnesses have the same impact on families...and the family's reaction is not always a direct function of the medical severity of the illness" (Danielson, Hamel-Bissell & Winstead-Fry, 1993, p.99).

> Trajectory as the illness/chronic condition course requires the combined efforts of the affected individual, family and health care practitioners in order to shape it. That is, to determine its eventual outcome, manage any symptoms, and handle associated disability. Trajectories are often uncertain ... for although each illness has a potential course, its details cannot be fully determined ahead of time. Much depends upon the individual, the action taken to shape that course, and the turn of events that occur (Corbin & Strauss, 1992, p.16).

In Robinson's (1987) qualitative study parents said that hospitalization for an acute episode impacted significantly on the trajectory of the child's chronic condition. Parents found that health care professionals tended to ignore the child's chronic condition and disregarded the parents' experience with the child's chronic condition. The professionals focused on curing the current presenting acute condition rather than looking at how the hospitalization could also affect the course of the child's chronic condition. Health care providers neglected to take into account the family's normal routines and tended to promote dependency among the child and family care givers. Parental decisions concerning the child's physical and medical care were ignored. "Family involvement was hindered by the 'life' of a busy acute care hospital, with multiple care givers oriented to meeting personal learning needs, fixing a problem, and discharging the patient" (Robinson, 1987, p.190).

Since caring for a child with a chronic condition often encompasses a multiplicity of problems, the illness trajectory framework can be utilized to help mothers develop a course of action that enables the caregiver to adjust the management plan as the child's condition changes. This flexibility can enhance the mothering role.

The Mothering Role

The mother as the primary health care provider plays a significant role in nurturing the child's growth and development. Meeting needs of mothers should be a primary concern to nurses. The mother is the "central person" in the child's life and acts as the child's representative (Perkins, 1993). The mother is the constant in a child's life and is the primary caregiver and advocate during the toddler and preschool years (Hostler, 1991; Jessop & Stein, 1989; Rose & Thomas, 1992; Stein, 1989; Thomas, 1987). These children's greatest fears are loss of love and separation from their primary caregivers (Erikson, 1963). In order for the children to cope they need the continued support and love from their primary care giver (Ashburn, 1986; Ashburn & Schuster, 1986).

Child health care nurses need to pay specific attention to mothers' perceptions of how nurses support the mothering role. According to Hymovich and Hagopin, (1992) mothers of children with a chronic condition are often unhappy with their encounters with the present health care system. Mothers of hospitalized children with a chronic condition need to exercise their right of being the active health care provider so that improved mother and child functioning can take place (Berman, 1991; Knafl, Cavallari & Dixon, 1988; Hayes & Knox, 1983; Knox & Hayes, 1983; Perkins, 1993; Robinson, 1987). Children tend to have a more positive hospital experience when mothers are able to offer support, comfort and attention (Wolfer &

Visintainer, 1975, 1979). However mothers can not meet their child's needs until they have met their own (Lynn, 1986).

Wolfer and Visintainer (1975) carried out an experimental study on children (N=80) aged 3-14 years and their mothers (N=80). The children were scheduled for minor surgery and had no previous hospitalizations within the past year. A random selection of children and their mothers (N=80) were assigned to either an experimental or control group. In the experimental group (n=45) the children received special stress point preparation and supportive care provided by the same primary nurse at six different times during the hospitalization. Mother and child preparation occurred at the same time. All mothers received individualized attention and accurate and appropriate reassurance was provided. Explanations of how the mother could help in their child's care was explained. The importance of the mother's presence during the child's hospitalization was emphasized.

The control group (n=35) received regular nursing care. The nurses provided no formal preparatory education for the child or mother and made no systematic attempt to determine the mother's and child's need for information or emotional support.

> The study supported the hypotheses that children who receive systematic psychologic preparation and continued supportive care, in contrast to those who do not, would show less upset behavior and more cooperation in the hospital and fewer post hospital adjustment problems and that their parents would be less anxious and more satisfied with information and care received (p.244).

This study did not include children with a chronic condition. Further insight is needed about mothers of children with a chronic condition who are admitted to the hospital for an acute problem.

Kristjansdottir (1991) conducted a qualitative study to identify the needs, concerns and ideas of five parents (three mothers and two fathers) whose children aged 2-6 years were hospitalized. A descriptive exploratory design was implemented. After a literature review informal interviews with the five parents and six pediatric health care professionals were conducted. Knowledge about their child's condition as well as being educated in how to care for their child were among the six groups of needs identified. According to this study the needs identified by the parents and the needs identified by the health care professionals were congruent. However, this study is inadequate because only five parents were informally interviewed while their children were in the hospital and a set of specific questions were asked. The parents were not asked to talk extemporaneously about their total experience. In addition the researcher has not identified whether or not the hospitalized child had a chronic or an acute condition. Furthermore, the researcher stated that the study's findings need further clarification.

Kirschbaum (1990) interviewed 41 parents (mothers and fathers) of children (newborn through 15 years) hospitalized in a pediatric intensive care unit. The purpose was to assess parental needs during a child's critical illness that would prepare them for the child's early discharge, as well as explore the degree of importance of each need. A list of 53 need statements were randomly ordered and read to the parent who was asked to rate each item on a four point scale from not important to very important. Parents were also asked if they experienced other needs that were not part of the original 53 items. Five of the most important needs expressed related to obtaining information about the child's diagnosis, prognosis and treatment. Recognition of the parent playing an important role in their child's recovery was ranked as the most important need.

This study did not look at parents of children with a chronic condition. Furthermore, giving a prepared list of items can influence a parent's response. Asking a question that would allow the parents to describe their total experience without any outside biases could provide additional information.

Hymovich and Baker (1991) utilized the Chronicity Impact and Coping Instrument: Parent Questionnaire to measure the perceived needs of parents (N=116) who had children with Cystic Fibrosis. Seventy-three percent of the parents requested help in understanding their child's condition and daily management and fifty-three percent were concerned with expected child development. The findings clearly indicate the importance of providing the parents with appropriate information regarding their child's chronic condition, management and anticipatory guidance.

This study is important because it focused on parents of children with a chronic condition. However, it is too limited because it focused only on children with Cystic Fibrosis. The questionnaires were not sent to any parent who had a child with a different chronic condition.

Knowledge as an Enabler

An enabling experience occurs when opportunities for displaying competence are created (Dunst & Trivette, 1987). Knowledge is a critical factor in enabling a mother to become an active participant in the decision making process and in preventing a feeling of powerlessness. Mothers need information to develop realistic coping strategies (Danielson, Hamel-Bissell & Winstead-Fry, 1993). A sound knowledge base helps the mother maintain a sense of control. Nurses have the responsibility of providing mothers with the necessary knowledge and skills that enable them to function as the primary decision makers and care givers for their child (Park,1991; Horner, Rawlins & Giles, 1987; Knafl, Breitmeyer, Gallo & Zoeller, 1992; Leff, Chan & Walizer, 1989; Perkins, 1993; Price, 1993; Robinson, 1987; Shelton, 1987). According to Robinson (1987) "parental involvement in decision making and care taking is often restricted by lack of information" (p.189).

The Importance of Dialogue

Sharing of information is an essential part of the mother/nurse dyad, however, the information should be transmitted in a supportive non-threatening manner, and in clear, understandable terms that are not overwhelming to the mother (Burke, Kauffman, Costello & Dillon, 1991; Dunst, Trivette, Davis & Cornwell, 1988; Knafl, Breitmeyer, Gallo, & Zoeller, 1992; Perkins, 1993; Robinson, 1987). Discussions of options available in relation to caring for a child with a chronic condition establishes opportunities for joint decision making. A mother needs an enabling environment that is conducive to learning, and receptive to parent needs. Open communication between a mother and nursing staff is a requisite. Nurses and mothers can develop a rich relationship through effective communication and the appropriate use of language.

According to Bohm (1992) dialogue is a stream of meaning that flows through us and between us, and produces a new understanding. Each individual not only becomes sensitive to what is occurring to them but also to what is occurring to others. This new shared meaning helps one better understand the other. Thus by dialoguing we learn to listen to each other's ideas without being judgmental, defensive or acting as an expert. There is participation and sharing of ideas which lends itself to a relationship.

Individuals involved in a relationship have to feel a real commitment and connectedness to each other in order to foster growth and change (Perkins, 1993; Robinson, 1987). Sensitivity, receptiveness, and flexibility can lead to change without losing a sense of connectedness. According to Surrey (1991), to be able to respond to the thoughts, feelings and perceptions of others helps promote an ongoing relationship based on mutual trust and respect. "Learning how to open, create, repair, and let go in relationships with sustained awareness of how interconnected we are" (Surrey, 1991, p.174), contributes to the growth supporting aspects of the relationship during periods of both weakness and strength. A collaborative relationship can provide insight into one another's expertise and affect how each one relates to the other (Patterson, Jernell, Leonard & Titus, 1994; Perkins, 1993). According to Palmer (1993), "the success of parental involvement is dependent on both parents' and staff's attitudes, enthusiasm and willingness to work together" (p. 185).

Parental Views of Relationships with Health Care Providers

Knafl, Breitmeyer, Gallo, and Zoeller (1992) used a qualitative approach to gather data about health care provider behaviors that promote and sustain a positive working relationship with family members. The researchers interviewed a combined total of 102 mothers and fathers (51 couples) of children aged 7-14 years who had chronic illnesses, but no major mental or physical impairments.

Members from the same family were interviewed separately. The child with the chronic illness and school age siblings were also encouraged to participate in the research. Investigators developed separate sets of questions for the parent, the child with the chronic illness and the well school-age sibling that addressed areas pertinent to how the family member defined and managed the child's chronic condition.

Results demonstrated that overall parents expressed satisfaction with their health care providers although not every encounter described was a positive one. The parents described provider expertise and information communicated with compassion and respect, as behaviors being contributory to a positive relationship between health care providers and parents.

In exploring the components of a positive parent professional working relationship, Knafl, et al. (1992) asked parents (N=94) what nurses can do to help establish a positive working relationship. The parents stated that exchange of information, interactional style, establishing a relationship with the ill child and the fostering of parental competence were essential. The information communicated should be clear, accurate and complete with emphasis on the positive aspects of the child's future. The health care providers should exhibit a sense of empathy and be available to answer questions.

According to Robinson (1987), parents of hospitalized chronically ill children stated that health care professionals failed to "dialogue about professional and parental therapeutic goals" (p.187).

Parent/Professional Relationship

In 1966, the Association for the Care of Children's Health (ACCH) defined family centered care as "care that acknowledges and respects the pivotal role that families play in the care of their children. It is a philosophy that strives to support families in their care giving roles " (Johnson, 1990, pp.236-237).

According to Thorne and Robinson (1988), two qualitative studies were conducted simultaneously by Sally Thorne and Carole Robinson in 1983. Thorne interviewed 17 members from 8 families to explore the experiences of families with adult members who had cancer over a long term period. Robinson interviewed nine participants from six families who had a child with a chronic illness exploring the meaning of hospitalization for parents of a chronically ill child. Both researchers carried out indepth interviews with all subjects and obtained clarification of their findings and validated the accuracy of their findings.

A significant theme that emerged from both studies was family members' concerns with the nature of their relationships with health care providers (Thorne & Robinson 1988). Thorne and Robinson (1989) then decided to do a more indepth analysis to gain a better understanding of relationships from the perspective of family members involved with chronic illness. The results of the analysis showed that relationships were seen as evolving over time through three predictable stages. In the first stage, naive trust, family members assumed that they and the health care providers shared common perspectives concerning health care management of the patient, and that there would be a collaborative approach in decisions made. Family members soon realized there were discrepancies in expected health care ideas held by family members and health care providers. The professionals were interested in the patient's present problem rather than the total experience of the chronic illness. As family members realized their needs were not being addressed they progressed to the next stage, disenchantment. Family members became less trusting of the health care providers and realized that they had to leave the care of the ill patient in the hands of the health professional. This realization increased their frustrations. They became fearful that the ill member needed to be protected from the professional which often led family members to either become passive or aggressive towards the health care provider. The third stage, guarded alliance, resulted in reconstructing a trusting relationship by actively seeking to be kept informed, stating their expectations and actively participating in decisions to be made. The three stages are representative of the degrees of trust families have in health care workers. In the final stage of guarded alliance, a reciprocal trust is reestablished on a more guarded basis, reflective of revised expectations of roles of patient, family members and health care providers (Thorne & Robinson, 1988; 1989).

The stages of naive trust, disenchantment and guarded alliance were further validated through a phenomenological and grounded theory study individually conducted over a three year period by each researcher, Thorne and Robinson (1989).

A purposive sample (N=77) of subjects involved in an ongoing health care relationship because of a chronic condition either in themselves or a close family member, was selected. The findings confirmed the previous 1988 study's result of three stages evolving during health care relationships. A core variable, " reconstructed trust" (patients' trust in a health care professional and their trust in their own competence), frequently emerged and linked various components of the data together. Within this core variable four patterns emerged, hero worship, resignation, consumerism and team playing.

In hero worship one person was selected as the expert health care professional. This was the individual who provided the security towards developing a trusting relationship. Resignation was characterized by hopelessness and despair. The informants pretended to seek health care without really expecting anyone to provide meaningful help. There was minimal evidence of reconstructed trust. Consumerism represented a strategy that was used by the family to convince professionals that certain services were needed. They learned how to manipulate the system to achieve their goals. Team playing was characterized by reciprocal and negotiated alliance between the family and health care professional. Both parties participated in the decision making process which required a reciprocal trusting relationship.

The existence of the core variable "reconstructed trust" generated analysis by the researchers to proceed from a descriptive to a theory-generating level (Thorne & Robinson, 1989). Since this study involved only a few families with children with a chronic condition additional research needs to be done to see if the findings are consistent within all populations of chronically ill children.

Acute Episodic Hospitalizations

Children with chronic conditions are generally hospitalized in an acute care setting whether or not the hospitalization is for the chronic condition or for an acute episodic problem. When the hospital admission is for an acute problem "the contextual issues that are so significant to families who are managing the problems arising from living with long-term illness" (Robinson, 1987, p.185) are frequently disregarded.

According to Stein and Jessop (1984) mothers' anxiety levels increase when their child with a chronic condition develops an acute illness because the parents worry that the acute illness will negatively impact on the chronic condition. Any change in a child's condition such as an acute illness triggers a heightened degree of uncertainty concerning the child's chronic condition which then increases parental stress (Cohen, 1995).

The only studies found that addressed an episodic problem of a child with a chronic condition were those of Ferraro & Longo (1985), Ogilvie (1990), and Robinson (1987).

Ferraro and Longo (1985) used a case study to explore how to assist families that are coping simultaneously with a pediatric chronic disabling condition and an acute medical problem. Staff who were involved with a family whose child had a chronic condition but was admitted for an acute illness assessed the family as being dysfunctional and in crisis. The staff consulted with Ferraro and Longo about implementing crisis intervention with the family.

Ferraro and Longo (1985) interviewed the family, and based on their clinical findings found that the use of crisis intervention was inappropriate because the family was very comfortable in dealing with all their child's problems. The problem was that nurses had misinterpreted the parents' actions and what the parents said. The parents tried to maintain their normal routine of caring for their child even though the child was hospitalized. However, the nurses' perspective of the parents' requests was that the parents were being unrealistic and denying the severity of their child's illness.

Ferraro and Longo (1985) found that the parents' "power resources of self-concept, physical strength and reserve, energy, and knowledge were being compromised during this hospitalization" (p.80). Strategies were then implemented to restore the parents' power resources which lead to more positive interactions between the family and staff.

This study demonstrated the importance of good communication skills between family and staff and the need for staff to allow families to maintain as normal a routine as possible, so that disruption of family functioning is minimized. Additional studies of families with children who have a chronic condition and are hospitalized for an acute illness need to be done to obtain credibility and auditability of findings.

Ogilvie (1990) in a qualitative study using participant observation and indepth interviews, interviewed nine families to determine the parental experience during their child's hospitalization for elective surgery. Both mother and father were interviewed in seven of the families. In the remaining two single parent families the mother was interviewed because she was the primary care giver. The ages of the hospitalized children ranged from 2-8 years. Four of the children had chronic conditions, the remaining five did not and were admitted for curative surgery. Two interviews were done. The first interview was carried out while the child was in surgery; the second was conducted in the child's home 5-20 days after discharge.

Parents stated they did not receive enough information to help them care for their child and felt confused about their roles during the child's hospitalization. Parents who had previous experiences with their child's hospitalizations tended to discuss their past experiences as well as the current one.

A primary finding was that communication was a crucial factor in decreasing parental stress. Parents expressed pleasure with nurses who showed an interest in the parent or child as a person, provided accurate and consistent information, listened to parent concerns, showed parents how to comfort and care for their child and negotiated with the parent.

In a qualitative study, Robinson (1987) interviewed nine parents considered to be extremely knowledgeable about having a child with a chronic illness who was repeatedly hospitalized. The purpose of the study was to elicit views of their experiences during the hospitalization of their child with a chronic illness. Nine parents from six families who assumed the role of primary health care provider in the daily management of their child's illness discussed obstacles they perceived that negatively affected implementation of family centered care. Two obstacles mentioned were disregarding the family experience with the child's chronic illness and not understanding that the parent's expected outcome criterion for each hospitalization was achievement of a positive experience. Parents wanted "to maintain a commitment to wellness within the illness experience" (p. 187). However what they did experience were feelings of frustration, anger and occasional helplessness as they encountered roadblocks trying to implement family centered care. According to Shelton, Jeppson and Johnson (1987), family centered care recognizes the family as a constant in the child's life. The parent/professional partnership needs to provide for flexibility, accessibility and responsiveness to family needs, and to recognize family strengths.

Hayes and Knox (1984) carried out a qualitative study to examine parents' stress related to the hospitalizations of their children with long term disabilities as well as exploring the parents' perceptions of how health care professionals help to mediate parents' stress. Forty parents divided into two groups, group 1 (n=13), group 2 (n=27) were interviewed in the hospital while their child was hospitalized. Two groups were formed because data were collected in two phases due to problems in accessing suitable families.

The findings showed that parents' perceived stress was a combination of their expectations of their parenting role during their child's hospitalization and nurses' expectations of the parent's parenting role. The dissonance that existed between the two potentiated the stress experienced by the parents. Similar findings were established in a previous qualitative study by Hayes and Knox, (1983). The researchers suggested that further research be done that would identify interventions that would promote positive parent/professional interactions.

Burke, Kauffman, Costello and Dillon, (1991) over a four year time period used grounded theory to investigate parents' stress and coping responses to repeated hospitalizations of children with chronic conditions. The sample included mothers of children with a chronic condition or disability (n=30), mothers of healthy children (n=30); mothers of disabled children attending a weekend retreat (n=100); mothers of chronically ill and disabled children (n=9) before, during and after a hospitalization; and community health nurses with caseloads of physically disabled children (n=6). Subjects were selected who were able to answer the study question; some were reinterviewed for clarification of findings. A dominant finding was repeated hospitalizations of children with chronic conditions was a stressful event for parents, who utilized a variety of coping strategies.

Although this was an indepth study of mothers with chronically ill children, the study addressed a population of children who were repeatedly hospitalized for their chronic condition rather than for an acute episodic problem. Therefore it would be helpful to find out if parents experience the same type of stress and use the same type of coping strategies when the chronically ill child is admitted for an unexpected acute medical or surgical problem.

A review of the literature reveals a limited number of nursing studies that focus on the parent during the hospitalization of a child with a chronic condition (Hayes & Knox, 1983, 1984; Horner, Rawlins & Giles, 1987; Knafl, Cavallari & Dixon, 1988; Robinson, 1987). Several earlier studies were directed towards the needs of the child and how these needs were met by nurses (Lynn, 1986; Wolfer & Visintainer, 1975).

Investigation of literature also revealed a paucity of information available addressing the parents' lived experience during the hospitalization of their child with a chronic condition.

Park (1991) using Glaser's and Strauss' grounded theory method, conducted a qualitative study that looked at 12 parents, mothers' (n=10), fathers' (n=2) experiences during the hospitalization of their children in a traditional ward setting in Canada. The children had the following conditions: chronic and potentially fatal (n=5), long term but correctable (n=2), short term (n=4), and one child had died eight months prior to the interview. A secondary sample of twenty additional parents was interviewed to clarify specific aspects of the emerging theory that the parents' experience during their child's hospitalization is a process of parenting that emerges in stages. Park also included as part of her data collection, an article that was written by four parents who provided accounts of their experiences while their children were hospitalized. The article was written expressly for the health care provider and Park considered their written experiences as additional data.

The first stage, losing control, occurring prior to the actual hospitalization consisted of four phases: sensing change, showing concern, becoming alarmed and seeking information. The parent sensed something was medically wrong with the child and showed concern by trying to figure out what changes were occurring. A sudden change caused the parent to become alarmed and seek further acknowledgement and expert intervention from the physician that the concerns with the child's behavior were accurate.

Stage two, relinguishing responsibility, occurred at the time of hospitalization when the parent gave over responsibility of the child to the physician.

The third stage, being liberated, developed as parents became frustrated and angry because of "doctors and nurses lack of respect for the parents' opinions" (p.87). As parents became more knowledgeable about their child's illness they became more active in the decisions made about the child and participated more in the child's care.

In stage four, increasing parental resources, parents realized they had the power to enhance the child's health care by obtaining additional knowledge, developing parent/professional relationships and assuming responsibilities that were previously allocated to the health care professionals. These newly assumed responsibilities enabled the parent to continue providing for the child's care after discharge. Once the child was discharged from the hospital, stage five, parenting the child became the parents' sole responsibility again.

Some parents in the study repressed their feelings of frustration and did not assume responsibility for the care of their child until the child was discharged. These parents expressed anger at themselves for not taking on a more aggressive role during the child's hospitalization. Some felt unprepared to assume total responsibility for the child's health care at home because of their lack of involvement during the child's hospitalization. Relinguishing and regaining the responsibility for parenting the hospitalized child emerged as a major theme. All parents at some point stated they were angry because of being ignored as a source of information.

Although this study examined parents' experiences during their child's hospitalization, it did not focus on an episodic hospitalization. An episodic hospitalization often negates consideration of the child's chronic condition because the focus of attention is on the acute illness.

Perkins (1993) interviewed 23 parents of children aged 2-13 years with a variety of disabling conditions and cognitive impairments who were currently hospitalized or recently hospitalized. The purpose was to learn about parental caregiving experiences. Two groups of parents were interviewed. Group 1 (n=18) was interviewed while the child was hospitalized. Group 2 (n=5) was interviewed 2-4 weeks after hospitalization. Ten mothers and five fathers were interviewed once. Five couples were interviewed together and eight mothers from group 1 were interviewed a second time to confirm interpretations.

Perkins found that the greater the parents' knowledge, the more sophisticated their involvement with their child's care. According to Perkins (1993), parents as caregivers go through three phases of caregiving: knowledge, involvement and commitment. Each phase supports the others. Therefore it was suggested that nurses pay greater attention to the parents' need for specific information concerning their care taking roles during their child's hospitalization. Perkin's study provides valuable information for nurses working with parents of children with a chronic condition so that nurses can provide guidance in parental caregiving. Additional studies are needed to establish credibility and auditability of findings. Perkins' study looks specifically at parental care giving experiences but does not look at the total parent experience during the child's hospitalization.

Communicating and Dialoguing with Mothers of Hospitalized Children

In a study by Stein, Jessop and Riessman (1983) concerning health care services provided to hospitalized children with a chronic illness, 31% of the mothers cited a need for additional information in caring for their child. Other studies looking at parents' perceived needs showed a consistent desire for increased communication between parents and nurses (Algren, 1985; Horner, Rawlins & Giles, 1987; Robinson. 1987).

Several studies have been done that have shown that a child's adjustment to hospitalization is better and mothers are more satisfied with the experience when the mother receives information and support from nursing (Horner, Rawlins & Giles, 1987; Melnyk, 1994; Peterson & Mori,1988; Wolfer & Visintainer, 1975, 1979).

According to Wolfer and Visintainer (1975), parents who received information about their child's care were much happier than the parents who received limited information. A good understanding of their child's needs helps maintain a sense of control (Canam, 1993).

Horner, Rawlins, and Giles (1987) conducted a survey to determine how parents of children with a chronic condition perceive their own needs. A questionnaire was mailed to a convenience sample (N=493) who had children with a variety of chronic conditions, physical as well as developmental. A total of 164 questionnaires were returned and tabulated. Those who completed the questionnaire included mothers (87%), fathers (9%), guardians (3%) and other categories (1%). Twenty five percent of the parents stated they lacked knowledge in 12 out of 24 items listed in the survey. Many parents took the time to write in additional comments. A large number expressed frustration with professional's lack of understanding parents' problems and not listening to their concerns. These findings are limited to the specific group sampled since the questionnaire was mailed to a convenience sample rather than a random sample, and there were no personal interviews done that would elicit more indepth data.

The nurse's goal of educating mothers should be to stimulate mothers' insight as to what they need to learn in order to provide optimal health care for the child. This tends to shift the onus of responsibility of what nurses think should be taught to what the mother sees as a need to learn. Thus, the nurses' teaching role would be guided by the mothers' perceived lack of knowledge. The structuring of mothers' education to decrease parental stress can impact on a child's recovery and their positive response to the hospitalization (Lynn, 1986).

Education of a mother is an essential component of quality health care, therefore a responsibility of the nurse is to facilitate the mother's learning process. However, according to Shelton, Jeppson and Johnson (1987) "educational programs have not taught professionals how to encourage families in their natural caregiving roles" (p. 9) and as a result many professionals tend to foster dependence in families rather than independence.

Communicative Action

The goal of communicative action is clarification of conditions for communication and intersubjectivity. Communicative action tries to understand the meaning of things rather than their causes through the "science of interpretation and explanation" (Mezirow, 1981, p.5) and not just observation of facts (Mezirow, 1981, 1985). Benner (1984) stated we both shape and are shaped by language. Language is the communication of one's individual representation of reality to another (Taylor, 1971). According to Benner (1984) "greater understanding is made possible by making meanings, expectations, and values explicit, that doing so allows for greater clarity, that even in the presence of shared understandings it is still preferable to spell things out explicitly" (p. 236). When individuals do not share the same meaning it makes it difficult to compare practices.

In Robinson's study (1987) the parents and health care providers had different perspectives regarding care provided by family members. Parents expected to remain active participants in caring for the child as well as remain active participants in decision making. Maintaining adherence to the family's normal routines was a priority goal. However health care providers often misinterpreted and/or ignored the family's expressed needs resulting in misconceptions between parents' and health care providers' therapeutic goals. Thus an adversarial relationship developed.

Taylor (1971) said one can only understand the meaning of something as it relates to a particular situation. Meaning is not only verbalized, it is also expressed in action and practices, therefore it is important to observe actual practice rather than to ask about one's beliefs. The meaning and significance of human action is rarely fixed or clear. It is constantly negotiated in on going interactions, and changes over time in different contexts and for different individuals. Language takes on different meanings within different contexts of situations. Human behavior is bound up with the level and type of culture which is inseparable from these distinctions. Through interpretive inquiry one can elucidate and make more explicit our understanding of human actions.

Tanner, Benner, Chesla and Gordon (1993) interviewed nurses (N=130) in intensive care units of eight hospitals. Groups of four to six nurses were interviewed at a time. Nurses were requested to provide narrative exemplars of particular clinical situations that help describe what nurses mean by knowing the patient and why knowing the patient makes a difference in the nursing care provided. Additionally, nurses (N=48) within the group were observed in their practice and individually interviewed about their work history, early perception of nursing, and nursing education.

Analysis of data implied that knowing the patient plays a major role in nursing practice. According to Tanner, Benner, Chesla and Gordon (1993) "knowing the patient means both knowing the patient's typical pattern of responses and knowing the patient as a person. Knowing the patient is central to skilled clinical judgment, requires involvement and sets up the possibility for patient advocacy and learning about patient populations" (p. 273).

Tacit Knowledge

Mothers have an inherent sense of their child's needs (Park, 1991; Perkins, 1993). According to Perkins (1993) as the mother provides care for their child the "parent gains intimate knowledge of the child's signs or signals and gradually becomes aware that this child may not be able to convert his own signs into appropriate communication to relate to others" (p.5). The mother develops an insight into the child's whole response system and is able to communicate to others the child's needs (Park, 1991; Perkins, 1993). The mother can detect the subtlest changes in their child's behavior before anyone else, usually before even the most "expert practitioner" is able to denote changes. Often the mother can't explain why she perceives a change occurring, it is a gut feeling that can't be put into words. An individual knows more than she can actually describe because some knowledge just can't be communicated. Knowing encompasses both practical (knowing how) and theoretical knowledge (knowing what) and each of these components never acts alone (Polanyi, 1966). Polanyi (cited in Lincoln & Guba, 1985) called this tacit knowledge; knowledge gained from experience. "It is all that is remembered...minus that which is remembered in the form of words....It...permits us to "know ourselves" (pp.195-196).

According to Polanyi (1966), the emergence of tacit knowledge is built upon a set of fixed logical operations, "the growing mind recreates the whole conceptual framework and all the rules and reasoning bequeathed to it by its culture" (pp.45-46). Through one's communicative powers one interprets how things/occurrences impact us and through a logical sequencing of happenings give meaning to the occurrences. Each occurrence as we see and interpret it builds on the other (Polanyi, 1966). Thoughts have intrinsic powers that evoke hidden truths which allow an individual to perceive a problem that is not yet visible to others. These intrinsic thoughts can not be controlled (Polanyi, 1966). Polanyi's ideas illustrate how a mother gets to know her child so intimately and is therefore able to recognize something is remiss before an outsider can.

Family members play an important role in relation to the nurse/patient/family relationship. A family member, ie. mother plays a significant role in helping the nurse learn about the child's behavioral cues signaling significant changes that call for closer monitoring or that indicate a sign of recovery. The mother also helps the nurse become cognizant of the child's personality, likes, dislikes, habits and normal modes of expression (Park, 1991; Tanner, Benner, Chesla, & Gordon, 1993).

Nurses are remiss when they ignore the tacit knowledge of a mother. "Perception has this inexhaustible profundity, because what we perceive is an aspect of reality, and aspects of reality are clues to boundless undisclosed and perhaps yet unthinkable, experiences" (Polanyi, 1966, p.68). Polanyi (cited in Lincoln & Guba, 1985) "recognized that each person, novice or expert, has great stores of tacit knowledge with which to build new understanding" (p. 196). Nurses need to acknowledge the mother as the "expert", the one who knows the child best, and listen to the information provided by the mother, carefully assess the data, and discuss the findings with the mother in a nonjudgmental manner so that solutions can be mutually arrived at. Maintaining open communication with the mother is recognition of the mother as the primary caregiver and mainstay of the child's life (Leff, Chan & Walizer, 1989; Park, 1991; Perkins, 1993; Robinson, 1987).

Since children are believed to thrive in a family centered environment it is incumbent upon health care professionals to "support, encourage, and enhance the competence of parents in their role as caregivers" (Shelton, Jeppson & Johnson, 1987, p.1). The survival and well-being of a child, especially one who is hospitalized, is dependent on a well functioning family (Danielson, Hamel-Bissel & Winstead-Fry, 1993).

Mothers of children with chronic conditions should ideally be in an integral working partnership with nurses. However, many inconsistencies continue to exist between nurses' philosophy and actual practice modalities, with mothers' roles still poorly defined and the nurse/mother relationship poorly explicated (Algren, 1985; Berman, 1991; Brown & Ritchie, 1990; Canam, 1993; Chesler,1985; Hayes & Knox, 1984; Knox & Hayes, 1983). Johnson (1990) and Robinson (1987) believe these discrepancies surface because professionals lack insight into the inconsistencies of their practice with family-centered care. "Unacknowledged discrepancies in perspective between parents of children with chronic illnesses and health care providers are major roadblocks to implementing family centered care" (Robinson, 1987, p.192).

According to Robinson (1987) "one of the major sources of stress for parents when their chronically ill child is hospitalized is the discrepancy between the parents' perspective about how to enact the parent role in hospital and the perspective held by health care professionals" (p.183). To ease the transition, strategies need to be implemented to augment the mothers' role in the decision making process concerning their child. Child health care nurses have to focus on establishing mother/professional partnerships with mothers who have a hospitalized child with a chronic condition.

The nursing literature demonstrates that research concerning the lived experience of mothers who have a child aged 3-6 years hospitalized with a chronic condition is scarce. No nursing studies to date exist that explore the actual mother lived experience during an acute episodic hospitalization of a child with a chronic condition. As the population of children with a chronic condition rapidly increases (Newacheck and Taylor, 1992), it behooves nursing to understand what mothers experience during an acute episodic hospitalization of a child with a chronic condition and what mothers perceive the hospital experience and mother/professional relationship to be. Therefore, this researcher carried out a qualitative research study looking at a mother's lived experience during an acute episodic hospitalization of her child aged 3-6 years with a chronic condition.

Summary

Hospitalization of a child can be a stressful experience for both the mother and child (Burke, Kauffman, Costello & Dillon, 1991; Hobbs, Perrin & Irreys, 1985; Thomas, 1987; Wright & Leahy, 1987). It can be even more stressful if the hospitalization is for an acute episode (Stein & Jessop, 1984) and the child is between the ages of 3-6 years (Jessop & Stein, 1989).

Children 3-6 years old are extremely vulnerable. They lack the necessary coping skills to deal with the hospitalization. Their cognitive and psychosocial development do not enable them to comprehend the reasons for illness or the hospitalization. Their active imaginations increase their fears (Erikson, 1963; Piaget, 1962). How the child handles the hospitalization is dependent on the mother's ability to attenuate their fears (Wolfer & Visintainer, 1975, 1979).

The child needs the comfort, support and love of their primary care giver, the mother (Ambert, 1992; Bowlby, 1973; Clements, Copeland & Loftus, 1990) to help them adjust to the hospital experience. If the mother is not coping well she will not be able to meet her needs (Lynn, 1988) or the child's needs which can have a negative impact on the child's future development (Melnyk, 1994; Wolfer & Visintainer, 1975; 1979).

During a child's hospitalization, health care professionals can create stressful environments for the mother generating feelings of powerlessness and hopelessness (Knox, 1984). Mothers have expressed frustration with professional nurses' lack of acknowledgement of their expertise as well as stressors that impact on parental functioning (Burke, Kauffman, Costello & Dillon, 1991; Clark, 1991; Dunst, Trivette & Deal, 1988; Hayes & Knox, 1984; Knox & Hayes, 1983; Ray & Ritchie, 1993; Robinson, 1987; Schepp, 1991).

Nurses have failed to view the mother as the "expert" care giver for the child. Park (1991) and Perkins (1993) said that mothers have an inherent sense about their child and notice changes before health care professionals do. However, the mothers' "feelings" often go unheeded as the nurses fail to listen to what the mothers are saying. Open, honest communication between a mother and nurse establishing an environment conducive to learning and being receptive to mothers' needs is essential to establishing parent professional relationships (Lynn, 1988; Thorne & Robinson, 1988; 1989).

Relationships between mothers and health care professionals is a concept that is evident in many studies (Knafl, Breitmayer, Gallo and Zoeller, 1992; Ogilvie, 1990; Robinson, 1987; Thorne and Robinson, 1988, 1989). Mothers articulate health care provider behaviors they find that promote and sustain relationships. Mothers want health care providers to communicate with respect, compassion, and empathy and to foster mothers' participation by building on mothers' strengths (Johnson,1990; Kristjansdottir, 1991; Robinson, 1987).

Mothers of a child with a chronic condition primarily focus on their child's strengths and try to help their child achieve their maximal potential, whatever that may be (Robinson, 1987). Staff tends to orchestrate the care that the mother is permitted to participate in. The mothers care giving is often framed to benefit the health care professional rather than the child or mother. A more caring rather than curing attitude amongst health care professionals needs to transcend the health care system (Thorne and Robinson, 1988). According to Hobbs, Perrin and Irreys

(1985), a child's family inevitably will share the child's suffering, however the impact of the issues, burdens and challenges affect each member differently.

Several studies (Knafl, Breitmeyer, Gallo, & Zoller, 1992; Thorne & Robinson, 1988; 1989) have explored the mother/nurse relationship, or parental perception of the mother/nurse collaborative relationship. Other studies have addressed the importance of nurses utilizing strategies that foster a mother/professional partnership (Algren, 1985; Berman, 1991; Brown & Ritchie, 1990; Copeland, 1993; Hayes & Knox, 1984; Kirschbaum, 1990; Knafl, Cavallari & Dixon, 1988; Knox & Hayes, 1983; Robinson, 1987; Thorne & Robinson, 1988; 1989).

Robinson's study (1987) found roadblocks to family centered care exists because mothers are oriented toward the child's chronic condition, while health care professionals primarily focus on the acute problem. Mothers talk about the chronic illness even if the child is hospitalized for an acute problem.
Mothers look at the child's trajectory (Corbin & Strauss, 1992), the present problem and how it will impact the child's future (Stein & Jessop, 1984), while nurses are more interested in dealing with the present

(Robinson, 1987).

Although research studies (Bowlby, 1973; Hayes & Knox, 1984; Thomas, 1987) have looked at the effects of hospitalization on the child and mother, most of these studies have focused on acute problems that are usually resolved in a short period of time (Ogilvie, 1990). Hymovich and Baker (1991) have looked at the child with a specific chronic illness and the impact the illness has on both the child and mother. Ferraro and Longo's (1985) case study of a child with a chronic condition admitted for an acute medical problem, examined the response of family members and the parent/professional relationship during the hospitalization of the child. However, additional studies are still needed that focus on the mothers of children with a chronic condition who are hospitalized for an acute problem.

Health care professionals focus on the acute condition often disregarding the chronic condition with it's frequent hospitalizations. According to Robinson (1987) "over a period of time the perceived disregard for family experiences with chronic illness promoted feelings of anger, frustration, and resentment" (p.186).

Nurses must listen to what mothers' of children with a chronic condition perceive during their child's acute episodic hospitalization. The data can provide health care professionals with information that nurses can use to develop necessary skills that promote positive mother/professional relationships.

Providing mothers with information in clear understandable terms, helps to decrease their anxiety levels. When the information is offered with honesty, sensitivity and respect the mother is more apt to listen. The mother is also more likely to develop a trusting relationship with the health care provider (Algren, 1985; Melnyk, 1994, Knox & Hayes, 1983; Robinson, 1987; Thorne & Robinson, 1988, 1989).

A successful relationship between mothers and health care professionals is dependent on both mothers' and professionals' attitudes, honesty and willingness to communicate and work with one another (Knafl, Breitmayer, Gallo & Zoeller, 1992; Palmer, 1993; Thorne et al.). Although many nurses believe in this philosophy, Algren (1990), Berman (1991), Brown and Ritchie (1990), Hayes and Knox (1984) suggested that incongruencies in nurses' practice exist. Studies (Algren, 1985; Robinson, 1987; Thorne & Robinson, 1987; 1988) about the parent/professional relationship found that nurses say they agree with the concept of family centered care but research results have shown that nurses do not really adhere to the practice of family centered nursing (Shelton, Jeppson & Johnson, 1987). The dissonance that exists between the mother and nurse prevents successful family centered care (Algren, 1985; Berman, 1991; Robinson, 1987).

According to Hobbs, Perrin and Ireys (1985) "the fact of chronicity itself creates a special problem of coping for the child and family and links families with diverse conditions" (p. 21). The crisis of an acute illness passes fairly quickly, but the chronic condition remains a constant that requires specialty care at the time of diagnosis and periodically thereafter (Hobbs, Perrin & Ireys, 1985).

The importance of nurses developing an understanding of the complexities of mothering a child with a chronic condition can not be over emphasized. Common issues and dissimilarities exist. There are numerous types of childrens' chronic conditions and each one may not share all of the same characteristics, but there are definitive strands forming patterns that tie the disease entities together.

Unless professionals are willing to listen to mothers' perceptions of their child's hospitalizations, the discrepancies that currently exist cannot be remediated. Roadblocks to mother/professional relationships will continue to escalate. Anger, frustration and dissatisfaction will permeate, making the hospital experience difficult for everyone involved.

Significance to Nursing

Chronic conditions affect approximately 31% of children less than 18 years of age almost 20 million nationwide (National Health Interview Survey, 1988; Newacheck & Taylor, 1992; Newacheck, Stoddard & McManus, 1993). As the population of children with a chronic condition rapidly increases (Newacheck and Taylor, 1992), it behooves nursing to investigate what mothers experience during an acute episodic hospitalization of a child with a chronic condition.

A mother is the central figure in a growing and developing child, therefore child health care nurse researchers need to conduct studies describing mothers' lived experiences, paying specific attention to mothers' perceptions of how nurses and other health care professionals support the mothering role and the strategies implemented that augment the mother's role in the decision making process concerning their child's needs. According to Corbin and Strauss (1992) nurses need to understand what chronicity means to a family and develop a philosophy of care that reflects an understanding of parental needs.

Practitioners learn from experience. When working with human beings experience can play a vital role in directing nurses' decision making processes. Actions are often automatically carried out without much thought because the individual's actions have become habituated. Reflection-in-action, a technique advocated by Schön (1983) encourages nurses to reflect on how they handle situations.

Reflection-in-practice allows one to critically analyze what is occurring and help uncover those unconscious rules and acts that guide nurses' practices. As practitioners reflect on their clinical practice, new approaches towards handling phenomena can result and change nursing practice.

Thus far, relationships between professionals and family members have received minimal attention from nursing. Attention has been primarily focused on the health care provider's management of the child's condition rather than on family centered management.

Family centered care and the establishment of a mother/nurse relationship can make a difference in the way nurses and mothers relate to one another during the acute episodic hospitalization of a child with a chronic condition. The newly acquired knowledge can lead to the development and enhancement of the mother/nurse relationship and a change in future practice modalities.

CHAPTER 3

STUDY DESIGN AND METHODOLOGY

Study Design

Phenomenology as a philosophical orientation, was initially planned for this study. Phenomenology is a method of inquiry that identifies the essence of a phenomenon through the descriptive narratives of a person's lived experience. Emphasis is placed on the human experience as it is actually experienced, rather than on objects or subjects (Bogdan & Biklen, 1992; Denzin & Lincoln, 1994; Field & Morse, 1985; Munhall & Oiler, 1986; Swanson-Kauffman & Schonwald, 1988). It is a form of philosophical inquiry that views humans as a whole rather than in parts (Munhall, 1988; Omery, 1983).

According to Denzin and Lincoln (1994), qualitative researchers think reflectively and draw upon their own experiences as a resource for their inquiries. Qualitative enables nurse researchers to focus on the humanistic aspects of practice. Qualitative permits the nurse to investigate and understand individuals' human experience as they live it (Omery, 1983; Rose, Beeby & Parker, 1995; Sandelowski, 1986), which enables the researcher to understand the data obtained from the perspective of the participants (Omery, 1983).

I began this qualitative study with the intention of interviewing mothers who experienced an acute episodic hospitalization of their child who has a chronic condition. Interviews were to continue until redundancy of themes was reached. However, my second interview yielded such rich and complex data that my dissertation committee suggested and I agreed to change my methodology and to utilize the second interview as a case study.

Three other interviews, one completely analyzed and two partially analyzed, supported the data from the second interview without adding any additional information and were therefore not used directly for this study. The purpose of a case study according Sandelowski (1996) is to look at the particular elements of the case and the manner in which "they come together to uniquely characterize the case" (p. 527). Stake (1994) says a case study represents the particulars of the case that may yield unusual insight into the phenomenon. "It is a major vehicle for the dissemination, application, and (individual) aggregation of knowledge" (Guba & Lincoln, 1989,

p. 181). It can suggest findings that need further investigation (Sandelowski, 1996) and can ultimately lead to improved patient/family services (Meier & Pugh, 1986).

Qualitative research is an evolving process that allows the researcher to change directions that will produce a richer more relevant study. Under the umbrella of qualitative research several methodologies are noted. Naturalistic inquiry is one of them.

Naturalistic investigation operates under the premise of two tenets that are the prime directives. According to Lincoln and Guba (1985) "first no manipulation on the part of the inquirer is implied, and, second the inquirer imposes no a priori units on the outcome" (p. 8). According to Lincoln and Guba (1985) "the design of a naturalistic inquiry ... *cannot* be given in advance; it must emerge, develop, unfold" (p.225). "The naturalist begins inquiry with a particular focus in mind (however tenuous) but has no qualms about altering the focus as new information makes it relevant to do so" (Lincoln & Guba, 1985, p. 229). The naturalistic investigator cannot confine him or herself to the variables that are so rigorously controlled in a quantitative study. The researcher is obliged to take into account all factors and influences within a setting that may make a difference (Lincoln & Guba, 1985).

"The epistemological thrust of qualitative research is case oriented. Regardless of qualitative methodology or sample size, qualitative research is quintessentially about understanding a particular in the all-together" (Sandelowski, 1996, p. 525). A case study "is not restricted by any procedural considerations" (Meier & Pugh, 1986, p.195) such as a specified series of steps (Meir & Pugh, 1986). In fact according to Lincoln and Guba (1985) and Meier and Pugh (1986) a case study should be referred to as a strategy rather than a method. The method or strategy used should be dependent on the information that the investigator hopes to obtain.

A case study should be considered when investigating clinical nursing problems that can elicit data that add to nursings' knowledge base and bridge the research practice gap which can ultimately lead to improved parent/professional partnerships and patient/family services. A specific case study can provide reflection on human experience and indepth insight into a phenomenon of interest (Stake, 1994).

The change to a case study design was supported by a statement of Lincoln and Guba (1985), that

> within the naturalistic paradigm, designs must be emergent rather than preordinate: because meaning is determined by context to such a great extent; because the existence of multiple realities constrains the development of a design based on only one (the investigator's) construction; because what will be learned at a site is always dependent on the *interaction* between investigator and context, and the interaction is also not fully predictable; and because the nature of mutual shapings can not be known until they are witnessed. All of these factors underscore the *indeterminacy* under which the naturalistic inquirer functions; the design must therefore be "played by ear"; it must unfold, cascade, roll, emerge". (pp. 208-209)

Lincoln and Guba (1985) perceive "the human-as-instrument of choice for naturalistic inquiry" (p.193). As investigator of the phenomenon in question I was the research tool. The human-as-instrument is infinitely adaptable and is able to sense and respond to personal and environmental cues. Humans have the capability of immediately processing information, summarizing and feeding the information "back to the respondent for clarification, correction and amplification" (Lincoln & Guba, 1985, p. 194) which can culminate in a higher level of understanding. This form of inquiry allowed me as the researcher to employ the strategies and methods which yielded information to help one understand the phenomenon in question. It is my hope that the knowledge gained from this case study enhances the practice of parent child nursing and improves parent/professional relationships.

The Purpose of the Research Study

The purpose of this case study was to provide an inquiry into a mother's lived experience during an acute episodic hospitalization of her child with a chronic condition. The data gathered provides an emic perspective of the mother's relationship with nurses, other health care professionals and family members, and the impact each one had as she experienced her child's hospitalization.

Definition of Terms

Chronic Condition: A health condition that is long term, lasts three months or more within a year or requires at least 1 month of hospitalization, and leads to actual or potential interference with a system's level of functioning (Hymovich & Hagopian, 1992; Jackson & Vessey, 1992).

Child: For the purposes of this study the child will be between the ages of 3-6 years with a known chronic condition (inclusive of physical and cognitive disabilities; exclusive of psychiatric problems).

Parent: For the purposes of this study the parent will be the mother.

Acute Episode: Having a rapid onset, severe symptoms and a short course that requires hospitalization for management (Corbin & Strauss, 1992; Thomas, 1989).

Hospitalization: Confinement to an institution for the care of the sick (Thomas, 1989).

Lived Experience: The experience as it exists in the consciousness of the mother's mind (Field & Morse, 1985).

Assumption

Stories related by the mother will explicate the mother's lived experience during the acute episodic hospitalization of her child with a chronic condition.

Delimitations

1. A mother was selected for this study because

mothers are generally the primary caregiver (Ambert, 1992; Betz, Hunsberger & Wright, 1994; Burke, Kauffmann, Costello & Dillon, 1991; Clements, Copeland & Loftus, 1990).

2. The child's age was limited to 3 to 6 years old. The family is the primary caregiver and advocate during the pre-school and toddler years (Hostler, 1991; Jessop & Stein, 1989; Rose & Thomas, 1992). According to Piaget (1962) and Erikson (1963) children in this age group need the parent to be intimately involved with their care, because the children are not sufficiently capable of seeing that their needs are met.

3. The chronic condition of the child was to be inclusive of physical and cognitive disabilities and exclusive of psychiatric problems. Children with psychiatric diagnoses have additional problems that may have been too overwhelming to address in this particular study.

Selection of Participants

Qualitative researchers seek out individuals and settings that will provide information for the phenomenon being studied (Denzin & Lincoln, 1994). Therefore a purposive sample was to be used for the original phenomenological design confined to a population of mothers who have a child with a known chronic condition aged 3-6 years old, who have had a recent hospitalization for an acute episodic problem within the last year. "Good informants are informants who have gone through the entire experience under study and are able to look back and reflect on the situation. They are also willing to share their experience with much detail" (Park, 1991, p.52). Interviewing parents after their child has been discharged home is preferable because the parents' stress level is usually decreased. They have had the opportunity to reflect back on their experience with insight that is not overshadowed by the anxiety of the hospitalization. The purposive sample was to be obtained from various parent support groups and colleagues who provide health care services for children with a chronic condition.

Fliers explaining the purpose of the study and sample needed (See Appendix B) and a recruitment letter (See Appendix C) were distributed to various support groups and colleagues who serve families who have a child with a chronic condition. The recruitment of subjects proved to be more difficult than I had expected probably because of the strict criteria established.

It took several months before I was given the names of potential subjects. Subjects were obtained through recommendations made by colleagues and one support group mother aware of the research study and the specific criteria that the participant had to meet.

Prior to my initial communication with the subjects the person who initiated the contact briefly informed the potential subjects about the proposed study and asked their permission to give their telephone numbers to me. I telephoned each potential subject and introduced myself, briefly explained the purpose of the study, and verified that each potential subject met the proposed criteria established for the study. If everything checked out, I asked each one if they were willing to participate and to be interviewed. I asked permission to tape record the interview. If they agreed to the interview, a time and place that was convenient to them was chosen. I asked them to select a place where we would have approximately 1 1/2 to 2 hours of privacy without interruptions. A total of six potential subjects were recommended, five by colleagues and one by a parent who knew the subject. However, with the change in research strategy only one purposive participant was actually used. The mother was recommended by another mother who also has a child with a chronic condition.

Protection of Human Subjects

Researchers must take on the responsibility of following all procedures that are required prior to implementation of a study that involves human subjects. The risk/benefit ratio and ethical dimensions are normally subjected to external review by Institutional Review Boards (Burns & Grove, 1987; Morse, 1991; Polit & Hungler, 1991). "APA's (1982) code of ethics stipulates that investigators should seek the advice of others with issues relating to human subjects" (Polit & Hungler, 1991, p.41), to show that individual rights and human dignity are being protected.

Protocols were followed to obtain permission from the Human Subjects Review Board at Adelphi School of Nursing. A letter explaining the purpose of this research study and the necessary informed consents were formulated (See Appendix A). Subjects were told that all audio tapes would be destroyed at completion of the study. Respondents would be identified by code only and they could withdraw from the study at any time. Names of individuals and institutions were changed if mentioned in the interview, and their true identity was known by the researcher only. Confidentiality was maintained at all times.

The decision to use a specific case study can cause additional problems in protecting a subject's human rights. According to Stake (1994),

> the case study research shares an intense interest in personal views and circumstances. Those whose lives and expressions are portrayed risk exposure and embarrassment: ... . Issues of observation and reportage should be discussed in advance. Limits of accessibility should be suggested and agreements heeded. It is important but not sufficient for targeted persons to receive drafts of how they are presented, quoted, or interpreted, and for the researcher to listen well for cries of concern. It is imperative that great caution be exercised to minimize the risks. Rules for protection of human subjects should be heeded. (p.244)

Once the decision was made to focus on a specific interview I called the participant and asked her if she had any objections or concerns. I reiterated the fact that confidentiality would be strictly maintained. She said she felt comfortable with the change and gave me verbal permission to go ahead (written consent was previously obtained).

Method of Data Collection

According to Lincoln and Guba (1985) data recording modes should have high fidelity; the researcher should produce the exact data as they become evident to him/her in the field. The best way to accomplish this is to use a tape recorder and keep field notes (Lincoln & Guba 1985). Field notes need to be both descriptive and reflective, and are a "written account of what the researcher hears, sees, experiences and thinks in the course of collecting and reflecting on the data in a qualitative study" (Bogdan & Biklen, 1992, p. 107).

Prior to beginning the interview process I reviewed the purpose of the study, how the interview would be conducted, and reviewed the consent form (See Appendix A) before asking for a signature. Then the participant was asked to fill out a demographic sheet (See Appendix D). She was told she did not have to fill out any information she was uncomfortable with. Some brief socialization took place as I set up the audio tape recorder which helped develop rapport and put the participant and the interviewer at ease.

Semistructured interviews were used to allow considerable flexibility while still maintaining a focus (Morse, 1991; Taylor & Bogdan, 1984). The interview began with a broad statement that enabled the researcher to get a relatively complete picture of the interviewee's experiences. Additional probes were used as needed (See Appendix E). According to Taylor and Bogdan (1984), as informants talk about specific experiences one can probe for greater detail and/or clarification. Two tape recorders were used in case one did not function properly. The primary tape recorder had a table microphone attached (with the interviewee's consent) so that each word of the conversation when reproduced would be clear and easily understood. A timer was set so that the tape could be turned over if additional time was needed for the interview. The timer also allowed me to stay focused because I did not have to watch the time. Field notes were recorded during and immediately after the interview. The information was used in developing the introduction to help the reader gain a better perspective of the subject and setting.

The introduction describes the essence of what the researcher saw, heard, and observed in the field, to enable the reader to become more personally involved with the story. The story is a reflection of the investigator's impressions that cannot be captured on an audio cassette (Bergum, 1991; Bogdan & Biklen, 1992). A total of 2 two hour long interviews, a 20 minute telephone interview and a 2 hour observation in the subject's home were needed to get exhaustive data.

At the end of the first interview I thanked the mother for her willingness to participate and told her I would mail her a copy of the signed consent form, which I did.

Probes

The following two probes were used at the beginning of the interview:

Describe your experience during the hospitalization of your child.

Tell me what it was like for you while your child was in the hospital.

Other probes were available for use as needed to keep the interview focused (See Appendix E).

The first two interviews and the observation took place in the subject's home. The first taped interview took approximately 2 hours and contained an enormous amount of information. I spent a total of 2 1/2 hours with this participant. The second interview lasted about two hours. The third interview was a 20 minute telephone interview to obtain additional data and to ask the mother's permission to make a third visit to the home so that I could meet her son Andy. The visit was made that same day, and it was primarily an observational visit that lasted two hours.

According to Lincoln and Guba (1985) an observation can take place in a natural setting. "The selection of observational situations is guided by principles similar to those guiding selection of inquiry sites and interview respondents-purposive sampling intended to maximize the scope of information obtained" (p.274). The major advantage of direct observation "is that it provides here-and-now experience in depth" (Lincoln & Guba, 1985, p. 273). "Observation...allows the inquirer to see the world as his subjects see it, to live in their time frames, to capture the phenomenon in and on its own terms, and to grasp the culture in its own natural, on going environment" (Guba & Lincoln as cited in Lincoln & Guba, 1985, p. 273).

Method of Data Analysis

All interviews were transcribed for thematic analysis. Inductive analysis is used by qualitative researchers. Categories, patterns and themes emerge from the collected data and are not imposed prior to the data collection (Janesick, 1994).

Analysis and coding was done utilizing the system suggested by Bogdan and Biklen (1992) who developed a typology of 11 coding families to help sort the data and develop coding categories. The process requires one to search for patterns, regularities and topics that evolve from the data and write down words or phrases that are representative of the findings. The descriptive words and phrases help sort the data and become the coding categories (Bogdan & Biklen, 1992).

Immediately after each interview I had the tape transcribed with a turn around time of one week. As soon as the transcription of the tape was completed, I took the typed transcript and checked it for accuracy, changes in voice tone, significant inflections and pauses while I listened to the tape. I corrected spelling errors, bolded areas that the subject emphasized, made notations if the participant laughed or paused for long periods of time, but did not alter the contents of the interview. The transcript disk was then put into the computer for minor editing and reprinted.

Every word in the written transcript was read. Significant words, and/or phrases and patterns of behavior were underlined and major coding categories listed in the margins (transcript 1 was coded in pencil; transcript 2 was coded in red; transcript 3 was coded in blue to avoid confusion when categories were blended). Each major code category was assigned a letter. Coding categories are used so that similar data can be filed together (Bogdan & Biklen, 1992).

The monitor screen was split in half so that as I started to sort out descriptive words and/or phrases I was able to transfer the data to the other half of the screen that displayed the family code, major code and descriptive code categories. Under each major code category (identified by a letter code in the transcripts) that evolved from the analysis of data, key words and/or statements were listed with the page number. This method allowed easy access to finding the data within the transcript. A duplicate of each transcript was made so that one complete set was available in its entirety. The other set with the major coding categories and respective phrases was cut up and placed into envelopes representing the appropriate family codes. Some coding categories fit under more than one coding family. The contents in each envelope were reviewed to check for appropriateness and broken down further into descriptive codes. This process was repeated until I was satisfied the data were sorted correctly. Six coding families were selected with 23 major codes and 82 descriptive codes. The six family codes selected were:

1. Situation Codes (#2)
2. Perspectives Held by Subjects (#3)
3. Subject's Ways of Thinking About People and Objects (#4)
4. Process Codes (#5)
5. Strategy Codes (#8)
6. Relationship and Social Codes (#9)

The following is a list of all major and descriptive codes under each of the family codes:

Family Code	Major Code	Descriptive Code Category
Situation (#2)	Hospital	1. Limited visiting
		2. Secretive
		3. Safety

		4. No facilities
		5. Hospital Policy
		6. Not family centered
		7. No continuity care
		8. PICU safer
		9. Regular Peds unsafe less staff
		10. HCP not caring
	DNR	11. Child in pain
		12. Quality of life
Perspectives Held by Subjects (#3)	Nurses and Physicians	13. Need compassion
		14. Need to understand mother
		15. Need to understand Family Centered Care
		16. Need better understanding of children
		17. Advocate better
		18. Develop better knowledge of available resources
	Physicians	19. Secretive
		20. Non-communicative

	21. Don't listen
	22. erroneous asumptions
	23. Takes time to develop relationships
	24. Lack understanding of 24 hr. child care
Hospitalized Child	25. Unsafe
	26. Frightened
	27. In Pain
	28. Critical
	29. Status compromised
Child with Chronic Condition	30. Very limited physical and mental
	31. Function 9 mo. level
	32. Requires 24 hr. care
Impact of Child on Family	33. Stressful
	34. Resentment
	35. Guilt
	36. Anger
	37. Lack of privacy
	38. Restricts family
	39. Siblings must work
	40. Andy's care priority
	41. Financial

		42. Marital
Subjects Way of Thinking About People and Objects (#4)	Mother/ Professional Relationship	43. Not encouraged
		44. Residents disrespectful
		45. Stressful
		46. Not part of decisions
		47. Takes time
		48. Need caring approach
	Other Health Professionals	49. Need to listen
		50. Non verbal gestures
	Husband	51. Non-supportive
		52. Clueless
	Other Children	53. Worry about brother
		54. Earn money for extra activities
	Grandparents	55. Supportive
		56. Live far
Process Code (#5)	Accept child's Diagnosis	57. Difficult
		58. Sporadic
		59. Takes time
	Future	60. Worries
		61. Home or ?
		62. Sister
		63. Husband ?

	Finances	64. Very limited
		65. Affects employment
Strategy Code (#8)	Child in Pain	66. Refuses to leave
	Medical Coverage	67. Battles for coverage
	Home Care	68. Long term
		69. Nurse not all qualified
		70. Mom expected to cover
		71. Lack of privacy
		72. Family needs don't count
	Support	73. Groups
		74. Neighbor/Others
		75. Not for Dad
	Respite	76. Home care nurses
		77. Vacation
Relationship Code (#9)	Wife/Husband	78. Time limited
		79. Seeks wife's support
		80. Avoids problem solving

Mom/Children	81.	Guilty lack of time spent
Mom/Home Care	82.	Resents when she has to provide care, train staff

Once the above was completed, I went back into the computer, split the screen, took the information that each envelope contained and placed it in a chart that contained the family code, major code and descriptive coding category. I reviewed, edited, and made corrections until I was satisfied with the final product.

After the initial data analysis was done each member on my dissertation committee was given a copy of each interview that was transcribed word for word. Different names were substituted for persons, places, hospitals, and geographic locations in order to maintain anonymity. Each member was also provided with a copy of the supplemental field notes that were recorded immediately after each interview, a copy of the preliminary thematic analysis, and an introduction. The introduction provided a more in depth perspective of the researcher's impression of the subject and setting that enabled the reader to become immersed in the story. Suggestions amd recommendations made by the committee members were heeded which enabled me to interpret and more clearly articulate the findings.

Guided by the recommendations from my committee members, I went back into the computer and narrowed down the coding categories several times. Each time I carried out data analysis I listened again to the taped interviews in order to become immersed in the setting. Material listed under each code was re-analyzed for similarities. The data that were closely related were consolidated. The process continued until I was satisfied with the final selection of categories which were then developed into the themes accompanied by supporting phrases from the transcript (themes will be further explicated in chapter 4). "In naturalistic inquiry, data processing is a continuously ongoing activity, making possible the meaningful emergence of unfolding of the design and the successive focusing of the study" (Lincoln & Guba, 1985, p. 11).

Controlling for Bias

At the beginning of this study I articulated the conceptual framework for this study and thought about my thirty plus years as a child health nurse. The researcher's own experiences are an important component of phenomenologic research (Bergum, 1991). Being cognizant of my biases I tried to maintain objectivity at all times. Biases exist in all types of research. "Bias is *used* as a tool to facilitate the research" (Morse, J. 1991, p. 138). The researcher can never completely eliminate biases. A means to control for biases can occur by acknowledging that certain biases exist and by keeping detailed fieldnotes containing subjective reflections (Bogdan & Biklen, 1992).

My method for data collection included two audio taped interviews, word for word transcription of interviews, a telephone interview, one observation, supplemental fieldnotes, and independent data and thematic analysis reviewed by each member of the dissertation committee. After the first interview the committee made suggestions as to wording the probes. Morse (1991) suggests letting the informant's story help structure the interview. As the research instrument I tried to carefully monitor the interview sessions. I heeded the advise of my committee as to how to structure the probes that would establish rapport, would not influence the information that was elicited from the subject, yet allow for flexibility and a free flowing dialogue that would provide indepth data. Avoiding excessive control during the interview process further controls for bias (Morse, 1991).

The interviewer needs to communicate a personal interest in what the subject is saying. This is accomplished by remaining attentive and maintaining good eye contact and appropriate facial expressions (Bogdan & Biklen, 1992). Since the investigator is the research tool it is incumbent that the researcher interact with the subject in a non intrusive, non threatening manner. I conducted a semi structured interview using a minimal number of non threatening probes. Eye contact was always maintained, and throughout the interview there were occasional nods of the head that indicated I was listening and interested in what she said.

Validity and Reliability

Internal validity, external validity, and generalizability are terms well known in the scientific world of research. These criteria have been the axioms adhered to, to attain rigor in scientific research. A major criticism of qualitative research relates to the validity and reliability of findings. Much of the debate is in response to the multiplicity of methods that exist and the increasing number of terms (credibility, descriptive validity, transferability, fittingness, applicability, dependability and auditability) (Guba & Lincoln, 1989; Lincoln & Guba, 1985; Maxwell, 1992; Sandelowski, 1986) generated by qualitative researchers who have tried to emulate the methods proposed by the scientific world. Each one of these terms is a correlate of one of the more conventional terms that the qualitative researcher has to become familiar with in order to ascertain which one is appropriate to utilize.

Initially qualitative nurse researchers strived to maintain rigor of the study by using criteria that were established for quantitative research. However this has proven to be inadequate because the assumptions of a qualitative and quantitative study differ (Sandelowski, 1986). Qualitative assumptions are constructed by individuals often influenced by social and cultural factors. "There *is no reality* except that created by people as they attempt to "make sense" of their surrounds (Guba & Lincoln, 1989, pp.12-13). Quantitative assumptions have an "objective reality ... that makes it possible for the observer to stand *outside* the arena of the observed, neither influencing it nor being influenced by it" (Guba & Lincoln, 1989, p. 12). The findings are not influenced by the subject or researcher (Guba & Lincoln, 1989).

Qualitative research is conducted to identify specific characteristics of a phenomenon and is becoming more acceptable as a legitimate mode of nursing inquiry. The investigator is concerned with accuracy and comprehensiveness of the data that describe the subject's (emic) perspective of a particular experience (Bogdan & Biklen, 1992). According to Morse (1994) the amount of data rather than the number of subjects is what is important in a qualitative study. The quality of the data and how the selection of information fits with the theoretical needs of the study contribute to the accuracy and appropriateness of the study.

Various modes of criteria to achieve rigor have been espoused by a number of researchers. Most are in agreement that the criteria to be followed need to become more standardized. Each researcher's criteria tend to differ slightly (Beck, 1993; Bogdan & Biklen, 1992; Guba & Lincoln, 1989; Lincoln & Guba, 1985; Maxwell, 1992; Sandelowski, 1986, 1992).

Beck, (1993), Lincoln and Guba (1985), Maxwell,

(1992) and Sandelowski (1986, 1996) have identified similar approaches that can be utilized in the evaluation of qualitative research. They have also suggested guidelines for critiquing each criterion.

In this qualitative research study the following criteria have been used to determine rigor of the study: credibility (validity) others who read the study can recognize the experience, (Lincoln & Guba, 1985); auditability (dependability) another researcher reaches the same conclusions when "given the researcher's data, perspective and situation" (Sandelowski, 1986, p.33); fittingness (transferability) findings fit into contexts outside of the study situation, and others find meaning and applicability in terms of their own experiences (Beck, 1993; Lincoln & Guba, 1985; Sandelowski, 1986); confirmability is the criterion of neutrality which refers to the findings themselves and not the subjective or objective position of the researcher (Sandelowski, 1986). It is "the degree of congruence between sending and receiving contexts (Lincoln & Guba, 1985, p. 124). Confirmability occurs when auditability, credibility, and applicability are established (Lincoln & Guba, 1985; Sandelowski, 1986). The transcripts of the three interviews have been included (See Appendices F, G & H) so the reader can confirm the implicit and explicit data as interpreted by the researcher and the logic used to present the interpretations in a cogent manner. This becomes part of the confirmability audit (Guba & Lincoln, 1989).

Credibility

Maxwell (1992) envisions validity somewhat differently from his colleagues and has proposed five types of validity that can be used in qualitative research, three of which can be applied to the present study: descriptive, interpretive and theoretical. Validity should be based on the kinds of understanding the researcher has of the phenomenon of study.

Descriptive validity pertains to the factual accuracy of what is reported by the researcher. This is accomplished if intersubjective agreement is evident.

Interpretive validity is concerned with comprehending the phenomenon from the participant's point of view not the researcher's. It is from an emic perspective, the subject's view of the experience.

> Interpretive accounts are grounded in the language of the people studied and rely as much as possible on their own words and concepts. .... It is not

> the appropriateness of these concepts for the account, but their accuracy as applied to the perspective of the individuals included in the account. (Maxwell, 1992, p. 289)

Theoretical validity "explicitly addresses the theoretical constructions that the researcher brings to, or develops during the study" (Maxwell, 1992, p. 291). "Validity is not an inherent property of a particular method, but pertains to data, accounts or conclusions reached by using that method in a particular context for a particular purpose" (Maxwell, 1992, p. 284).

For this study the researcher transcribed the first audio taped interview word for word, editing for spelling. All names for persons, places, hospitals and geographic locations were changed in order to maintain anonymity. Field notes were used providing description of subject, demographic data, setting, and researcher's reflections. All of the above were then given for independent review to two members of my committee. Committee members reviewed the introduction, read the unmarked transcript and field notes and then reviewed the thematic analysis. Both members then discussed their findings with me and validated what I had deducted. Verification of data analysis by additional raters helps affirm what the researcher has identified as themes and adds to the validity of the study (Morse, 1994). A follow up phone call to verify the husband's type of employment and the second and third interview provided additional information as well as confirming data gleaned in the first interview. The two hour observation reinforced the data that were ascertained from the interviews. Confirming information with the subject and soliciting additional data further establish credibility (Guba & Lincoln, 1985). According to Adler and Adler (1994)

> observation produces great rigor when combined with other methods .... Researcher's observations of their setting and subjects can be considered hard evidence .... Although direct observation may be marred by researcher biases, at least these are consistent and known. Direct observation, when added onto other research yielding depth and/or breadth, enhances consistency and validity (p. 382).

Auditability

An audio tape recorder and field notes were used during the interviews. I provided the two committee members with the following description: how subjects were selected, strategies used to collect and analyze data, and copies of verbatim transcripts followed by copies of the thematic analysis. The committee members were able to follow the audit trail as suggested by Guba and Lincoln (1989) and Maxwell,(1992), and identified the same categories, patterns and themes that I had.

Fittingness

The study findings fit the data from which they were generated (Beck, 1993, & Sandelowski, 1986). The defined themes were substantiated by data found in the literature.

Limitations

The findings in this study are limited to the participant as defined in the criteria for selection. The subject selection is limited to one mother's experience of a child aged 6 years who has a chronic condition and was hospitalized for an acute episodic problem. The chronic condition is inclusive of physical and cognitive disabilities, and the child had no psychiatric condition that would exclude him from the study.

The selection of this participant was purposive.

Selection was on a voluntary basis therefore limiting generalizability of findings. Sandelowski (1986) states that generalizability should be left for scientific researchers who follow specific criteria to control for variables. The qualitative researcher looks at a particular context. Subjects are purposively selected to provide an emic view of a phenomenon of interest in natural settings that have minimal controls. Lincoln and Guba (1985) state "an investigator can make *no* statements about transferability for his or her findings based solely on data from the studied context alone" (p. 217). However if the findings of the study provide a thick description of data that others find meaningful and applicable in relation to their own experience, this transfer of findings becomes more tenable (Lincoln & Guba, 1985; Sandelowski, 1986), and the individual who uses the research study findings assumes responsibility for generalizing the findings to a subsequent case (Meier & Pugh, 1986).

The methodology utilized was based on a case study design. Based on the committee's recommendations only one case was analyzed because of the richness of data realized. This type of analysis can lead to biases on the part of the researcher even if the researcher carefully controls for it. However, the richness of the data that were obtained from the participant's lived experience can add a wealth of knowledge that would not have been gleaned from a quantitative study.

CHAPTER 4

FINDINGS AND DISCUSSION

This qualitative research study evolved into a case study that looked at a mother's lived experience during an acute episodic hospitalization of a child with a chronic condition. The subject interviewed was a mother of a 6 year old boy who had multiple chronic problems and disabilities and who had an episodic hospitalization within the last year. Data were obtained through three interviews, an observation and field notes recorded by the researcher. Analysis of data was done following the coding method suggested by Bogdan and Biklen (1992). The findings include an introduction, the 15 themes that clustered within six primary categories and the supportive data for each theme.

The findings in this case study were confirmed by the findings in the three other interviews that were analyzed but not used, and were supported by the literature. Overall, the data gleaned confirmed the lack of communication between the mother and health care professionals, the need to implement family centered care, the problems encountered during the transfer of the child from home to hospital and hospital to home, and the impact a child with a chronic condition\disabilities has on family members, especially the mother.

Introduction

All names for persons, places, hospitals and geographic locations were changed in order to maintain anonymity. This was a purposive sample. Since this research was a case study, only one subject was used. The child was cared for in a 500 bed publicly supported tertiary care medical center with a 10 bed pediatric intensive care unit and a 30 bed regular pediatric unit. The units are staffed by registered nurses, licensed practical nurses and nursing assistants. The medical staff consists of pediatric residents and pediatric attendings.

I arrived at the house where I was going to interview Pam Jay, the mother of a 6 year old boy with a chronic condition. The area the home was in was a quiet well groomed residential area so I was quite in awe of the appearance of the subject's house. The yard had broken toys scattered around, the wooden fence was broken in numerous spots, and the door to the main entrance was broken. I walked around the property trying to determine where the entrance to the house was. It took several circlings around before I found what I thought was a means of entry. My initial impression as I wandered around was that I misinterpreted the directions and arrived at an abandoned house. I walked up a few rickety stairs, knocked on the door, and prayed this was the correct house.

I was greeted by the husband who was neatly attired in a suit and tie. I introduced myself. As he led me into the kitchen he told me his wife was upstairs getting ready. I walked through several rooms of clutter. Toys, clothing, and papers were scattered all around. The kitchen had dishes piled up high in the sink and on every available counter space. Laundry was dispersed on chairs as well as dangling out of the laundry basket. Actually every accessible space visible to the naked eye revealed different size piles of assorted items. The chairs surrounding the kitchen table had broken slats and looked very unsturdy. I discretely surveyed the chairs and selected one that looked the least ominous and sat down cautiously. The clutter, untidiness, and disarray depicted a chaotic household. This was definitely a lively household with unrelenting activity.

Mr. Jay said his wife Pam would be down in a few minutes. As he called up to his wife to tell her I was in the kitchen she walked in. Pam came down in her robe and apologized for not being ready, but she had just finished getting all the kids off to school and thought the appointment was for a half hour later. Pam kissed her husband goodbye and wished him a good day as she handed him his attache case.

Pam offered me a cup of coffee, which I declined but told her to please finish her breakfast. She apologized for the disheveled appearance of her home. She explained that with a child with special needs, four other children each having their own individual needs, her part-time job, and her role as a wife tended to make things very difficult and at times untenable. Pam talked a little about how she had hoped her home would have been fixed up by now, but due to extenuating circumstances, time and financial problems, her and her family's dreams are on hold.

As we chatted, I set up the equipment for the first interview. I explained the purpose of the interview and gave her the consent form to sign and the demographic sheet to fill out. I spent more than two hours with Pam, but the interview itself lasted two hours.

Pam is a very pleasant, articulate 39 year old wife of an architect and mother of five children, four boys aged 14, 11, 9 and 6 years, called Bobby, Mark, Tom, and Andy and one daughter Lisa aged 15 years. Pam is a registered nurse who has just recently returned to nursing. She works part-time doing home care cases. She is presently enrolled in inservice courses to update her skills and become familiar with new equipment and technology.

Pam's six year old son Andy has multiple health problems, has been chronically ill since birth, and functions at the level of a 9 month old. He is diagnosed as having microcephaly, cerebral palsy, profound mental retardation, a seizure disorder, and vocal cord paralysis. He has a tracheotomy because of vocal cord paralysis. He requires gastrostomy tube feedings, frequent suctioning, and the administration of oxygen when he becomes apneic and/or cyanotic as a result of aspiration or respiratory infections. He requires constant surveillance and has twenty four hour nursing care. Andy falls within Taylor's (1992) 2% population of children with a severe chronic condition.

"Microcephaly is defined as a head circumference which measures more than three standard deviations below the mean for age and sex" (Haslam, 1996, p. 1681), and the child is frequently mentally retarded. Mental retardation presents with varying degrees of cognitive functioning and adaptive behaviors. A delay in meeting developmental milestones is a cardinal symptom of mental retardation. Additional complications are often found in children with developmental disabilities such as a seizure disorder (Haslam, 1996) which Andy has.

According to Haslam (1996) seizures result from a paroxysmal involuntary disturbance of brain function that can manifest with abnormal motor activity, attacks of altered consciousness, apnea, cyanosis, and a multitude of other clinical features. The vocal cord paralysis, that Andy has, results in regurgitation of fluid, aspiration, and respiratory distress. Chronic aspiration led to recurrent episodes of pneumonia, necessitating a tracheotomy to alleviate the problems encountered by Andy.

Cerebral palsy is often associated with seizures. It is a "non progressive disorder of posture and movement associated with developmental disabilities, mental retardation, speech, vision, hearing, cognitive and behavioral abnormalities and seizures resulting from a defect or lesion of the brain" (Haslam, 1996, p. 1713).

A multidisciplinary approach and an early intervention program that provides educational and therapeutic management is of great importance in the management of children who present with a multitude of chronic problems (Shonkoff, 1996). Andy, who requires 24 hour nursing care, is presently receiving SSI (Supplemental Security Income) and medicaid benefits and is enrolled in an early intervention program that provides him with multidisciplinary services.

Andy's last acute episodic hospitalization was one year ago at age five. He was hospitalized with pneumonia for 21 days in a well known tertiary care hospital affiliated with a medical school.

Andy lives at home with his mother, father, and four other siblings and is cared for by live in nurses. However, Pam considers herself the child's primary caregiver. Andy accompanied by a nurse attends a special school that provides for his special educational and medical needs on a daily basis. Pam maintains a constant vigilance over Andy's education and medical interventions. She has recently had Andy's school switched because she felt the educational curriculum was inadequate and was not helping Andy meet his maximal potential. However, she is not as happy with the medical care and physical therapy provided at the new school.

The first interview went smoothly. Once I asked the lead question information flowed freely. Although Pam leads a very hectic life with almost every minute accounted for, she seemed to enjoy the time we spent together. The interview had taken longer than I intended, and I did not want to take up any more of her precious time so I thanked her and told her I appreciated her willingness to participate in the research study. Pam stated she was glad to be of help and really enjoyed speaking with me. She then recommenced the conversation which clearly demonstrated Pam's anger with the health care system.

She proceeded to tell me how she has to fight for everything she needs for her child in order to make his life better. She wants to help Andy achieve his maximal potential and that's the reason she switched his schools. Pam is incensed that strangers try to determine her son's quality of life. She is his mother, the primary care giver, therefore,the decisions should be hers.

Pam also spoke about the lack of education physicians receive that relates to families with fragile children. She alluded to the fact that physicians and other health care providers view children with disabilities as being very different from "normal" children. They assume disabled children are incapable of increasing their activity and cognitive levels. Pam was adamant in declaring that every child is unique and has the capacity to change. She verbalized that the progression in growth and development is influenced by the child's environment and the physical and mental capacities the child is born with.

This led to a discussion about a unique group of parents who have children with chronic conditions and disabilities. I briefly described that the goal of the group is to educate physicians and other health care workers who provide care for children with chronic conditions and their families. The program has been so enlightening to the medical world that they have been asked to present nationally and provide seminars for physicians and medical students. Pam said she heard someone mention this group before but really wasn't aware of their present activities.

Pam talked about how Andy's illness impacted the rest of the family. She expressed feelings of guilt because Andy's tenuous health often requires her to cancel plans she has with her other children. She also identified how each member of the family reacts towards Andy and how Andy responds to them.

As Pam was walking me to the door she spoke about how all members function as a family. They go out to restaurants and visit the grandparents. Pam stated that she is extremely grateful to her immediate family for all of the support and assistance they offer. Without them life would be unbearable. It was at this point that we said goodbye, and I left.

I called Pam several months after the initial interview to clarify some information (financial, spousal relationship, Andy's prognosis) she previously communicated and to ascertain if she would meet with me again for a follow-up interview. I explained that the members of my dissertation committee suggested I use her and her family as subjects in a case study because of the richness of the information I had gleaned during the first interview. I explained that all names, geographic areas, hospitals, and places that were mentioned would be assigned pseudonyms to maintain anonymity. She gave me permission and agreed to a second interview. We made an appointment for three weeks later because she was going away with her older daughter, and she had some previous commitments that she had to attend to.

The day of the second interview I arrived at Pam Jay's home a little early. Cognizant of the family's hectic schedule in the morning I decided to ride around the area where the family resides to gain a better perspective of the neighborhood. The Jay's home is in a nice quiet residential area that has moderately large private homes with well kept lawns. The house that the Jay's live in was designed by both the husband and wife and built primarily by her husband who is an architect and works in construction at several different places of employment. They started building their home prior to the birth of their child Andy. Once Andy was born completion of the home came to an abrupt stop because of his chronic health problems that severely impacted the family's finances.

I returned to the house at the scheduled time for the second interview. The mother greeted me at the door, and as we walked to the kitchen I met her son Tom who was in the den playing. The house again was in disarray but did not appear as chaotic as it was the first time, although there were still things scattered all over the floors and counter tops. Mom mentioned there was a sleepover party the night before accounting for the multiple blankets and sleeping bags all around in the family room. The kitchen table was neater than it was at the time of my first visit, however, there still were dishes piled up in the sink and a variety of items strewn around.

While I was setting up the tape recorder and microphone to tape the interview Mom and I just started to converse about nursing in general and things that she might like to do to enrich her career. She is a registered nurse who graduated from a diploma school program and has been doing home care nursing because it adapts best with her present schedule. She talked about nursing and her interest in infectious diseases. She discussed her ambivalence about remaining in nursing but in case she did I explained the different programs that were available and the various pathways that she could pursue.

The impromptu conversation continued for 15 minutes. I felt very comfortable, and it appeared that

Pam was very comfortable and at ease. The conversation was free flowing. We talked about her four other children, the jobs they held during the summer to earn extra money for themselves, and the family's financial crises. In order for Andy to remain on Medicaid the family income level must remain at a level designated by the federal and state government. Therefore, if the husband gets a better paying job within one firm and the yearly income increases their son Andy would lose all his required medical services and equipment. Mom works part-time to supplement the income, however, when the home care nurses are not available to care for Andy the responsibility of his care falls on her. She has to cover their shifts because Andy's health care needs necessitate continuous 24 hour care.

Once I started the tape recorder the easy flow of conversation continued. Pam just kept adding more and more information. Originally I told her that I would need about a half hour of her time to obtain some additional data. The interview lasted two hours. I just let Pam continue talking because she was relating significant information. I didn't have to ask many questions. Pam initiated the discussions on the family's financial problems, the many different needs of the family, and the impact of the child's chronic condition on the entire family. She also discussed the relationship with her husband Hal and how he handles his son's chronic condition.

Pam expressed her concerns about Andy's future. She stated that she frequently thinks about who would be the best person(s) to take care of him. She is extremely worried that if something happened to her Andy's care would become her husband's and children's responsibility. Pam felt her husband would become overwhelmed and incapable of dealing with such an enormous responsibility, and she did not want the children to inherit such a burden.

An interesting situation occurred while the interview was in progress. Pam's husband walked in while Pam was talking about their relationship and about support groups. There was a long pause, but I left the tape recorder on. She did not seem comfortable talking about their relationship while he remained in the room with us. Hal had come in to say good-bye to Pam because he was leaving for work. He put his hand on her shoulder and said, "I'll see you tonight". After he said good-bye and Pam heard the front door close she said "I had to stop talking because I just was not comfortable speaking about the relationship in front of my husband; I don't think he would have understood what I was saying". I said that I understood and then Pam continued to speak. I tried to bring the interview to closure several times, but Pam kept reopening the conversation.

After what I thought was the end of the interview Pam's phone rang. I suggested she answer it just in case it was one of her children calling. It was the Vice Principal of the school where her children attend. He was calling about the Special Education Committee that she sits on as a parent of a child who has a chronic condition, which enables Pam to advocate on her son's behalf.

Pam is a permanent member of the committee. The committee is composed of each child's teacher, a psychologist, a school administrator, sometimes the teacher who represents the program that the child is scheduled to attend, and sometimes a social worker. If the child requires the services from a physical therapist, an occupational therapist, or any other ancillary practitioners they will also be invited to attend the meeting.

The child's parent is also granted an invitation to attend the meeting, but Pam said the parents often do not understand why the meeting is being held and are unaware of how to advocate for the services their child requires. Although Pam cannot advocate for the parents themselves, she often acts as an advocate for other children that have special needs and require special services. She said that if certain decisions are made which she doesn't agree with and/or the parent is unhappy with, she can't go and advocate for the services, but she can speak to the parent and tell the parent how to advocate for the benefits that the child needs.

Although Pam is very busy, she does make the time to sit on this committee. She finds it very beneficial to gain insight into how the system functions and to become acquainted with the district leaders. Establishing a presence affords her the opportunity to gain greater access to the people with power when she needs to advocate for her own son and for his needs. She thinks that by being an active participant, the school district members also become more empathetic to her needs.

She is well versed in the legal rights of handicapped children and the services they are entitled to. If a discrepancy does arise during the committee's meeting she can discuss it and help the board members reach a decision. The committee usually meets starting in April when they begin doing the annual review of the children that are currently in the system and those children who are scheduled to enter the system. The committee meets for annual reviews three to four times a month, and it is usually a full day meeting. The rest of the year Pam meets with the committee if a child's special education needs have changed and the child requires different services. These additional meetings are sporadically held when needed.

After we finished discussing the Committee on Special Education I thanked her again for agreeing to participate in this research study. This precipitated a conversation about disabled children and their quality of life. She inferred that she has a hard time when people start judging her child's quality of life and that people do not understand services that children like her son need which results in limiting or complete elimination of services. It's at this point that she becomes infuriated because she has to start the process all over again and fight to get the necessary services reinstated.

In order for her child to receive Medicaid reimbursement and financial aid the family must be on SSI. SSI is based on the child's diagnosis and the financial needs of the family. Once SSI is approved a specific amount of money is allocated on a monthly basis. Intermittently she has to file papers with SSI in order to continue the services. The money is sent to her, and then she distributes the money for the child's services that are needed. She said she has to have an exact accounting of every single penny that she spends, and she has to give reasons for the services that she needs. Pam finds this disconcerting and is upset with the lack of trust that is exhibited by governmental officials.

The Jays do seem to be a cohesive family in spite of all the financial problems they have and the fact that they have four other children to deal with and a son with a multiplicity of chronic problems. The mother does try to spend as much time with the children as possible and strives to get everyone to do things as a family whenever feasible.

I met two of the children, Lisa and Tom, during the first two interviews and spoke a few minutes with each one. They were clean, neatly dressed, and well mannered. I didn't sense any tension between the children, Pam, or the husband Hal during my two visits. Unfortunately, I did not have the opportunity to meet Andy during the first two visits. He was at school both of the days I was at the house.

I realized that I needed to see Andy to verify the data that I had gleaned from the first two interviews. There were also some other sensitive issues such as a DNR directive that I needed to question Pam about that I was not comfortable addressing during the first two interviews. I contacted the mother approximately four months later to ask her if I could make another visit to meet Andy. The day I called Pam sounded relaxed so I asked her if I could interview her over the phone. She agreed immediately. The interview lasted 20 minutes. As the interview was coming to a close I told her that I had never met Andy and was wondering if I could meet him at some point. She said "of course" and I set up an appointment for that same day.

I arrived at the house approximately a half hour after Andy had returned home from his day at school. I found Andy awake positioned on his side in bed. The day nurse was in the process of finishing his gastrostomy tube feeding and repositioning him. We chatted for about ten minutes, and then she was relieved by the evening nurse. Pam was present during the entire time I was there. Pam, the nurses and myself chatted about things in general as the normal activites of the day proceeded. Pam assisted the nurses as care was being provided to Andy. She told me that Andy was not as active that day because he was up the entire night before. Both nurses agreed that he is usually more active and smiles a lot more. In fact, after I was there talking to him and touching him for about an hour, he started to react more to my voice and touch.

He was not irritable while I was there. He did not seem to experience any discomfort when the nurse exercised his legs and arms or performed chest physiotherapy. I was surprised to see how tall and slender Andy was. I had pictured a much smaller and heavier child. His head was smaller than the norm, but larger than I had pictured (he has microcephaly). His eyes deviated towards the right, however he was able to focus on objects for a few seconds. In fact I had brought him a toy that he was able to track, grasp and hold. His head control was that of a two to three month old. He could not sit up by himself but the nurse stated he could roll from his side to his back. He turned his head towards his mother's and nurse's voice, and gave them a smile every so often.

I spent two hours observing the interactions between the nurse, Andy, his mother and three siblings. Each sibling came in at different times to either speak, touch and or kiss their brother. I observed unconditional love between these siblings. In fact the evening nurse had said to me (without any solicitation from me) how much she admired and respected Andy's siblings. They were loving towards him, and the youngest always kissed him on the forehead.

Andy's sister, a junior in high school came in and we started to converse. I had spoken with her about her love for horses the last time I met her, and she updated me on her future college plans. She also spoke about her love for Andy and her resentment towards the strangers that were always in the house. She was especially resentful when new nurses would be assigned to care for Andy, because they often did not know when to provide the family some privacy. Although this resentment exists she said she understood Andy's need for continuous nursing care. After we spoke for about 15 minutes she retreated back into the den with her other two brothers.

The observational visit supported the data I had gleaned from the interviews. Andy functions at a 9 month level and probably will not progress to a much higher level. He requires constant nursing care (ie. suctioning, tracheotomy care, chest PT, stretching exercises, etc.) He did not appear to be in any discomfort. He was not fidgety or irritable. The other siblings appeared happy and treated Andy as part of the family.

During all three visits to the Jay's home, I found the children were well mannered and interacted well with one another. They appeared happy despite the constant intrusion of strangers and having to deal with a sibling that was severely retarded and required continuous care that often took precedence over their needs.

As I reflected back on each of the interviews and my visits to the home it became clear that Pam utilized the interview times as a kind of respite period where she could relax and communicate with someone other than she normally does on a daily basis. It allowed her the freedom to address issues that she may not easily be able to discuss so freely and honestly.

Themes

The thematic analysis of data obtained from the three interviews revealed six primary categories with several themes clustering together under each. A total of 15 themes emerged. Each primary category with its respective cluster of themes is listed below.

Mother/Professional Relationship

Theme 1. The mother wants the health care professionals' approach to be individualized and caring.

Theme 2. The mother/professional relationship evolves slowly.

Theme 3. Health care professionals providing care for the handicapped child require a special understanding and compassion for the child's physical, emotional and psychological needs.

Theme 4. The mother needs the health care professionals to listen to what she relates about her child.

Theme 5. The mother perceives the hospital environment as discordant.

Theme 6. The constancy of nurses within the hospital and home is tantamount to good communication between the mother, nurses, and other health care professionals.

Mother's Ways of Dealing With Stress is Related To The Hospitalization Of Her Child

Theme 7. Mother's ways of dealing with stress is related to how health care professionals perceive her and their expectations of her because she is a nurse.

Theme 8. Mother's ways of dealing with stress is related to her child's environment.

Mother/Child/Family Relationships

Theme 9. While the mother is very perceptive about her child's physical and mental capacities her acceptance of her child's chronic condition is difficult, sporadic, and transpires over time.

Theme 10. As the primary caregiver the mother assumes a multiplicity of roles .

Theme 11. Family relationships are impacted by the child's chronic condition.

Stress Related To Financial Deprivation and Inadequate Services

Theme 12. The family struggles because of insufficient finances, inadequate health care coverage, and constraints placed on the husband's employment opportunites.

Sources Of Support That Are Acceptable And Helpful

Theme 13. A disparity emerges between the mother's and father's vision of supportive relationships.

Theme 14. Respite periods for the mother help decrease her stress levels and allow her some free time to address her own personal needs.

Ethical And Social Policy Issues

Theme 15. Ethical dilemmas and legislative policies confronting the mother.

Discussion of Themes

Following each of the 15 themes, verbatim exemplars are given with page numbers that indicate the place in the subject's transcript (see Appendix F, G & H).

Mother/Professional Relationship

Theme 1. The mother wants the health care professionals' approach to be individualized and caring

Pam voiced her dissatisfaction with the reception she received when her child was hospitalized. She did not feel that the nurses or physicians made any attempt to facilitate her stay with her son Andy. They implied that hospital policy prevented Pam's participation in the care of Andy. The lack of family centered care is apparent in Pam's statement:

> They just don't encourage family participation or families to stay. I don't know why. And the ICU doesn't allow it, so forget it. Some of the nurses say that's the policy .... the doctors will say that's the policy. The nurses say that there are some families that just abuse it .... you can understand that too. But then the hospital should deal with that. That shouldn't affect every family .... I think ... there are times ... families ... come from ... other areas or other countries that have special surgery for their children .... they bring along all their equipment and everything they have, and they bring it in, but that should be dealt with ... on an individual basis. It shouldn't affect every single family that's there. That's not fair to my family, to my child. (p. 312 F)
>
> I just think that parents um...their opinions don't really count. I think that the doctors ... they are here (pointing up) and the parents are here (pointing down) and their ideas and their opinions are gold, and they don't really ask the opinion of the parents. (p. 304 F)

Pam's perception of the non-existence of family centered care is consistent with other study findings in the literature (Algren, 1985; Berman, 1991; Brown & Ritchie, 1990; Coyne, 1995; 1996). According to Algren (1985) and Berman (1991) nurses need to assess the extent of participation the mother wishes to take on. The assessment process should begin with the admission of the child to the hospital unless the timing is inappropriate because of the child's acuity. The literature discusses the incongruencies encountered when nurses claim they welcome family centered nursing but their actions demonstrate otherwise. They really do not comprehend the concept of family centered care (Berman, 1991; Brown & Ritchie (1990). As in Pam's case a parent's presence on the child's unit is not always welcomed. Some nurses complain there is no comfortable space for mothers and that some mothers expect to be catered to. According to Berman (1991) the allocation of specific care activities has often been based on individual nurse's subjective assessments or feelings. The nurses who seem to be more accepting of the mothers are those who are parents themselves and those who are more experienced.

Algren (1985) and Coyne (1995, 1996) confirmed that the majority of mothers like Pam want to participate to some degree in their hospitalized child's care, but they do not want to take over the total care. In their research studies nurses rarely asked the mother about the role she wished to assume. If the nurse did inquire, and the mother wanted to help, appropriate directions were not given to the mothers. Poor communication during times of crises can be very unsettling to a mother causing increased anxiety and distrust of the health care professionals which negatively impacts the development of the mother/professional relationship.

Health care professionals need to communicate that they respect the mother's commitment to her child and provide the necessary information and knowledge that will enable a mother's participation. The mother is very vulnerable at the time of her child's hospitalization and is ultra sensitive to what goes on around her. The nurse needs to become an excellent communicator so that the information provided to the mother is not misconstrued. The mother's interpretation of what is communicated to her will have a long range impact on the mother/professional relationship (Leff, Chan & Walizer, 1989).

Theme 2. The mother/professional relationship evolves slowly.

It has taken approximately five years for the health care professionals to show some concern for Pam's needs during Andy's hospitalizations. It was not until this last episodic hospitalization that Dr. A. felt comfortable performing a procedure while Pam was present. Pam thinks that a contributory factor to understanding Pam's need to become part of the mother/professional relationship was Dr. A.'s previous experience and interactions with her and that Dr. A. became a mother herself. Pam talked about her relationship with the physicians several times.

> This ... hospital experience .... was one of the more positive ones. It has taken ... 5 years for the doctors to get ... to know me and to know him. .... As we were standing in the room, and she (Dr.) was doing her thing with this um--femoral line. I said to her "you know this is the first time that you've allowed me to stay". She said something like "well yeah I guess so". (pp. 315 & 316 F)
>
> This is not Andy's first hospitalization, so this time actually was a better one as far as the

> relationship went with Dr. A. and Dr. B. She actually let me stay when they were putting in a central line and things like that which never happens, never never happens. So I was very surprised. But it has taken me many hospitalizations to get to the point. I thought that it was a major step that she even allowed me to stay. That was really very very good. (p. 315 F)
>
> The positive aspect ... Dr. A. ... did allow me to stay, I didn't get in her way, and it got to be a little bit more personal ..., but it has taken almost six years. (p. 342 F)

Pam's perceptions of her acceptance by health care professionals is supported by Brown and Ritchie's (1990) finding that many nurses discourage mothers from being present while their child is going through a painful procedure because they assume the mothers would become upset. They never ask the mothers what their preference is. Mothers in the Ogilvie (1990) study had a high regard for nurses who clarified perceptions before they made assumptions. Although children who are exposed to multiple painful procedures require the presence of their mother to provide comfort and support

(Leff & Walizer, 1992), the nurses clearly demonstrated their reservations about mothers' participation in technical and medical procedures. On the other hand the nurses did expect the mothers to provide the normal activities such as bathing and feeding (Brown & Ritchie, 1990).

When Pam was ill and unable to visit Andy at the hospital Dr. A. contacted her at home to inform her of Andy's current health status. This action showed greater understanding of her needs and was greatly appreciated by Pam. She said:

> I finally ended up getting the flu very badly .... it's Christmas time, my child is in the hospital for his birthday, Thanksgiving, Christmas, New Years, you know the whole bit. And at that particular time was when Andy was the most acute ... she (physician) did call ... quite a number of times ... she knew she couldn't speak to me because I had 103 fever, so she'd call my husband, and then there would be a 3-way conversation. These are things that she didn't do before, and I don't know if it's because she now has gotten to know us a little bit better, or if it's because she's actually had children of her own, or because

> she has more experience now as a doctor .... you know treating families in an acute setting, I don't know. But that was a much more positive experience, but it didn't happen before. (p. 316F)

Pam was also upset because she thinks health care providers who do not know her assume she is going to react in a non-acceptable manner. She said:

> They are worried about the emotions of the family person, ... they also have this assumption that you are going to overreact to everything because you are in a stressful situation. And that may be true for a lot of people but it's not true for everybody .... I wish that they wouldn't assume .... I resent that they come with that immediate assumption without feeling you out to see how you are ... it has taken a couple of years....dealing with any one of the doctors ... to change that feeling just in myself. (p. 304 F)

In order to establish a mother/professional relationship a mutual respect must develop which takes time. All members of the team have to be willing to become active participants and be commited to the concept of family centered care. When children are critically ill their immediate physiological needs have to be addressed. Once the child is stabilized the mother needs to be included and permitted to assume her parenting role. It is essential that the mother is asked to what degree she wishes to participate. This will help minimize any disruption in the mother/child routines. Excellent communication skills are requisite to building a trusting, collaborative relationship where all members of the team understand one another's expectations. Recognizing parental strengths and further developing the mother's capabilities creates an empowering environment, an environment in which she is not being controlled by others but is in control of what she can and wants to do to help with her child's care (Dunst, Trivette & Deal, 1994; Leff & Walizer, 1992; Rushton, 1990; Shelton & Stepanek, 1994).

Although Pam thinks she has the beginnings of a relationship with Dr. A. she still expresses dissatisfaction with the rest of the health care professionals. She reads their facial expressions and body gestures their true thoughts and feelings about how she might react during her child's hospitalization. Their presuppositions blind them from seeing her as a mother with unique coping mechanisms.

> .... they make a face. It's body expression more than anything else .... They get a little stiff. I don't know they'll make a face, they'll try to encourage you to leave. Well he's really not going to be happy...well I know he's not going to be happy but I'm going to stay anyway. ... these gestures ... that's really the relationship between the physician and the medical staff and the parent anyway. That's the attitude, it's them against me, where it really shouldn't be that way. It should be they're working with me to make my child better. And that's not the feeling that you get for the most part ... You don't get it. (p. 331 F)

Pam's perceptions are consistent with findings in the literature. The development of a mother/professional relationship is based on trust (Perrin & MacLean, 1988; Thorne & Robinson, 1988). A key to successful relationships is when health care professionals and mothers show respect for each other and maintain open communications as they get to know one another (Gibson, 1995). The professionals' verbal and non-verbal actions impact parent and nurse interactions (Price, 1993). Mothers become very attuned to nurses' feelings, beliefs, and attitudes as the professional's behavior is closely observed (Hays & Knox, 1983).

Pam suggested that mothers and health care professionals might be able to develop a better working relationship if they met periodically to discuss pertinent issues. But she was not convinced that this would be a viable solution.

> I always thought that if parents could get together and just speak with physicians in a very informal setting it would be a very ideal thing, but I almost think that it wouldn't work because it would still be them against us. They already have their ideas about how things should be ... they already have their preconceived ideas ... they would feel like we were attacking them ... I think a lot has to do with personalities. (p. 343 F)

Pam's suggestion about mothers sharing experiences is supported by Gibson (1995) and Knox and Hays (1983). In their studies mothers articulated that a true understanding of a situation and a mother's experiences comes from other mothers who find themselves in similar situations and share their experiences (Knox & Hays, 1995). Gibson (1995) found that mothers felt connected when they associated with other mothers in similar situations. As they learned from one another's experience they were able to give as well as receive support.

Theme 3. Health care professionals providing care for the handicapped child require a special understanding and compassion for the child's physical, emotional and psychological needs.

Pam wished health care professionals would take a more in depth history about her child's coping behaviors so that Andy's hospitalizations would be less traumatizing. She expected to see a more caring approach to Andy during necessary therapeutic interventions so that he would be subjected to the least amount of pain and emotional trauma. Pam was upset when medical staff failed to show concern for Andy's feelings. She did perceive the nurses to be more caring than the physicians.

> Every time they take a history.... I wish they could just take it out of the computer. They ask the same questions about birth and up until this time health wise, but they never ask anything as far as day to day living, they never ask that kind

of stuff. They'll ask what he eats, no big deal. And they are so concerned about his nutrition that it drives you crazy. But they don't ask about how he responds to certain things. They never ask things like that. The doctors ... are not interested in that kind of stuff, they're not. So when anybody would approach him face on, he really backs away and it's very distressful to him. So when you approach him you kinda have to come from the side .... and you have to approach him as if you are playing. Make it a pleasant thing. It doesn't have to be my way, but whatever your relationship with him is, you just have to make it play. He has to understand that you are not doing anything bad to him. The nurses will listen, but I don't think doctors listen. You know even if they go to put an IV into him they go over his face. You don't have to be over his face. Your arm can't be there. Because he won't stay relaxed, because you are in his face. He doesn't know you are trying to access his arm or his leg or whatever. If you are near his face he assumes you are going to do something bad to him and he starts flinging himself around so these are the kinds of

> things that they don't listen to, they don't hear. (p. 311 F)
>
> ... especially on the peds floor ... the staff... I think should ... care ... be more concerned about how all of these treatments affect kids and their own psychological feelings about being in a medical setting. If it's not going to be so painful, they are going to get calmer children. Calmer parents and they are going to have more cooperation. (p. 329 F)

Pam's concerns are supported by findings in Gibson's study (1995). Mothers realized that they had to speak on their child's behalf because no one else would. They knew their child best, and they persevered to obtain the best care available for their child. Mothers were often frustrated by physicians and nurses who minimized, negated, or ignored their concerns, especially if there was a change in the child's health status.

The following exemplar reveals Pam's concern with health care professionals who demonstrated a lack of understanding of her handicapped child's needs. She was upset because the health care professionals failed to provide the necessary support services that would maintain the skills Andy had already mastered.

> Doctors only treat acute illness. They make that acute illness okay and then discharge .... when you are dealing with a handicapped child who does not respond the same way that a usual healthy child responds you can't treat them the same way. (p. 308 F)
>
> They (physicians) only see him also when he is acutely ill, they don't see him on a normal basis. On a normal basis he sits up, ... he's active ... responsive ... playful ... very smiley ... enjoys people, social things ... and although he's very handicapped and can't do a whole lot, his personality is very alive .... They ... have assumptions about handicapped children .... When he is in an acute setting and he has an acute illness, all they see is a lump in the bed .... they don't understand that there is more to him .... this is the way they are ... they can't do much more .... so if that's how he looks well that's the way he is anyway. (p. 308 F)
>
> PT would come in...because I had requested it. That's another thing that they don't do. This is a handicapped child. He's already going

> to be so behind and...what happens with handicapped children and especially with Andy is they regress. Instead of just staying where they are they regress ... when they are acutely ill ... you have PT and OT available even if you can only do passive range of motion, don't you think we should put that on the chart right away? You know for whatever the child can tolerate at least he can do that much, and they don't unless I ask. (p. 321 F)

Pam's perceptions were similar to those of Leff and Walizer (1992) who stated that the professional needs to "reflect ... and challenge prejudices and fears concerning a child's appearance" (p. 43). The child with a chronic condition and disabilities is often devalued by the professional who harbors stereotypic attitudes and prejudices concerning these children. Children who are mentally retarded are often approached in a brusque and hurried manner. The health care professional needs to appreciate that these children require more attention, skill, and patience. Every child should be viewed as a unique and valued individual who is an integral member of a family. Health care professionals need to rid themselves of their preconceived ideas and recognize that this special child holds a unique place within the mother's heart. She loves this child as she loves her other children (Leff & Walizer, 1992).

Pam is concerned about the limited knowledge health care professionals conveyed about how the family manages Andy's chronic condition on a continuous 24 hour basis. She is disheartened because the health care providers are concerned mainly with remediating Andy's acute problems. They lack insight into the complexities of her child who has a chronic condition that the family has to learn to deal with. Pam suggested that physicians be required to spend part of their clinical rotation in a home of a child with a chronic condition. This would expose the physician in training to the realities of what Pam and her family have to deal with on a perpetual basis and hopefully sensitize them so they are better prepared for practice after graduation.

In the next exemplars Pam addresses more of the home care issues.

> If he's in such an acute way I'm not going to take him home unless there is nursing care and if they are not able to schedule them then I'm not going

> to take him home until it's set because even though I'm a nurse (pause) it's very difficult, it's very different for me to treat Andy than for me to go out and treat another child, and I have to deal with everybody else in my family and also worry about him. (p. 334 F)
>
> The health care system is now all switching to home care. So they get you in there, ... take care of whatever the acute illness is and then they boot you out the door but nobody's worrying about what happens to children afterwards. (p. 337 F)
>
> The Health Department .... they were trying to change his level of nursing care and the amount of nursing care that he received. They want to change him to LPN care ... I really don't feel that is suitable for him because he has a lot of needs ... and for the most part LPNs are not skilled really to do that .... they also wanted to decrease his hours which would create total havoc here. (p. 350 G)

The discharge of a child from hospital to home has proliferated. It has been determined that home care is less costly compared to institutional care (Kohrman &

Kaufman, 1997). Andy was cared for in a 500 bed publicly supported tertiary care medical center. The hospital has a 10 bed pediatric intensive care unit, and a 30 bed regular pediatric unit. Research has shown that to care for a child in a tertiary care facility costs approximately $150,000 or greater/year. Conversely providing the same therapeutic modalities at home dramatically decreases the cost to approximately $90,000/year (Perrin, 1985). However in Andy's case the medical cost may prove to be greater because of the use of registered nurses. "Paid 24-hour nursing may make home care as expensive as hospital care" (U.S. Congress, OTA, 1987, p.47). If this is the case, it might be more prudent to keep the child in an institution and decrease the amount of money that society is forced to pay through taxed income.

Pam also addresses the need for physicians to become more cognizant of what she experiences on a 24 hour basis.

> I think ... their (physicians) training ... has to change, ... physicians ... have to ... spend time ... have rotations ... at home. Spend a long time with the family and actually take on the care of the child .... Not just go in as an observer, but

> actually be there and care for somebody at home so they can know what it's like if they are going to be treating children .... that are going to be home with disabilities. .... If the physician is more aware of what happens in a true home as they are trained, their decisions .... would involve understanding. They (physicians) don't see him on a healthy basis but if they would try to understand a little bit better what he's like normally then they would understand when I was telling him "no he's not right, no he's not really well enough to go home, no if you send him home I think you have to do something else with him because he's completely not right" I think they would understand that a little bit better. (pp. 336 & 337 F)

Parents like Pam want the therapeutic management of their child to incorporate the chronic and acute needs of the child that enables the child to lead as normal a life as possible. According to Cohen (1995), Gravelle, (1997) and Robinson (1987) parents want to achieve a sense of normalcy in their lives. Unless a professional has "actually lived with and been responsible for a handicapped child, it is probably impossible for them to fully comprehend the 24-hour-a day, 52-week-a-year implication of that child's problems for the rest of the family" (Leff & Walizer, 1992, pp. 29-30). Robinson (1987) found that parents felt that the professionals ignored the child's chronic condition and only focused on the child's acute problems trying to cure or fix it. When Robinson (1987) interviewed parents she found "the parents always began their stories at the beginning of their experiences with chronic illness" (p. 185), and the current hospitalization was discussed as an on going occurrence with the chronic condition. The acute hospitalization was not considered an isolated incidence and therefore was not discussed without regard to previous experiences. This is different from the health care professional's goal of remediating the child's present acute problem.

Theme 4. The mother needs the health care professionals to critically listen to what she relates about her child.

The following exemplars illustrate why Pam became frustrated and angry with the physician's lack of response to her assessment of Andy's physical status which resulted in her child's condition becoming seriously compromised.

> The resident came in the second time she seemed a little bit put off .... I said to her "you know he is desatting, I keep doing chest PT I keep suctioning him, sats are fine right now because I just did it and now you are walking in when they are fine. They keep going down into the 80's. It's not good, his respirations are very very high, his heart rate is going very high," .... he was getting worse and it was happening more frequently, ... and it didn't make a difference. She just assumed that I was another wacko mother who is overreacting to the situation. And she assessed him and that was the end of it, and she went away. The next thing you know, I guess it was the following morning, he wasn't so acute during the night, but I saw it coming, I knew this was coming, but nobody was really listening to me. All of a sudden now and it happened in a flash, all of a sudden his heart rate went way over 200, his respirations were well over 80, and that's when they started calling the code, and his sats were going down, down, down. But why did it have to get to that? Maybe if they had listened to me

he wouldn't be in that situation so badly, so quickly. But they don't listen to you. (p. 319 F)

Sometimes he's crying and all you have to do is vent him, ...but they don't listen to that. And they didn't for quite a while, and they took another chest x-ray, and they saw a monumental amount of air in this chest x-ray that the physicians came in and told the nurses they had to vent him. So it's kind of like these little things that you say like this if they would just do this...but they don't listen .... So they really don't put credence into what you say. So I find that hard. (p. 323 F)

The residents ... they really don't listen. Residents do not listen at all. I kept calling. I called a resident three times in one night, and she probably thought I was nuts, she would come in she would look at him, she only came in twice, she didn't come in the third time. Finally the kid bottoms out so badly that they almost called...they actually did call a respiratory code although he hadn't stopped breathing, and then he wound up in the ICU. This is what makes families crazy. .... They don't listen because he's a

> handicapped kid. (p. 317 F)
>
> I said to the nursing staff and I said to the doctors, "it doesn't have to come to this, I told you he wasn't good and why didn't that doctor come in who was on call and listen to me. It didn't have to come to this". (p. 318 F)
>
> You're stuck with somebody who really already has a preconceived idea of families and they are not going to listen to you and I find that very distressful.... they ... don't ... give credence to what I say. (p. 342 F)

Situations similar to what Pam experienced were also identified by Gibson (1995). She found the mothers knew their child well and were able to detect changes and patterns in their child's functioning because of their empirical and intuitive knowledge. It is usually the mother who first detects a change in her child's behavior because she is so well aware of his normal actions (Ayer, 1978) . Consequently when the health care professionals ignored the mothers' concerns the mothers became very frustrated (Gibson, 1995). "Parental observations become vital sources of information when the sick child has severe communication difficulties" (Leff & Walizer, p. 143) therefore professionals should learn to value a mother's observations and listen carefully to what the mother reports.

In the next exemplar Pam talks about how physicians ignore what she says especially those who do not yet know her.

> I have to say now ... there are physicians that actually know my family and know how I react, they're more apt to listen .... it's the new ones that come along ... they're the ones that are on at night ... the attendings are nowhere around ... the people that know you are nowhere around. You're stuck with somebody who really already has a preconceived idea of families ... they are not going to listen to you ... I find that very distressful. (p. 342 F)

Communication skills such as listening are crucial in decreasing a mother's anxieties and facilitating a mother's comfort in the hospital setting (Ogilvie, 1990). Listening to what a mother has to say is the beginning towards developing a mother/professional partnership (Dunst, Trivette, Davis & Cornwall, 1988; Leff & Walizer, 1992). Mothers in several studies became very frustrated when health care professionals did not listen to what they were saying (Copeland, 1993; Gibson, 1995; Knafl, Breitmayer, Gallo & Zoeller, 1992; Leff, Chan & Walizer, 1989, 1992) and their suggestions were ignored (Gibson, 1995). Brown and Ritchie (1990) found only three out of twenty five nurses stated they listened to what the mothers said. Only one nurse thought mothers did not ask enough questions. The nurses thought it was the mother's responsibility to tell the health care professionals how she was handling the additional responsibilities she assumed as she became an active participant in caring for her child. Stein, Jessop and Reissman (1983) found that 30% of their subjects complained that physicians did not listen, and that the listenening skills of providers still needed to be improved. Careful listening to mother's cues is a skill that Stein and Jessop (1984) think physicians are capable of. However time constraints appear to be a primary obstacle to true dialogue. Hayes and Knox (1983) said mothers need to be encouraged to openly and honestly communicate with nurses. The mothers need to believe that nurses are genuinely prepared to listen to what they have to relate. Open communication between mothers and health care professionals is of primary importance (Hayes & Knox, 1983, 1984; Horner & Rawlins, 1987; Johnson, 1990).

In the exemplars that follow Pam verbalized frustration with health care workers who did not acknowledge her warnings about Andy's deteriorating condition. Pam was also very articulate in expressing frustration with health care providers who did not acknowledge that she knows her child's behavior better than anyone else.

> So okay, pneumonia may have looked like it was resolved, but I'm telling you, he's not okay. I'm telling you he is not fine. But you sent him home anyway and he is back in two weeks. So that's really another thing that was very frustrating.... He was never really fine the two weeks in between. And they discharged him anyway .... although I'm a nurse and although he has nursing care at home, I don't want him home when I know he has pneumonia because I know how bad he gets very quickly. So it's these kinds of things that they don't listen to you about and that's frustrating. (p. 308 F)
>
> I know he recognizes everybody in my house including the nurses, and he responds to people very differently. He knows the difference between

> each one and when there is new people that come in he becomes very quiet and just listens if it's a new nurse or new caregiver. He isn't, he isn't as vocal...as he is when he knows people. (p. 309 F)
>
> I knew he was getting sick and ... she actually did listen to me. This is my child I've known him a long time, I take care of him at home I know him (p. 318 F). .... By the time he needs to be hospitalized he's really, really sick so he's lethargic, so they never see...him healthy and happy and awake. They only see him when he's so sick so then they assume every time they see him that that's the way he is and he's really not that way (p. 310 F).

The mothers in Gibson's study (1995) corroborated the frustrations Pam discussed. The mothers monitored their child's condition constantly and were very cognizant of any changes that occurred. They reported their findings to the physician, and if the physician ignored them, the mothers became frustrated. Physicians often told them they were being over protective and overly concerned which frustrated them even more.

Pam used to be more compliant and less

confrontional with the health care providers because she feared they would retaliate by witholding information and by treating her child poorly. However, she soon realized that she needed to take a more aggressive approach in accessing information, obtaining the needed services for her child, and remaining with Andy during procedures. This is demonstrated by the following exemplars.

> I try very hard to be compliant and to do what they (physicians) want and to listen. I don't think it comes from the other way .... I'm very guarded .... I've learned to be aggressive and assertive .... I used to listen to everything everybody said and I would drag him to every kind of doctor ... everything that they said, I would do ... it's really not in the best interest of your child. (p. 342 F)
>
> If it was a procedure that they were doing and I intended to stay, they are not going to get me out of the room, but if they are doing rounds I just don't want anyone resenting my child. Because then it's like a block. They'll never tell you anything then. They'll never tell you anything, they'll never help you, it will just be

> an attitude thing and I don't want that either, so you have to try to do what's best...for the child involved. So I find that hard. (p. 305 F)

Park (1991) found that initially parents relinquished the care of their child to the professionals because they saw the professionals as the experts. However, the parents soon realized that the professionals were usurping their parental role. Parents' opinions and child care routines were ignored. Parents all verbalized anger and frustration with physicians and nurses because of the lack of respect shown for parents' opinions, as well as ignoring them as a source of information and assistance. Although the parents were angered by this many did not convey their feelings while their child was in the hospital, because they were afraid their child's care would be compromised (Hayes & Knox, 1983; Horner, Rawlins & Giles, 1987; Parker, 1991; Thorne & Robinson, 1988).

Theme 5. The mother perceives the hospital environment as discordant.

Pam communicated that a sense of secrecy permeated the hospital environment. Health care professionals acted in a secretive and aloof manner and ignored what Pam tried to relate about Andy's condition. Pam also verbalized that the health care professionals perceived her a as a threat because she was a nurse, creating an atmosphere of distrust at all levels. This was revealed by Pam as she reflected back on Andy's hospitalization.

> He was in the ICU, and it seems like it is very secretive. People, they don't volunteer information, ...especially when there's rounds and stuff like that, ... I think that they feel threatened by parents, so it almost feels as if it's them against you .... I find it very hard, they ask you to go outside, and my first thought is what are they hiding? (p. 302 F)
>
> This is my child and I feel that I have every right to listen to what they are discussing. This is about my child. You're learning about my child. And so...I should be allowed or permitted to sit there and listen. And maybe I'll learn something about him that you haven't told me. So that's the other thing, I don't think they tell you everything. (p. 304 F)
>
> I heard a couple of things being said about him when I went in afterwards, and I asked and they got very indignant that I had even heard

> that, and they tried not to answer those questions, so ... I always feel like they are hiding something ...they weren't very happy that I heard it anyway and it's about my child ...they make sure the doors are closed. They will try to do rounds when a parent is not around. (p. 305 F)
>
> In the ICU you are pretty much asked to leave. And it's hard you don't want to leave. He's already upset and not in a good way. They don't want you to hear anything that is going on. I really think that's it. (p. 305 F)

The literature confirms what Pam sensed. Communication of information is often inadequate during a child's critical illness. The intensive care unit often creates barriers that stifle communication between the mother and professional care providers (Rushton, 1990). Mothers have perceived that all known information was not given to them, and when inquiries were made about procedures being done on their child the inexperienced provider was unable to provide the needed answers (Burke, Kauffmann, Costello & Dillon, 1991; Robinson, 1987). Visiting hours are often limited, and the mother is asked to leave the child's bedside if procedures need to be done or the child's health status becomes more critical (Chesla, 1996). Chesla and Stannard (1997) found that nurses in ICU avoided interactions with parents at times when the patient was critically ill. They sent parents out of the room and made visitation more restrictive. These actions increased parents' anxieties even more. Nurses who distance themselves through resticted communication and or restricted contact decrease their capacity to provide parents with needed emotional support which confirms what Pam experienced.

Pam intimated that being a nurse was both a hindrance and an advantage depending on how the nurses and physicians perceived her at the time of encounter.

> The nursing staff knows I'm a nurse. The attendings that are there all the time know I'm a nurse, so if a resident comes in he will find out or she will find out that I'm a nurse so the approach is then a little different. Sometimes it's positive, but a lot of times it's very negative. They become more secretive (p. 319 F). .... they really really don't tell you anything then. They don't volunteer anything because they know that you know a lot more than a regular parent does, and they can't snow you, and they

> can't put you off. So I try very hard not to say anything and if its new residents I don't. But it gets around .... that I'm a nurse. (p. 319 F)

According to Ayer (1978) when the mother is a professional health care provider nurses may perceive the mother as being a "critical, knowledgeable observer of nursing activities and may magnify parents' reactions out of proportion" (p. 110). They may also feel threatened, and they may make erroneous assumptions that the mother wants to be actively involved with her child's care. The mother's desire to participate in providing care should not be expected just because she has health care experience.

Burke, Kauffmann, Costello and Dillon (1991) identified hazardous secrets as a consistent theme emerging from their study. These hazardous secrets were broken down into three different categories, one of which was information of a negative nature. During their child's hospitalization mothers felt they did not receive all the information that was available concerning their child's condition, diagnosis and treatments. Breakdowns in communication often are a result of the continually changing staff that becomes even more heightened in a teaching facility (Ferraro &

Longo, 1985) such as the one where Pam's child was hospitalized. Continous open communication during a child's hospitalization is a mother's expectation, and when it fails a mother's stress is increased, and the dissonance between the mother and health care professionals escalates (Hays & Knox, 1983; 1984).

Pam found the hospital environment was not at all family centered. Provisions were not made to accommodate her staying with her hospitalized child. She found the health care providers rude. They frequently came into the room to perform a function and never acknowledged her presence. She stated that she thought it would be beneficial to nurses to have inservice classes to better understand family centered nursing.

> The chair situation is another story. Um, you are lucky if you get a chair. ... I'm sitting on the radiator and things like ... there are no accommodations there. There's no comfortable chairs, you'd get ... some old rickety old chair and if you ever did get a comfortable chair some resident would come in and get it, swipe it from you (p. 315 F).
>
> There really is no facilities. The cafeteria

> closes by 8 o'clock. .... There's no way to get coffee anywhere. They make no accommodations for you at all. .... so they really don't want you, they really don't encourage it. And I don't really understand that. I find the need to stay with him, he's my child, he's in a very scary setting, and I don't get in the way, and I leave when I have to leave; so why can't I stay? They just don't make it comfortable at all. I find that very very frustrating. (p. 313 F)

Coyne (1995) found that all the mothers that were active participants in their child's care expressed dissatisfaction with the hospital accommodations. There was a lack of bathroom facilities, places to eat, and no where to rest which supports what Pam found. Pam also talked about the lack of respect and rudeness she encountered.

> The resident never introduced himself, just started working on my child, and I stopped him and said "you didn't tell me who you were". ... I think that is very rude.... It happens all the time people come in and they do not introduce themselves, and I'm the parent and this is my child, and you want me to have trust in who you

> are, but I don't even know who you are. I don't know what you're doing here and what you plan on doing to my son. You know he is still mine, and I still give consent.... You're already in a stressful situation and I shouldn't have to ask. (p. 306 F)
>
> If nurses had inservices ... relating to ... issues like working more closely with the family and understanding a baby, a child, is not just a child that's ... the ... patient, you really have the family to deal with. If they understood that a little bit better they could deal more effectively with parent's anxieties, and parents could work better with the staff .... I don't think nurses are kind of aware that sometimes they just fly in and fly out, but that's very stressful. (p. 338 F)

Chesla and Stannard (1997) and Chesla (1996) found that many nurses were educationally deficient in family nursing and therefore were unable to respond appropriately when parents demonstrated increased anxiety and anger in response to their child's increasing deterioration. The authors also found that the more experienced nurses tended to be able to develop a better mother/nurse relationship.

Darbyshire (1994) explored the lived experience of parents who "lived in" with their hospitalized child. He found that the nurses' and parents' accounts of participation lacked a true "sense of involvement, reciprocity, and mutuality" (p. 208). Mothers did not have an acceptable amount of control over their child's life or their own. They did not truly dialogue with the nurses or demonstrate that they felt their participation in their child's care was worthwhile or valuable other than being helpful to the nurses. The nurses stated that the mother's participation impacted upon their sense of professional identity. They recognized the importance of a mother/professional relationship, however they also recognized that the relationship could diminish their sense of self. Conversely, there were some mothers who felt valued and worthwhile and found the experience meaningful (Darbyshire, 1994).

Robinson (1986) also found mothers thought their involvement was directed by the health care providers who seemed to take into consideration their own needs first. The mothers' involvement was hindered "by the 'life' of a busy acute hospital, with multiple caregivers oriented to meeting personal learning needs, fixing a problem, and discharging the patient" (Robinson, 1987). The mothers eventually effected change by becoming assertive (Robinson, 1987), which is what Pam said she did in order to get the care that Andy needed.

In the following exemplar Pam states she wants the nurses to increase her knowledge base through education so that she can remain an active participant in her child's care.

> Just explain how it has to be done .... a nurse that's very good at teaching can come in and show the parent directly how to ... do the whole thing the first time. And then the second time around let the parent do it. .... They would have so much more cooperation from the child and from the family. (pp. 329 & 330 F)

The study by Perkins (1993) found that parents with greater knowledge about their child's care became more involved and more willing to take on increased child care responsibilities. This was also affirmed by Berman (1991), Haas and Gray (1992) and Robinson (1987). Parents acknowledged the importance of having information provided in clear simple terms that was easily comprehended (Kirschbaum, 1990). Gibson (1995) found mothers needed information that kept them informed of their child's health status, projected plan of care with rationale, and how they could become active participants. The parents feel empowered as their knowledge base increases (Gibson, 1995; Gravelle, 1997) and believe they are doing everything possible for their child (Copeland, 1993).

Theme 6. The constancy of nurses within the hospital and home is tantamount to good communication between the mother, nurses, and other health care professionals.

The following exemplar demonstrates Pam's wish for continuity of nursing care at home. Pam is upset when she has to train the new people who come into her home because it is time consuming and infringes on valuable time that she can be utilizing for other important projects. She does not want self employed nurses to care for Andy because it becomes her responsibility to train them and make sure they are providing Andy with the appropriate care. This necessitates that she be around and available all the time. This defeats the purpose of having a nurse for Andy.

Nurses who have ... a Medicaid provider number ...

> can bill directly so they really are self-employed. .... they don't have a supervisor ... checking up on their work or checking nursing notes or making sure they are doing all the treatments Andy needs ... I can't do that all the time. Why would I have somebody here if I have to be in there the whole time making sure they are doing what they are supposed to do. .... They come in probably the first time when they are on, and the nurse that's going off will give them a little background, and then it is up to me. I do all the training. People come in here sometimes they don't know much about Andy at all. Sometimes it is just hard, people come into your home, they don't know where anything is, they don't know anything about your child .... So as long as their skills are okay ... and ... they have a little bit of common sense ... it's not so hard ... otherwise it doesn't work as well. (pp.355 & 356 G)

According to the United States Congress Office of Technology Assessment (U.S. Congress OTA) (1987) home care is considered more effective than hospital care in promoting the psychological and emotional well being of the child. However paying for registered nurse coverage on a 24 hour basis can be as costly as hospital care. The availability of services, especially professional nursing skills, is crucial to the effectiveness of home care. There is great variability in home health care providers. One of the problems encountered with home care is that third party payers place restrictions on the activities that nurses with different levels of credentials can provide. There are some home health care agencies that specialize in caring for a child with high technological needs. This however is the exception more than the norm and this creates problems (U.S. Congress OTA, 1987) as was verified by Pam.

A child like Andy who is technology dependent and cared for at home can require full or part time presence of nurses in the home who can provide the complex nursing care. Strangers are now going in and out of the home which families often find intrusive. These specialized needs require extensive coordination of services and financial resources. There is also a need for a back up care giver when a home care nurse is not available which is usually a family member who has been taught how to perform the various procedures. Even when there are other nurses providing care in the home in most instances the mother or another family member assumes total responsibility for the child part of the day (Bonds, Phillips & Rollins, 1994; Leff & Walizer, 1992). This is exactly what Pam talked about.

Pam verbalized that better communication between the hospital staff and her would develop if the same group of nurses took care of Andy during his hospitalization. She talked about the lack of communication amongst staff members involved in Andy's care. She stated that some nurses do talk with her, but information shared is rarely communicated to others. Pam, being a nurse herself, understands the existing problems, ie. staff shortage, however the role of mother becomes her most important priority when her child is ill. The need for better communication among staff is illustrated in the following exemplars.

> ... for the most part they (nurses) really try to be very helpful and try to answer your questions.... It's an acute care setting so they don't follow ... my son, sometimes not even the same ones take care of him everyday.... I think that's hard ... you would like to have one person take care of him but they all take their rounds. They aren't able to always answer specific

questions.... for the most part they're willing to try to give you any answers. In the ICU only, there's always somebody available. On the regular pediatric ward... it's terrible. (pp. 306 & 307 F)

I really don't think that they (nurses) do (communicate to physicians). I don't think that they are ... that comfortable either with it. (p. 311 F)

The nurses .... care for him, ... give him baths and ... get to be more personal. .... nurses come in to do a procedure .... they ... pretty much will.... talk to you and tell you what they are going to do.... Sometimes ... I will have to ask. But it's not always. I guess it depends upon the individual. If I tell something to a nurse ... taking care of Andy on 7-3 it doesn't necessarily reach the next shift or the shift after .... they don't pass it along .... so I find that ... lack of communication sometimes ... a little difficult ... They also deal with the clinical part of it, they don't really always remember the stuff that to them is not quite as important. (p. 323 F)

You (nurses) have to remember that there is a

> family there too and you need to spend some time and not only the first nurse that sees you but it has to be all the nurses that take care of him. So that's another thing. The first nurse will talk to you and get a wonderful history even if it doesn't include everything that you need, but it (history) never follows through to the people behind her, it never does. (p. 338 F)

A mother acts as the child's protector and advocate "in the bureaucratic health care system of changing shifts, multiple personnel and inconsistent caregivers" (Leff & Walizer, 1992, p. 152). The acute care model does not provide the professional with the necessary knowledge needed to render the appropriate care for a child with a chronic condition and disabilities. Effective communication between staff and between staff and the mother does not always occur (Lynn, 1986; Robinson & Thorne, 1984), and often fails to address the needs of other family members such as the mother (Leff & Walizer, 1992). According to Thorne and Robinson (1988) they found that mothers developed a feeling of distrust and disenchantment for the health care providers. This prevented the mothers from actively advocating for their child because they were afraid of alienating the staff (Leff & Walizer, 1992) and thought they might place their child in jeopardy when they were not around (Leff & Walizer, 1992; Thorne & Robinson, 1988).

Mother's Ways of Dealing With Stress is Related to the Hospitalization of Her Child

Theme 7. Mother's ways of dealing with stress is related to how health care professionals perceive her and their expectations of her because she is a nurse.

Pam expressed resentment toward health care professionals who assumed because she was a nurse she would provide the nursing care for Andy. Pam verbalized that she tried to monitor her emotions so that the health care professionals would not think her behavior was irrational. However she often found it difficult to control her self actions as she reacted to the countless stresses of her child's hospitalization.

> If they're doing...beds and changes like that, a lot of times I'll do that. Sometimes they'll even leave a mess there which I don't think is so hot, because they know I'm a nurse. I'll do it, because I know what's in the thing and it's labeled, but legally they're not supposed to do that. But that's what they do. (p. 324 F)

As far as suctioning and chest PT I have to do it, because they don't do it. I resent it, yeah I do. I do it at home, and ... it's fine ... it's my child, and I do it, but I don't think that I should be the sole person doing it in the hospital because who's assessing him then. (p. 324 F)

Negotiations between mothers and nurses need to take place to determine the extent of care the mother wants to provide for her child. Even if the mother is a nurse the staff needs to speak with the mother to determine how active a participant she wishes to be (Ayer, 1978). Coyne (1995), Evans (1994), and Knafl (1988), found that mothers expected to take over the usual care giving activities that they normally perform at home. If the child required a more technical procedure that the mother was unfamiliar with she was willing to do the procedure as long as she received all the necessary information and instruction. The converse was found by Gibson (1995). Mothers preferred to entrust the more technical procedures to the health care professionals. Although the mothers did not want total control they wanted to be kept fully informed of what was happening. They also wanted the professionals to acknowledge their suggestions, abilities, and skills in caring for their child. This finding was similar to what Pam wanted.

Pam talked about her relationship with the physicians:

> My approach to the physicians isn't always as good as I want it to be. Because I'm so stressed out, and I have such anxiety that I'm already mad that it's this way. ... what I find also very stressful is that I always have to be aware of how they are perceiving me. I cannot just have emotions. I have to be very controlled. Because if I'm not controlled then their (physicians) assumption of me is going to be true, ... she's a nut and she overreacts, and then they really won't listen to you. So when you are already in a stressful situation and your child is already sick you have to be very guarded on how you approach anyway. And... that's extremely frustrating because you can't always be very... calm when your child is sick...and you can't always be, I don't know, you are trying not to be aggressive, but you

> wind up being aggressive and... that's not good either .... I try to be assertive, but when you are in a very acute situation you don't have control over your emotions all the time, that's why sometimes it turns aggressive when they are not listening to you which has a negative affect. (p. 326 F)

According to Rushton (1990) strong emotions often emerge when a child is critically ill and hospitalized. Professionals need to monitor their responses to a mother's behaviors they consider inappropriate and recognize that they may be the target of the parent's emotions and fears. Strategies for assessing parental stress need to be utilized by health care professionals to determine the mother's perception of her child's condition and the experience of the hospitalization. Mothers should be assisted in evaluating their response to their child's hospitalization. Assumptions about the parents' state of mind should be avoided. The health care professional should observe the mother's behavior and then validate the findings with the mother. Disparities between the mother's and professional's perspective may surface and should be addressed within a supportive environment. Open communication and dialoguing can alleviate misunderstandings before they reach the crisis stage (Rushton, 1990).

Theme 8. Mother's ways of dealing with stress is related to her child's environment.

Pam described her uneasiness concerning safety issues especially when she was unable to remain at Andy's bedside and her need to rush back to him. Pam also stated that she felt more secure when Andy was cared for in the pediatric intensive care unit rather than on the general pediatric unit because he was more closely observed.

> You can't leave your child. I wouldn't leave anybody there. There is not enough staff.... but ... experiences ... lead me to feel the way I feel .... He was four .... he had been in there for uncontrolled seizures ... on a regular pediatric floor ... in an isolated room .... a handicapped child, he can't call out, he can't even express his needs ... he was in a mist tent in an isolated room right up the hall from the nurses' station. I went out and told them that I was going to go downstairs and grab a cup of tea. I went downstairs, got the tea, brought it back upstairs,

> he was in an uncontrolled seizure in the bed, and the plastic bag from the mist tent was wrapped around his head .... actually he had even turned himself upside down in the bed .... his head was now at the bottom of the bed, his mist tent was around his head, and there was nobody there, and the monitors were going off. Nobody is available. Now that's not good, that's not good at all. I mean something could have happened to him. (p. 307 F)
>
> There are times the alarms will go off and nobody will go in because nobody hears it because there is nobody out on the floor. There's nobody there. I don't think that he's safe. I really don't think that he's safe there on a regular floor. When he's on a regular acute floor there isn't anybody there and the anxiety that I have, like I go home and do whatever I have to do right away, and either I make sure somebody's going to get there or I try to fly back. (p. 325 F)

In a study by Burke, Kauffmann, Costello and Dillon (1991) vigilance was one of the actions by a mother when she found her child was unattended and in need of help during her absence. She decided that she would never leave the child's bedside again the same as Pam.

The next set of exemplars elucidates how adamant Pam was about keeping Andy as pain free as possible. When a procedure had to be done she became very assertive. Pam took control and clearly stated who she would and would not allow to perform a procedure on Andy that she knew would cause him pain. She also insisted on staying with Andy while the procedure was done.

> They are going to do to your child whatever they want to when you're not there .... if they are having a hard time doing a stick or whatever and you are not there to say no stop or get somebody else. So that I find hard. (p. 306 F)
>
> I get aggressive and then they wonder what's wrong with me. Almost ... anything that I get angry about is because it causes pain to my son. I don't usually get angry... about anything else. But if it's causing pain to him and they are not listening to me and I know that they could change it...then I become very aggressive, very angry. I feel that if they need to start any kind of a line or draw any kind of blood they should get somebody

that is very very experienced with children who have very poor veins. And Andy has been stuck so many times that of course his veins are not the greatest anymore. And I tell them that from the start, and I don't feel that they listen to me at all. This is not a doll, this is not a piece of meat, this is my child. And you're causing him pain. So if you are not skilled at doing this go get somebody else. Go practice on your own kid. You know that's how I feel, and they don't listen. And so I've become very very aggressive for me, and I'm not a lunatic (laughs). .... that's it, stop! You know you have to stop, now go get somebody, ... I would learn names and say "no, no get this person, I don't care what floor they're on, I don't care where they're working. And I don't care if the person resents it I don't care, this is my child, and I know I don't want him stuck 100 times, so you go get that person who has had numerous successes". And I think they really have to respect that, especially in peds. And adults can tell you to stop, but a child can't and a handicapped child. That's not right, so that I find extremely frustrating. And it is a teaching

> hospital, and they need experience. But don't practice on mine when you know that he is going to give you a hard time. So that's something that I find extremely difficult ... (pp. 327 & 328 F)

The literature is in agreement with what Pam has so clearly explicated. Callery (1997) found that instead of mothers leaving their child during an unpleasant procedure some mothers were willing to actively participate during the painful procedure so that they could be supportive to their child. The findings by Coyne (1995) were the same. Chesla (1996) observed that the parent was often asked to leave when a painful procedure was to be performed. Burke, Kauffmann, Costello and Dillon (1991) found that the mother experiences distress when she watches an inexperienced care provider who is incapable of performing a procedure. The mother who finally insists that they get someone else is often perceived as a trouble maker when she stops or interferes with a procedure that is being attempted (Burke et al. 1991). In Gibson's study (1995) mothers felt compelled to advocate for their child because their child depended on them for care.

Mother/Child/Family Relationships

Theme 9. While the Mother is very perceptive about her child's physical and mental capacities, her acceptance of her child's chronic condition is difficult, sporadic, and transpires over time.

Pam experiences periodic recurrences of grief related feelings known as chronic sorrow. According to Eakes, Burke and Hainsworth (1988), chronic sorrow has been defined "as the periodic recurrence of permanent, pervasive sadness or other grief-related feelings associated with ongoing disparity resulting from a loss experience" (p. 180) such as the loss of a 'perfect' child. There are periods of happiness interspersed so the grief does not become incapacitating (Eakes et al.).

Pam talked about how she slowly came to the realization that Andy had serious problems and that he would be handicapped for the rest of his life. She also pointed out that she does not dwell on his problems and tries to maintain a sense of normalcy when he is not experiencing problems or is being clinically evaluated. This is revealed by Pam in the following exemplars.

I took him over to *Airy*, ... I forget which

> hospital, I didn't want to see anybody here because I figured there's a network ... I just wanted a completely different opinion. .... so I took him to a neurologist over there, ... The physician in *Airy* .... said that he was microcephalic .... the very next day when we came back he had a severe seizure where he was apneic for ten minutes, and we were bagging him at home so that's when we really knew, ... that's when it was clinically evident. .... So then from there we started to deal with the fact that he was going to be handicapped, and I think that the good thing for me was that it was a slow thing; I didn't find all of these things out all at once, although you know there is something wrong ... it didn't have to smack me ... right up front. This is it; this is how it's going to be. And as he has gotten older you just kind of accept that this is the way it is. As a baby you don't know how handicapped he is gonna be...but as he is older now and he is not meeting any of the milestones and he is probably really at the level of a nine month old at best, ... it's been hard. (pp. 359 & 360 G)

By the time he was four months old ... I realized that there was something wrong with him; he is my fifth child ... he wasn't responding the same way the others did .... he was in the NICU for a month after he was born, and the professionals were saying maybe it's because he was so long ... in the institution, but ... that wasn't really what it was. I couldn't put my finger on it, but I knew he wasn't the same as the other kids. .... He was born in December, he came home the beginning of February ... that ... was really stressful ... they sent him home on monitors and an oximeter, and they thought he would do just fine, and when he got home it was terrible because he couldn't do anything without being in any kind of distress. If he slept he was fine, but as babies get older they don't sleep that much anymore. He couldn't eat, he couldn't cry, you couldn't do anything with him, but he would be crying and getting very cyanotic so it was a vicious cycle. I held him all the time, and ...he wasn't thriving at all; he wasn't really able to gain weight; he wasn't able to suck on a bottle, all of those kind of things, and I even suspected at the time that he was having some kind

> of seizure problem because he just wasn't behaving the right way, and there would be times that he made these very distinctive kind of cries and throw out his arms and things like that. (pp. 357-358 G)
>
> There are times that you really have to think about it and face the fact that he is so handicapped; that's when it's difficult but you don't think like that every day. You know if he is sick and you have to deal with sickness and illness, that makes it hard. When he is in school and they have to do their reports and you have to listen to where he's at you know very clinically, that makes it very difficult, but on a day to day basis, Andy is just Andy, so that's how you deal with it. (p. 360 G)

Gibson (1995) found mothers experienced many different feelings as they realized the gravity of their child's condition. However they still held out hope that their child's condition would improve. According to Leff and Walizer (1992)

> hope is addressing the child's problem with courage, energy, and faith within oneself. For parents, hope embodies the belief, the conviction

> that their love, care, and hard work will help; will help build the best possible life for their child in need .... hope sustains parents as they create a new life for themselves and their child ... as they heal. Professionals who nurture hope leave parents with a lifeline (p. 104).

Although Pam is fully cognizant of her son's limitations she still demonstrates an appreciation of hope as she carries out her daily responsibilities. Pam freely spoke about Andy's physical and cognitive status. She stated that he has probably reached his milestones but still hopes that he can develop the ability to maintain a sitting position. His medical status has become more stable, and Pam has learned how to prevent frequent respiratory crises and thus to avoid frequent hospitalizations. The following exemplars demonstrate this.

> Andy's medical condition ... since birth .... has become a lot more stable within the last year, and he's a lot more healthy then he was .... But his diagnosis has not changed. He is not going to get any better. He is just the way he is. So ... it is just a matter of keeping him infection free. I mean I think his biggest problem would actually be

> respiratory because first of all he has a trach ... the fact that he is immobile, he is very prone to respiratory infections .... that is our biggest concern really. ... He's been pretty healthy, and he has not really gotten too many infections, and we started him on Intal four times a day, and so his respiratory problems have not been as severe as, say, they were a year ago ... when he does get some kind of a cold. If Albuterol nebulizer treatments don't cut it then we start with Prelone, so that's been a big help. That has kept him out of the hospital actually this year which is a great thing. He had an infection .... and he was very very sick but he was able to stay home, and I think it had to do with the Prelone that he was started on. .... he didn't get any worse, and so that was a good thing. We have oxygen and everything else here. (pp. 356-357 G)
>
> He doesn't even play like a nine month old; he's so limited physically ... he responds to visual, toys that have lights and sounds and noise. He has no self-care skills and no mobility skills or anything like that. He's very very limited. ... He can manipulate toys that are

> close to him, but he doesn't have the strength to reach out for too long and things like that. He doesn't walk or crawl or do any of those kinds of things at all. His trunk and head control are not as good as I wish they were .... My basic goal for him, ... I would love to see ... that he could sit up without falling over and I don't even mean to sit, I mean just to put him in a sitting position not even that he get there himself. (pp. 362 & 364 G)
>
> He has a wheelchair ... and there is a tray on it, and he has a prone stander. .... he has something called an advancement chair which has a lot of supports, and as he gets stronger and is able to do things and hold himself more we take more of the supports away....so he is doing very well with those kinds of things. For short periods of times we can take away a shoulder harness, and he is able to hold himself up a little bit; so that's good. Even with the prone stander he can tolerate lengths of time in it, which is a nice thing. (p. 364 G)

A child's diagnosis of a chronic and disabling condition is an overwhelming experience for a mother.

It is a time of intense emotional reaction and disequilibrium (Leff & Walizer, 1992). Nurses should not assume that there is a specific time period that is considered the norm for acceptance of a child's diagnosis. In a study done by Copeland (1993) parents stated that they actually surmised something was seriously wrong with their child before they were given a definitive diagnosis. For many it took a long time before they were able to accept that their child had a chronic condition. "Learning to accept and to understand the diagnosis is a gradual process for parents, and nurses should not assume acceptance is forthcoming after a month or two" (Copeland, 1993, p. 53) it takes an unspecified amount of time to comprehend the severity of the diagnosis. Sensitivity to a mother's adjustment period is crucial (Copeland, 1993).

In the next set of exemplars Pam provides insight into her worries about Andy's future. Pam expressed concern about how and where Andy would be cared for later on in life especially if something happened to her.

> ... plans for the future ... We think about it but there isn't any local place at this point. I mean

we have looked that far. People will ask me...what will happen with Andy. .... as he gets older; I don't know what's going to happen with him. But for now we are able to deal with it at home. I don't want him in a facility right now, there aren't any that I would choose to put him in and know that he would be cared for ... in the way I want him to be cared for; so that makes it hard too. I can't even say what's going to happen with him for next year, but at this point in our lives he's home .... He needs the stimulation of home and family .... that's the only plan that I have right now. (p. 361 G)

I worry about Andy because if I am not here or if something happens to me, what is really going to happen to him? .... If something happened to the both of us I would probably wind up asking my sister to take care of him ... with a network of people. There would have to be somebody, one person legally responsible. And I know that she ... would get what he needs. And she would make sure that he was taken care of. She feels as strongly about him as if he were her own; so I know that somebody would care for him if both of us weren't around, but if only one of us wasn't around, like if it was me not around, I don't know how Hal (husband) would deal with it. I think he would just tune out...When he is stressed out or things are overwhelming he just doesn't deal with it. (p. 367 G)

This particular nurse ... who is my friend, ... would be very helpful, ... she would be very supportive of my sister. So those kinds of things I don't have to worry about if both of us aren't here, but if only one of us wasn't here and it was me, then I think that I would worry. I would worry because he (husband) is clueless, he really is clueless. He doesn't know or understand the amount of time and effort that has to do with Andy. (p. 368 G)

If I wasn't as aware as I am he wouldn't be having needs met that he should have met or goals worked on that should be worked on. You have to make sure...that they have an educational plan, and you have to make sure that people are doing that because as good as some people are, some people are not .... I don't think that Hal would know a good nurse from a bad nurse. And that

> wouldn't help Andy. I don't want somebody just sitting and leaving him like a lump, not giving him medical attention that he needs, and you also need somebody who also likes him. (p. 368 G)
>
> If they take away some ... medical needs that SSI and Medicare is supplying for Andy .... the consequences of that would be very stressful on our family, financially and emotionally ... so it is something that we keep trying to push off and hope doesn't happen. The thing that would affect us the most is ... if they took ... away the nursing care. .... I have thought about it, it's probably not realistic, but I have thought about it, and I would just have to be the one to care for him. I would not at this point put him any place. I could not deal with that, I would have too much guilt. He is a part of our family, and we do love him, and I don't think that anybody right now would be very happy placing him somewhere and not being with him ... (p. 362 G)

The above exemplars demonstrate Pam's concern for Andy's future. She has discussed the possibility of having her sister take over. However the future is so unpredictable that she knows that she needs to think about other possibilities. She is not confident about her husband being able to handle Andy's care and she does not want to burden her children. According to Rose and Thomas (1987) the future of severely disabled children weigh heavily on the minds of parents. As the parents age they worry about who will provide the necesssary care for their child should they become ill and/or die. In our transient society family members can be scattered all over and are either unable or unwilling to accept the responsibility of caring for a child with a severe chronic condition and physical disabilities. Worrying about a child's immediate and future quality of life is a constant strain that is physically taxing and mentally wearing (Worthington, 1992).

Pam said that her other children have shown an increasing concern for their brother's future care as they have matured and gained a better perspective of their brother's chronic condition. This is illustrated in the exemplar that follows.

> As the older ones are getting older they start asking questions about the future and what's going to be with Andy .... they have those concerns too and I think it's very stressful for them when Andy

> is sick. .... If I take him to the doctors .... for regular check-ups .... they begin to get a little nervous....what's wrong, where are you going .... So they get worried, they are concerned about his future and how we are going to deal with that. (p. 360 G)

According to Leff and Walizer (1992) the worry and pain that siblings experience is often not recognized by professionals and/or the family. Siblings of a child with serious health problems often harbor fears, anger, and feelings of guilt. These children need compassion, understanding, and concern shown for their fears, anger and guilt. Health care professionals should never underestimate how traumatized these siblings may feel. Siblings should be encouraged to join their own support groups where they can communicate with other children experiencing similar feelings. These support groups can provide "guidance, and information...to well or non-disabled children coping with many confusing and ambivalent feelings toward sick or handicapped brothers or sisters" (Leff & Walizer, 1992, p. 229).

Theme 10. As the primary caregiver the mother assumes a multiplicity of roles.

In the exemplars that follow Pam discussed the many roles she has to assume. She is the primary caregiver for Andy necessitating that she keep fully abreast of Andy's health status and therapeutic management and school activities. She must remain acutely aware of all legislation that impacts the services Andy requires and must prepare all the paper work which at times she finds overwhelming. Pam also works part-time to help provide for family necessities. Pam expressed resentment toward her husband because of the passive role he seems to have chosen. She becomes especially resentful when she is faced with increasingly more stress. However, Pam also said that she generally does not ask her husband for help because he is usually working and not around.

> Nobody is able to care for him....other than me; so there really isn't anybody I could leave him with unless I have a nurse (p. 354 G). I do most of the care for Andy. Everything is pretty much up to me ... dad has a hard time, I think, dealing with that. If there is any discussion he would probably defer to me anyway and what I wanted. So basically all of Andy's needs and ... care really falls on me. I have the whole load; I carry the whole load by myself. It's stressful, it's

extremely stressful. You know I really don't know if he can deal with it. I have never left Andy for a real length of time with him, and I don't think that he would be able to deal with it if Andy had a problem. ... when he's uncomfortable and he's crying it could be pretty severe, and he becomes cyanotic .... I don't think that he can really deal with Andy .... so ... basically all the responsibility is mine (p. 352 G). He'll (husband) come up with me .... to Corner Hospital .... but he won't stay by himself. (p. 357 G)

My husband's salary is not what keeps us going, and although he works full-time what he makes is no where near what he used to make or what I could make if I worked full-time. And so I think that is frustrating for him .... Knowing even financially when I work, that's what keeps us going .... And the fact that he has to rely on me actually even to work makes it hard for him .... because that's not where he thought we would be at this point .... not that it is a conscious thing but sometimes I think ... sometimes there is resentment over the whole situation. .... Sometimes I am frustrated and sometimes I'm sad

> about it. You know it makes things for me, another responsibility that I have. (p. 352 G)
>
> If I said "you need to help me fill these forms" he could do that .... I guess if I asked for it; he would be able to give help, but I don't know if he can give the emotional support for what I need towards Andy. He doesn't know how to be supportive in that way. He doesn't know how to help out. And a lot of it has to do with the fact that he's mostly not here (pp. 366 & 369 G).

The literature supports what Pam verbalized about her relationship with her husband. Gibson (1995) found mothers to be the primary care givers, therefore the fathers' confidence and expertise in dealing with the child's chronic condition did not develop proportionately with those of the mothers. Mothers expressed frustration because their husbands often refused to listen to them vent about their concerns or their inner most feelings. The lack of support from their spouses made the mothers feel they had to face their problems alone.

When Pam becomes overwhelmed her stress level increases, and she becomes frustrated and angered which is illustrated in the following exemplar.

> When I am dealing with a lot of stress I get angry. On a day to day basis it's OK, but when I have a lot of stress and a lot of appointments or if I am fighting over a piece of equipment and I have to deal with Medicaid or today I have to sit and fill out SSI forms, like I am so sick of it, and I wish that I had a little bit more help. I find that extremely stressful especially....when I'm overwhelmed that I just can't go somewhere; I don't have the luxury. So that....I find it very hard that way. (p. 366 G)

A mother with a child who has continuous health care needs often finds she is over burdened with an enormous amount of paper work that has to be filled out and filed in order to receive financial assistance, equipment, and a variety of other services that will provide for her child's needs. Ongoing therapy progams, school evaluations and conferences, work schedules, attending to other children's needs, marital responsibilities, and the desire to maintain the normal rhythms of family life can become overpowering, causing the mother to feel isolated and alone (Leff & Walizer, 1992).

Theme 11. Family relationships are impacted by the child's chronic condition.

Pam was very open about how Andy's chronic condition has affected her marital relationship.

> As far as Andy goes, I don't talk too much to Hal .... I kind of keep my own feelings to myself on that score (p. 365 G). Very very rarely .... spend time alone with husband .... Very rarely so that's difficult too. We have a friend who is going to give us a week in *the country* in the beginning of August. They have a cabin up there so we are going to take the four older children, Andy is not going to be able to come. So that will give us time alone. (p. 354 G)

A resilient family has good communication skills. They are able to openly express their feelings, discuss their fears about the future, and resolve conflicts about role allocation with other members of the family. They are also able to share positive feelings of caring and commitment (Patterson, 1991). Family resilence is enhanced when families develop realistic expectations and flexible routines (Ferraro & Longo, 1985; Patterson, 1991). Pam and her family do try to go away on a vacation at least once a year without Andy. This helps them get reacquainted and spend quality time together. It is also a time when Pam and her husband can have some time alone.

Pam continued to talk about her husband.

> Hal ... kind of doesn't ever really think about ... the future or what is going to become of Andy or anything like that, and if I have those worries he is not the one that I would talk to about it because I don't think that he can even deal with it yet. (p. 366 G)
>
> I know he loves him, but he could never take care of him if I was not here; I don't know what would happen to Andy (p. 366 G). He tries to be supportive but he doesn't really know how. ... I don't think that he really realizes how much he is not supportive, and I don't think that I could even get it through to him. (p. 367 G)
>
> You know you have your ups and downs ... in a marriage ... and we have had some stressful things about other things...building this house and all that kind of stuff. He just tunes it out. .... He doesn't deal with it. .... that's how he deals with stress; so I don't know how he would deal with Andy, and I would worry that he wouldn't get

what he needs. And I don't even think that Hal realizes how much time and effort I put into getting Andy what he needs and making sure that he is taken care of because he takes things for granted. (p. 368 G)

Even with our financial situation, I need to go back to work, I need to work, but who does all of this when I am not here? That's when I start to get angry. I need to sit here and block a time and fill out forms again which I am sick of, and if I don't fill them out they'll be after me, they're already after me; because I have already put them off. I really have to fill them out, but it's that kind of thing. I have gone to fair hearings for equipment that he needs; I am fighting with the agencies all the time because they're not supportive in a way that I think that they should be. If a shift isn't covered, well, oh well, it's like what are you doing to recruit nurses, you are not doing a whole lot. And I know they are not. So it is always these things. And if I don't have a nurse life stops, and that has happened quite a lot in the last couple of months. You know I have had to cancel things that I would have liked to do or the kids would have liked to do because I haven't had someone to be able to be with Andy. So it is very stressful. I don't think he (husband) would even know how to, he doesn't know how to be supportive in that way. He doesn't know how to help out. And a lot of it has to do with the fact that he's mostly not here. You know most of the time he is not here at this point in the day, and he's gone all day, and he doesn't deal with the doctor appointments or the school situations or going up to the CSE committees where you go up to the school and that's when they plan Andy's care, and he doesn't have to deal with the agencies and trying to make sure there is coverage. He only worries that there is. If there isn't, he doesn't have to deal with it. So I think that part of it, ... time that he's not here, ... I seem to be the one who juggles everything around, and if I work I work night shifts. .... I am really miserable the next day. So... I kinda think that's hard too. I think that it is not fair, but I don't know how to change it. (p. 369 G)

The marital relationship can become strained as the demands of the child's chronic condition increases, the ability to discuss the child's problems becomes compromised, and there is a lack of support for one another . A dysfunctional relationship can develop when the mother assumes the entire responsibility of the child's care (Drotar, Crawford & Bush, 1984; Patterson, 1991; Worthington, 1992) which disrupts optimal family functioning (Patterson, 1991).

Pam also spoke about financial problems which is supported by Worthington (1992) who said families who have children with special needs usually encounter financial problems even if they have health insurance. Children with special needs require a lot of costly medical care, and as a result their families find it difficult to maintain their previous standard of living.

In the exemplars that follow Pam discussed the impact of Andy's chronicity on the rest of the family. She spoke about the lack of privacy and the family's, (especially the other children's) restricted activities. These restrictions often precipitated resentment and feelings of guilt.

> I can't deal with my other children, you know, with their needs at all if I am taking care of

Andy. His needs come first and he has a lot of needs. ... I can't just put him in the car to take kids to soccer games; I just can't do that. I can't bring them anywhere. He's basically home, and he goes to school. He is not able to really go out visiting or doing any of that, and even if we do go to Grandmas we lug oxygen and suction machines and all that kind of stuff. So... everyone else's life would be completely restricted because I would not be available. (p. 349 G)

I don't think that we ever sat down .... as a family .... to discuss Andy's condition .... but there has been times that I have needed to talk to ... the older kids ... about Andy because my daughter and my son who are almost 15 and 16, ... they're at that adolescent age, and ... things revolve around them at this age. .... they are both restricted in a lot of things. And they do have to...if they are going to do anything extra they have to earn it themselves, and that's the way it is. They don't have the things that other people have. They don't go out and buy new clothes every season; things that are important to a kid; they just don't do that. They don't go to camp, and they don't go away. I mean they go to basketball camp. My daughter is earning money so she just started giving herself riding lessons again, but they don't get that, from us, and I guess they see other kids that, you know, are able to do things. We don't go away; we don't do things like that; so I... think resentment comes...with that. And then they also feel guilty about that. So um... that's what I think they find difficult. (p. 353 G)

They also resent people in the house. ... The nurses that are here are of great help, and they know that if they weren't here, I'd be really restricted. It is also there's someone here all the time. .... There isn't the privacy that other people have, and we are fortunate because the people who do care for Andy have been here a long time, and they kind of go well with the flow of the family, and they kinda do know when to disappear, when to be around. Um and we never exclude anybody. ... Andy is part of our family. ... his bedroom is in our living room, and there is no way he is stuck in there .... I want him to

> be out among the rest of us...but there is always someone extra here. So...I think they resent that. (p. 353 G)

Pam's concerns are supported by the literature. When a child receives home care services there is an increased risk that families will become disempowered. Families are subject to a lack of privacy and loss of family routines because of the constant invasion of home health care providers. Professional attitudes are critical to empowering families. The quality of the family/professional relationship affects the family's adaptation process. A relationship that has developed with mutual respect, information sharing, and collaborative decision making helps the family become empowered. Family empowerment is also enhanced by the family who has developed competency in caring for their child and has maintained the integrity of the family boundaries (Patterson, 1991; Patterson, Jernell, Leonard & Titus 1994).

In the next set of exemplars Pam talked about the emotional and financial strain experienced by the family and the lack of understanding and support received from the professionals she encountered.

> It's almost like we have two sets of family. We

have us and the four children and then we have Andy (p. 354 G). A child like Andy affects the entire family and it is very, very stressful emotionally on everybody, and it's financially difficult so it just affects the whole family structure in a lot of ways. You need a lot of support...and... sometimes you don't know how to get it. (p. 364 G) The stress is on... the family and on your relationship when it comes to dealing with Andy. ... I think that you find out things ... accidentally, like support things that you really could have used a while ago; you find things out accidentally through other people. It would be nice if professionals knew a little bit more .... were more aware of things that are available .... that these families have ... such a need. .... if they could understand that it is really a difficult thing, especially these Medicaid nurses that come in from the Health Department, they really don't understand. They really don't understand what your life is like. ... if they could understand, they would have a very different outlook on families. ... If we never had the help that we had..., I don't know if

> my kids would be doing as well in school, ... if Hal and I would have even stayed together .... that's something that you don't even like to think about, ... and I... think that we have a good marriage. (pp. 364-365 G)
>
> Our whole family, although it is difficult as it is, ... if we never had the help we have ... it would be much, much more difficult. I really don't think that we would survive as a family. I really don't. That's how I feel at this point. (p. 365 G)

Mothers and professional health care providers are concerned with providing the child with the best care possible. However their approaches differ. The professional places emphasis on the disease process, disability, and therapeutic interventions. Conversely the mother focuses on the emotional and physical well being of the child (Leff & Walizer, 1992).

Pam explained the guilt she experiences because she does not have the time to spend with her other children and be supportive in their time of need. Conceptually she understands the reason, but emotionally she has difficulty dealing with the guilt.

> ... when you're involved in an admission it

affects everybody else in the family which then affects me. You know you're not there for the concerts. My daughter remembers it to this year. Like today she said to me, "next week is the high school concert" and um I didn't go last year, and I didn't go because Andy was in the hospital, and she still remembers you (mom) weren't there. She understands it logically. She understands why, but emotionally she can't. ... She's 15, that's the golden age where everything is narcissistic anyway. And... she's not being selfish ... she just remembers that somebody else had to take her. And I'm always there, I've been always there, but I couldn't be then, and so those are the things that affect everybody else at home. You know they come home from school, and nobody's there, or they have to go to the neighbor or whatever, and okay it works for the time but it still affects them (p. 339 F). ... they also worry, because they knew he was very sick last year. Anytime I take him to the doctors now they ask me is he going to the hospital. ... just ... a GI follow-up and they're worried he's going to be sick. So I don't only have to deal with this child that's sick and the people that are in my home 24 hours a day, I also have the other kids. It's very stressful, it's extremely stressful, and... I don't know how I deal with it. Sometimes I think that I don't deal with it very well at all. (p. 339 F)

I think ... the 15 year old is beginning .... resenting people in my home. She loves all the nurses, but she wants them out of here. .... Andy takes an awful lot of my time, and even though I have nursing at home he still takes a lot of my time which is above and beyond any other child who would be normal. So of course I think that she's angry with him and feeling guilty about that. You know it's the whole thing, and I think it affects all the other kids. My nine year old is not as mature as I think a nine year old should be. ... I think that he got cheated. That's the only term that I can use. He got cheated out of being a little guy because he was only two when Andy was born, and Mom wasn't there ... I know that I can't change that...but does it make me feel guilty? Yeah it does. Does it make me angry if Andy wasn't the way he was? Sure it does. It's the way it is, and I can deal with that, but those

> feelings come up every now and then you know what are you going to do; you know that's the way it is. (p. 340 F)

"The diagnosis of chronic illness or disability is one of those crisis events that challenges families' adaptive capabilities" (Patterson, 1991, p. 491). These families are faced with unique challenges that elicit a family's effective coping mechanisms to help them adapt. If they are successful at adapting then they will succeed in handling their problems. A family who has the ability to recover from adversity and adapt to change is a resilient family (Patterson, 1991).

According to Thomas (1990) each family has its own repetoire of coping mechanisms that they have previously used. These are coping strategies that they implement when faced with a crises. These coping strategies may not be effective and may not be recognized by the health care professionals as useful. However the family's reaction to stress demonstrates that they are aware that they need to take some kind of action to meet the present challenge that confronts them. Sometimes the health care professional does not recognize how effective the stategies implemented by the family are. "Family coping is always a sign of strength regardless of the success of the activity" (Thomas, 1990, p. 246). When the coping mechanisms are unsuccessful the health care provider needs to help the family select different ones.

Stress Related to Financial Deprivation and Inadequate Services

Theme 12. The family struggles because of insufficient finances, inadequate health care coverage, and constraints placed on the husband's employment opportunities.

The following exemplars are illustrative of the extreme financial problems Pam and her family are continually facing. Pam states that her husband isn't employed full time. Actually he works the equivalent of full time, but not for one employer resulting in lack of health insurance for the entire family.

> He (husband) is not employed full-time .... You know the way he works now is very very changed so our income has drastically been reduced. ... for him to take .... a full-time job where the salary was much better .... wouldn't be worthwhile because that would bring our income above the level that Medicaid would allow...with SSI. Andy would be covered by an insurance company but not

for the things that he needs. So we would be in a worse situation for Andy that way. He wouldn't be eligible for Medicaid plus the insurance company wouldn't cover his needs. .... he's very handicapped. ... He's total care, total needs .... so there is a lot of medical equipment, there's a lot of doctor visits, a lot of medications. ... He's constant care, all the entire time somebody is here. He needs 24 hour nursing care. ... If he wasn't under Medicare right now .... basically nothing would be covered, nothing at all I don't think. We would have to pay everything out of pocket. (pp. 348-349 G)

I am applying for .... Children's health insurance so the other kids will have it. I think that they are even covered until 19 .... The state sponsors it and certain health companies pick it up. We (Spouses) access the Health Center ... that's how we deal with .... insurance .... the fee for visits is on a sliding scale. (p. 347 G)

Financial matters when it deals with Andy .... It's very stressful. You know,... actually right now we are in a very stressful situation because we have no money at this point. We have less than no money. We are like trying to scramble around to pay the bills, and all we did was shuffle them last night, and... it's really difficult because if I worked full-time that would be a wonderful thing, but I can't because of Andy, there's lots of time that there isn't coverage, and I probably couldn't handle the stress of it, and the other part is... if you made too much money then you wouldn't have Medicaid anymore, and so we are actually between, you know, a rock and a hard place is really what we are between. He doesn't have private insurance anymore, and he could get private insurance but he would ... still ... not be ... covered ... for pre-existing .... So he could have insurance, but it wouldn't really do us any good. So he has to stay on Medicaid, and the only way for him to stay on Medicaid is to have it through SSI. And then SSI bases his eligibility on what our income is and assets; so it's never an easy thing. It is really quite stressful, quite hard (pp. 345-346 G). We have a family of seven and so .... So you struggle, you struggle, you struggle. It's not how we started. Everything is affected when you have a child with

> disabilities....And it didn't even start out this way.... we both were working, ... we had insurance. ... the company that we had the insurance through ... went bankrupt ... that's when Andy lost his insurance ... so .... he would be covered by a company that my husband worked for, but because he has no insurance, they don't have to pick him up. So...so that's the hard thing. If he didn't have insurance .... That would mean that I would not be able to go to work at all because I would be, you know, the total caregiver. ... that would even make financial situations around here a whole lot worse. (p. 349 G)

Gravelle (1997) found that many mothers expressed resentment and frustration when they assumed the role of primary caregiver. They had to continually rearrange their daily schedules in order to meet the extensive needs of their children. The father's involvement was often constrained because of employment or lack of desire to become involved (Gibson, 1995).

One of the major impacts of chronic illness is the financial burden that families experience. The time that is required to care for a child with a chronic condition diminishes the time the mother can devote to outside employment. According to Perrin and MacClean (1988) families are also faced with increased out of pocket cost, potential loss of health insurance benefits, and limited job mobility and advancement, which is true in Pam's case. Many families such as Pam's find themselves without health insurance either due to the child's preexisting condition or governmental stipulations that state a family can only earn a certain amount of money in order to be eligible for health care provided by the state and federal government. The amount of earned income is severely reduced for Pam's family because they receive supplemental insurance from governmental agencies for Andy's health care. The rest of the members of the family have no health insurance because of the bureaucratic rules and regulations that exist.

The child who is technology-dependent places an enormous financial burden on the family. Unless the family has adequate private insurance and/or governmental assistance, the family's financial resources can be severely reduced or completely exhausted within a short period of time. Adequate financing for the health care and home care of these children is dependent on the type of private insurance the child has and whether or not it covers long-term care at home, the availability of public health care programs and the coverage supplied, and whether the home care benefits are able to cover the medical needs of the child (U.S. Congress OTA, 1987).

The federal and state governments offer a wide variety of programs and services available for technology-dependent children. However, the eligibility criteria, covered services, and payment mechanisms for Medicaid vary tremendously across states. Many states do not publicize the availability of programs, some have very confusing rules and regulations, and others practice restrictions that limit the use of these programs for technology-dependent children (U.S. Congress OTA, 1987). Pam is well versed in the availability of federal and state funding and is extremely frustrated with the demands placed upon her to demonstrate that Andy meets the mandated criteria.

The following exemplars reveal the distrust that Pam has for health department nurses who make the decisions concerning Andy's care. She thinks her nursing background affects the allocation of nursing coverage and is angry that the needs of the rest of the family are not taken into consideration.

> The Health Department sends two nurses to make some kind of an assessment. It is very stressful when they come because they act as if they are your best friend, but in the meantime they're not. You learn that the hard way ... anything you say they are writing down. .... they talked for hours about Andy's needs, and then they left and told me they were switching everything to LPN. Now Andy had RNs and they were trying to decrease his hours, and it was just amazing because of all the things that we said. I was just totally stunned. And they also said things like it doesn't matter what the needs of the rest of your family are; it doesn't matter at all. All they hear are what Andy's needs are. And in reality Andy has all of those needs for all of this care...because if nobody was there to take care of him he wouldn't survive. So yes, he has to have care 24 hours a day whether it's me or somebody else, but the care is needed. And I also think that they take the fact that I am a registered nurse and it's like on one hand they use it to their advantage. They will say things like everything that we assess

> Andy for is only based on Andy, but in the meantime they also know that I am a nurse, so they use that; they assess his needs based on what I can do which really isn't fair. It's all used to their advantage. ... So I am very guarded when they come. They try to show up at your door just unannounced. They just come and knock on the door and expect to be let in which I don't allow. They even said to me things like ... "Well we're Medicaid, we're the people that supply the nursing care for your son", and I in return said ... "Well I didn't realize that Medicaid took away my right to privacy so you will have to make an appointment to come". And I don't allow them to see him at school, and I don't allow them to see him when I'm not around. I want to know when they are here, and I want to know everything that they ask and exactly what they do. ... I never was an untrusting person, but I am now I guess. I have become cynical. I don't trust anything or anybody when it comes to Medicaid or the Health Department. So that's a shame too. It's really not supposed to be that way. (pp. 350-351 G)

Pam also discussed the financial impact on her other children.

> She takes riding lessons, she works and does this on her own, ... she earns her own money and takes these lessons .... Right now she is working in Carvel but she also works with horses, cleaning up yucky stuff. She'll do anything, baby sitting, anything to just have a little extra money. Bobby is trying to get some kind of job at the beaches ... trying to hustle to have a little extra spending money. .... The camps ... they go to .... they actually pay themselves. They have to pay for the camps at school .... fifty dollars for two weeks. So that's not bad .... and they pay it out of their own money .... That's the way it is around this place. If they want to do it, they have to, cause we can't. No, there's no way. (p. 345 G)

In the next exemplars Pam verbalized how she advocated for Medicaid services and addressed the importance of having professionals advocate for the family.

> You can go to Medicaid ... to a fair hearing ... where you can dispute any changes that they're trying to make. ... I have done that too for a lot

of things, and when I started applying for a fair hearing because they were changing the level of his care that's when they decided to leave it alone. (p. 351 G)

... there were two of them (hospital discharge planners) at the time but we of course got the other one that I didn't want. The other one I just don't think that she's organized at all .... I would rather just do it myself. You wind up being your own case manager, your own discharge planner. So I wound up really having to do for myself. Paula ... the first nurse ... I think as a discharge planner she's very good ... she's unfavorable with all the physicians there, but she understands on a family basis what you need. You need an advocate for the patient. You don't need somebody that's going to bow to the physicians just because it's easier. You know even when she wasn't on Andy's case, ... she sought me out anyway and asked if things were okay. ... I guess after so much time ... you begin to know somebody. So... that's the kind of person you need, and I don't think that makes her have friends there... but for my needs it's better. ... I don't think

> she's there to meet the physicians needs; she's a discharge planner; she's there to meet the needs of the patient. ... she would advocate for Andy there. (pp. 333 & 334 F)

Gravelle (1997) stated that continuously having to negotiate with the bureaucracy for their child's needed services was extremely frustrating and exhausting for the mothers in the study. Many of them expressed frustration and anger with the way services were allocated. They expressed appreciation towards the health care providers who provided information that helped them negotiate and attain needed services.

Quality nursing care as described by parents in a study by Price (1993) "involves a process of parent and child interaction with the nurse that leads to the establishment of a positive relationship and ultimately results in the satisfaction of the biophysical needs of the parent and child" (p. 40). In Pam's case she viewed Paula as a true advocate for her child and for her own needs.

In the following exemplars Pam dialogued about the family's dream of a new home and how that came to an abrupt standstill when Andy was born. She also talked about someday being able to resume construction and decorating their dream home.

> The house is a disaster so that bothers me too, but there is nothing I can do about it. I can only do just so much. ... When Andy was born the entire place came to a standstill ... we are still doing it, slowly, but financially you need to be able to buy supplies....so that is a difficult thing too. .... Hal of course made the designs and the layout work and everything, and the only thing that we had somebody do is the foundation and the framework. ... we basically done the whole thing ourselves. We started it when we only had two children... so it has been a long, long time, and then everything was going smoothly until Andy came along, and that kind of put a squash on a lot of things. We did it ourselves to save money and to have what we wanted, the way we wanted, and once you have kids you don't have as much time. ... but things came to a standstill when Andy was born. ... I think that is a stress to my husband because ... I guess men look at things a lot differently than women, and well that's not supposed to be this way. This is not where I wanted to be. I wanted the house finished or I wanted to be in a

> financial situation that is different so it's hard. (p. 370 G)

Children with a chronic condition and/or disabilities who receive home care have caused changes in the parents'roles and have given them increased responsbilities (Ray & Ritchie, 1993). Although utilizing family members to provide care can substantially decrease monetary costs, it can be costly to the stability of the family structure. The family can be negatively impacted because there is lost income as a result of being unable to work, lack of leisure time, lack of time together as a family, disruption of the marital relationship, and inability to provide quality time for other children (U.S. Congress OTA, 1987) .

The next exemplars describe the inadequacies of the home care services. The home care agencies could not provide the necessary support that might have prevented Andy's hospitalization.

> There is a lack of support services available for the child being cared for in the home. Another difficulty was the second admission ... I was hoping not to have to admit him, and nobody anywhere could get IVs started at home which was

what we were trying to do. The agencies can't help you quick enough, what good is it if nobody can do it when you need it! So if we could have gotten IVs started at home he might not have gotten so bad, but it couldn't happen, so he had to be admitted anyway. So I find that hard. He just kept getting worse and I just finally said it isn't going to happen, I know we are going to wind up admitting him and then he was admitted .... I guess because the delay was longer than it could have been; then by the next day he was really sick .... they say all of these services are available but they're not, they're not there when you need them. (pp. 334 & 335 F)

The home care agencies, I don't really think that they had an IV team at the time ... if they did it wasn't available, you need it acutely, I need it now, ... they weren't willing to let the nurses here do it even though they have IV experience and they have also been ICU nurses ... they weren't willing to do that .... I think it always boils down to either money or liability, and in the meantime the kid in the middle ... is stuck, so I think the agency is worried about

> liability ... if these are all concerns then they should have this all set up to begin with you know it shouldn't all come to light when a patient needs something. (p. 336 F)

"Home health and nursing care agencies should be made aware that a person's experience in dealing with technology-dependent children in an intensive care unit in a hospital does not necessarily guarantee expertise delivering that care in the home setting, and vice versa" (Beckett, 1989, p. 112). Standards and guidelines need to be established and carefully monitored by qualified state agencies with expertise in monitoring home care for chronically ill and disabled children. Individuals sent into a child's home need to receive appropriate training and education that will enable them to provide quality nursing care deemed necessary for the child (Beckett, 1989; Bonds, Phillips & Rollins, 1994).

Sources of Support That Are Acceptable And Helpful

Theme 13. A disparity emerges between the mother and father's vision of supportive relationships.

Pam explicated why she turned to friends for support rather than support groups. She also discussed how difficult it was for her husband to seek support from others.

> I have friends that I can say things to and actually even some of the nurses here who have been here for years and years and years, they're here. They wind up being part of the family when they are here for their eight hours, so a lot of times I can express how I feel to them. And it just helps to be able to say things and ... to get somebody who is really not part of your family but can see into it, they can give you an outlook which is very helpful sometimes. In the community I have a lot of friends too ... they can be very supportive, and that's good. My family is far, ... I don't have them right next door to be able to talk to, but they are very supportive too. I used to try to go to support groups, but I find that they are not what I need .... I need the positive stuff, and sometimes people start talking too negatively, and I just couldn't deal with that. And I tried a few different kinds of support groups. There is a neighbor ... she has a child with disabilities ... she's supportive too. So ... we get it, we get the support that we need when we need it. (p. 366 G)

Pam did not find the support groups beneficial. Although she needs to talk to someone about her experiences she did not find that participating in groups fulfilled her needs. She did not want to hear about other mothers' problems. Since Pam's daily schedule is so fully packed she wants to spend time with people that have a positive outlook on life and are uplifting. However she did experience comfort from talking with a neighbor who is a mother of a child with a chronic condition and with other families she has met who have similar situations. She probably would seek out family members more if they lived closer. Pam's perspective of support groups are not always supported in the literature.

According to Perrin and MacLean (1988) mothers who participated in support groups often gained additional knowledge that enabled them to meet the many challenges they face. The group also provided a place for mothers to share feelings and recognize that there are many other mothers experiencing similar emotions and problems (Perrin & MacLean, 1988). Mothers in Gibson's (1995) study experienced a real sense of connection and felt understood through their association with other mothers. Some of the parents in Copeland's study

(1993) stated the best support for them was obtained from families that were dealing with the same situations. These parents realized they were not alone, and their feelings were validated by others who were in the same situation (Copeland, 1993).

While Pam did find support for herself her husband sought support only from her.

> Hal would not go to a support group, that's something that he would never do, and I don't know if I have met a lot of men that would do that. It's not something that they would do. They kind of keep their feelings inside. And so I think women are more apt to find support. That's why I feel women are active. I would go out and find somebody, but my husband would never do that. He keeps it to himself, and if he says anything at all he says it to me. And you know I think that that's hard; I don't know to deal with that or even what to do about that. Sometimes I think that he would benefit....from talking to people who maybe have similar things going on, but men don't talk about feelings. (p. 372 G)

Copeland (1993) found that fathers utilized support groups far less than mothers which correlates with what Pam stated.

In the following exemplars Pam explained why she would rather seek support from friends and relatives rather than from designated support groups.

> Families do need some kind of support, and I'm fortunate because I have a very supportive family. My husband's and my family and I also have a lot of support through friends and through people that I know here. I usually have a lot of help, I do. So I can't complain in that respect, but it still gets to you sometimes. It still gets to you (p. 339 F). There are parents that I will interact with. Not on a steady basis .... to have like ... a support group. There was no professional person ... a lot of times they get to be pity parties ... I can't deal with that .... I would rather speak with somebody that has same kind of ... difficulties ... sometimes that in itself is a help, and maybe I'll have an idea, or she'll have an idea for me, but I can't wallow in that, I can't I don't have time for it, and it doesn't help me. What helps ... somebody is positive or trying to be positive .... even though you have all these problems .... that's the kind of person

> that I can deal with .... I've gone to a number of support groups that have psychologists ... you're very guarded in what you say ... you always feel like it's them against you ... so we tried to do it ... with families just mothers, and sometimes that doesn't work either. What'll happen is...one family will resent, like they think they have it harder than another.... that's no good. Everybody has their own problems, no matter how I perceive them, mine are mine, and theirs are theirs. You wind up ... finding families that have children with disabilities whether you meet them at the doctor's office or you meet them through schools or things like that, and you wind up having the same physicians that's who you form relationships with. (pp. 341 & 342 F)

Copeland (1993) found that some families did not always find support from their extended families. One parent said when she asked her mother for help her mother told her it was her problem and offered no support at all. Another family stated they did not even bother to tell members of their extended family. Copeland's findings are not consistent with the findings in this study in respect to extended family support. Pam's family members are very supportive.

Theme 14. Respite periods for the mother help decrease her stress levels and allow her some free time to address her own personal needs.

Respite periods for Pam were provided by home care nurses and by a friend. Pam discussed how important it is that respite is provided for her during Andy's hospitalizations.

> Sometimes I have to leave him alone. I have high anxiety over that. Not particularly when he's in the ICU because he's hooked up to every kind of monitor. I'm treating these last two admissions pretty much the same because they were just so close, and the very last one I was solely in the ICU, I could leave comfortably because I knew that there was always somebody there, and he was hooked up to so many things, and if an alarm goes off there is somebody there. When he's on a regular acute floor there isn't anybody there, and the anxiety that I have, like I go home and do whatever I have to do right away, and either I make sure somebody's going to get there, or I try to fly back, because I don't think that he's safe. (p. 325 F) I was basically the only one .... that

stayed with him when he was on the regular unit, but I would get breaks. (p. 357 G)

Each day I would take care of what I had to deal with at home. I have 5 children as you know, get everybody off to school, I'd go in probably by 10, and I would stay well into the night. I would leave maybe 1 or 2 in the morning. .... And that was pretty much every day. And if I couldn't be there then someone else would be there. ... And of course this was Christmas also. Christmas season that I had to deal with getting gifts for my other children, finish dealing with that kind of stuff. So there were times that I couldn't stay, so I would have somebody else go in. And that I have to say was something that was good about...this admission. If I let the nursing staff know and they would relate it to I guess to the resident or the attending on. It didn't necessarily have to be my immediate family. Nurses that cared for Andy were able to stay with him. They didn't do the nursing duties that Corner nurses are responsible for. But they could stay with him and be with him because that was somebody he recognized...I also have a friend who is a nurse,

> and she sometimes will go up with him...if I am not there depending on her own work schedule and things like that. (p. 357 G)
>
> Very very rarely spend ... time alone ... with husband. Very rarely so that's difficult too. We have a friend who is going to give us a week in New Hampshire in the beginning of August. They have a cabin up there, so we are going to take the four older children. .... So that will give us time alone. .... they need a week of normal, you know being a family without all the stress from Andy. (p. 354 G)

Respite care is a concern of most mothers, and many express dissatisfaction with the lack of it which is often associated with the inability of finding qualified persons (Perrin & MacLean, 1988). Pam discussed how the home care nurses would come up to the hospital so she could get some time to herself.

Parents in a study by Gravelle (1997) also discussed the relevance of respite care and the importance of having a qualified, competent person provide the needed care for the child in their absence. In order for respite care to be beneficial, the health care provider must be aware of the child's illness trajectory so that respite care accommodates the mother's diverse needs as well as the child's (Gravelle, 1997).

Ethical And Social Policy Issues

Theme 15. Ethical dilemmas and legislative policies confronting the mother.

In the following exemplars Pam speaks about Andy's resuscitation during his delivery and her thoughts about future DNR directives.

> He was very blue and not breathing. He had to be resuscitated ....The nurses were having a hard time intubating him, but there was an anesthesiologist around, so he was able to intubate him. So it took longer than normal to get him to breath. That could be part of his problem too. (p. 374 H)

I asked Pam if she was asked if she wanted the resuscitation efforts to continue. She said she was not asked and if she was she stated:

> I probably would have told them to continue, because at the time I had no idea how sick he was. (p. 374 H)

When I asked Pam how and when she would consider a DNR directive she stated:

> I probably would only think about Andy's quality of life and if he would be in pain. .... My husband and I talked about it once, during one of his hospitalizations, after they (physicians) spoke to me about a DNR. .... I told them we would decide at a time when an incident occurred. (p. 375 H)

When I made the third visit to see Andy, Pam reopened the discussion of a DNR. She said she had been thinking about what we had discussed over the telephone earlier that day and stated:

> I would consider a DNR on an situation per situation basis. I would only consider it if I thought Andy's quality of life was decreasing and/or he was in pain. If I saw he was in pain and his quality of life had changed from what it is now I would okay a DNR. Right now he seems happy in the world he knows as his. He doesn't seem to be in pain and his quality of life has remained stabile.

Philosophers have tried to define what makes a human being into a person and therefore deserving of life and support. Bandman and Bandman (1995) looked at the question of what is a person. In providing an answer they applied the concept of "quorum features". "A being who lacks the quorum or majority of essential features of an ordinary person, such as one with multiple deformities or lacks consciousness, such as a trisomy 18 infant does not satisfy the quorum features of being a person" (p. 177). According to Mason (1998) a person possesses the qualities of self consciousness, self control and a sense of the past and future. Magnet and Kluge (1985) state that any offspring of a human parent is a human being and therefore a person. Humanity is a biological concept and personhood is an ethical concept. " Person implies a self-aware rational being .... The material basis of awareness resides in the brain. A neonate is a person only if his cerebral development can progress so that the cerebral centres scientifically identifiable as the basis for self-awareness are present. This provides medically useful criteria for determining the ethical fact of personhood" (p. 166). By some of these definitions Andy would be considered a person by others not.

If an infant is severely retarded as a result of incomplete brain growth then who becomes the spokesperson for that child? Magnet and Kluge (1985) identify the parents. They are responsible for the child. However their decisions should be based on objective standards and medical data and not on the basis of personal preference. "The role of medical and nursing personnel is critical to developing and interpreting this data for parents" (Magnet & Kluge, 1985, p. 190). "When a handicapped child can experience some pleasure or fulfillment and can lead a life that is not dominated by pain or suffering, prolonging life would seem to be in the best interests of the future person. It may not, however, be in the best interests of parents or siblings" (Kuhse & Singer, 1985). The decision to maintain the child's life is usually upheld even if the parents disagree. According to Kuhse and Singer (1985) the United States President's Commission for the study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1983) stated:

> within constraints of equity and availability, infants should receive all therapies that are clearly beneficial to them. .... The Commission is quite explicit about rejection of family interests: This is a very strict standard in that it excludes consideration of the negative effects

> of an impaired child's life on other persons, including parents, siblings, and society. Although abiding by this standard may be difficult in specific cases, it is all too easy to undervalue the lives of handicapped infants; the Commission finds it imperative to counteract this by treating them no less vigorously than their healthy peers or than older children with similar handicaps would be treated (cited in Kuhse & Singer, 1985, p. 154).

Kuhse and Singer (1985) disagree since an older child may have developed a sense of self awareness unless profoundly retarded and s/he may have a sense of the future that an infant is incapable of having. As a society we have to decide if preserving the life of an individual at all costs is the path to follow especially when resources are limited (Callahan 1990; Kuhse & Singer, 1985). According to Magnet and Kluge (1985)

> Principle suggests that where treatment is initiated in high hopes of success, but results only in unacceptable levels of suffering with no further expectations of improvement, life saving treatment ought to be discontinued. (p. 181)

In Andy's case at the time of delivery the medical staff had no idea of the degree of problems that this child had. Pam's pregnancy was normal, and her sonograms did not reveal any fetal problems. Therefore resuscitative measures were immediately initiated during delivery. The successful resuscitation of Andy has had profound effects on the family as well as society.

The birth of Andy dramatically changed the lives of six other family members. The extent of his medical problems was not clearly evident until approximately three months after his birth. The complexity of this child's physical and cognitive aberrations will always necessitate some degree of nursing and medical interventions to keep him alive. Complementary services from other disciplines such as physical, occupational, and cognitive therapy are also required to maximize his limited capabilities. All of these modalities are extremely costly. All of the funding is provided through governmental insurance. One must therefore look at the beneficence of these interventions to determine whether or not these actions are providing a quality of life for this child and if the outcomes justify the means. One must also evaluate the impact these interventions have on the rest of the family and society.

All members of Andy's family have been impacted in some way by his chronic condition and disabilities. The father has been unable to pursue his career goals. He has been prevented from seeking full time employment with one employer because of public policy laws that stipulate a family's income level must remain at a specified level to be eligible to receive the necessary medical and nursing services required for the child's health care needs. One needs to question the validity of this. Wouldn't it be more equitable to allow the father to earn whatever he is capable of so that the family income can be partially used towards payment of the child's catastrophic health care costs? Is it morally acceptable to impose this type of life style on a family who has the potential of achieving more?

As health care professionals did we provide the necessary information about the child's present and future health status that would have enabled the mother and father to find alternative solutions for caring for this child? Were the mother and father made aware that their son would not become a functional person in adulthood and would always require intense custodial care? If they were provided with this knowledge we can only speculate as to why they had not opted to provide only the minimal amount of care that would keep the child from undue suffering? Would they have decided to institutionalize Andy rather than care for him at home? They may have been made aware of this option, however the mother spoke about the limited availability of quality long term institutions. The mother is aware that at some point in time someone other than herself will have to take over Andy's care. She hopes to have major input into the decision.

Andy's other four siblings suffer from the loss of their mother's and father's time and guidance. When Andy develops an acute exacerbation of his health problems his needs become the priority, while the rest of the family needs become secondary. These four siblings appear to be physically, mentally and cognitively able to develop into mature productive adults who can make positive contributions to society. However they require the loving support and guidance from their parents who are often unavailable.

The government funded programs of Medicaid and SSI have been and are continuing to eliminate services that have become costly and deemed medically unnecessary from their perspective. Therefore it is becoming necessary for the nursing and medical profession to reevaluate their clinical practice modalities and make adjustments that will still enable them to provide quality care. Many of the changes impact the care of children with chronic conditions and disabilities similar to Andy, the child in this case study.

In 1984, The American Academy of Pediatrics in conjunction with eight other national organizations dealing with the handicapped issued a joint policy statement that addressed the principles of treating disabled infants. According to the policy statement if treatment provided only prolongs the act of dying then it is ethically and legally justifiable to withold treatment. The decision is to be based soley on the child's medical condition. However, once a decision is made to treat, government and private agencies must make provisions for the allocation of adequate resources and services needed by the child and family. The federal and state governments are obligated by law to protect the rights of their citizens (American Academy of Pediatrics, 1984; Bandman & Bandman, 1995).

Whenever one addresses bioethical issues differences of opinion amongst all persons involved need to be carefully evaluated before a final decision is made. Whatever that final determination is, someone will be unhappy especially if the decision may negatively impact a child. As educated professionals we must bear in mind that it is our ethical and moral responsibility to carefully weigh all the presenting evidence and try to reach an equitable decision that will be communicated to the parents as being in the child's best interest.

Approximately 1% of the total childhood population have severe chronic conditions/disabilities (Perrin, 1985). Many of these children who would have previously died early in life are now living much longer. Many are surviving to adulthood because of the advanced technological modalites that have been developed. Public policy in the last few decades has focused primarily on children with developmental disabilities and mental retardation. A significant portion of the total dollars spent on child health has been allocated in providing services for these children (Perrin, 1985). Approximately $7.5 billion are spent annually on physician visits and hospitalizations to care for children with chronic conditions (Perrin, 1992).

Andy is one of the recipients of the various health and social policies that have been implemented, and that provide services whose goals are to maintain or improve his health and his physical and cognitive abilities. His health care is paid for by SSI and Medicaid, and his physical and cognitive needs are met through the early intervention programs mandated by Public Law 99-457.

"The Federal Government requires that the states provide certain services to designated eligible populations; it also limits the services that will be supported by the Federal Government" (U.S. Congress OTA, 1987, p. 55). Governmental programs such as Medicaid provide some form of health care coverage. Medicaid is jointly funded by the Federal and State governments. It was established through the Title XIX of the Social Security Act in 1965. Medicaid is an entitlement program which means that any individual who meets the program's eligibility requirements is entitled to receive the benefits provided by the program (Hutchins & Hutchins, 1997). As a result of a congressional amendment to Title XIX legislation expansion of Medicaid eligibility "all states are now required to furnish Medicaid coverage to children up to

6 years of age in families with incomes at or below 133% of federal poverty level and to phase in by the year 2001 coverage for all children up to age 19 below 100% of the poverty level" (Hutchins & Hutchins, 1997, p. 36). "Medicaid is often the third party payer of last resort for the technology-dependent child" (U.S. Congress OTA, 1987, p. 57). Supplemental Security Income (SSI) is a federally funded program for the aged, blind, and disabled who meet the eligibility and income requirements. The criteria for eligibility are that the

> individual must have a disability that is expected to last at least a year (or until death) and must have available income and resources no higher than the established limits. By statute, the income and resources of certain relatives, specifically a parent or spouse if he or she is living in the same household as the individual, must be deemed available to the individual (U.S. Congress OTA, 1987, p.57).

In most states if an individual is eligible for SSI they automatically are entitled to Medicaid. This is significant because it ensures financial assistance as well as access to needed health care services (U.S.

Congress OTA, 1987; Wallace & Gittler, 1997). The following services must be paid for by Medicaid: "inpatient and outpatient hospital services, physician services, laboratory tests, and other primary services. States can choose to fund additional services; such optional services include prescription drugs, physical, occupational, and speech therapy, case management, and hospice, dental, and respiratory care" (Hutchins & Hutchins, 1997, p. 36).

If Medicaid is paying for home care it must also provide some funding for home nursing. The amount of funding varies from state to state (Hutchins & Hutchins, 1997). States can tailor their programs to fit their needs. Each state has its own criteria for eligibility, coverage and reimbursement which can interfere with access to the program's coverage (U.S. Congress OTA, 1987; Wallace, Biehl, MacQueen & Blackman, 1997). Many of the states are requiring that Medicaid beneficiaries be enrolled in a managed care plan, however many of the managed care plans do not meet the costly and complex needs of children with a chronic condition and/or disabilities.

In 1987 "PL 99-457 mandated that states serve handicapped 3, 4 and 5 year old children with disabilities and it established an early intervention system for infants and toddlers" (Ruppert, 1997, p. 340). Subsequently the Individuals with Disabilities Education Act (IDEA) was introduced. IDEA is a federal law that states all children with special health care needs have a right to an education. According to Gittler (1997) "the IDEA's central principle is that special education and related services provided for children with disabilities must be appropriate .... and specially designed...to meet the unique needs of a child with a disability" (p. 103). Grants are given to the states to provide the funding for the programs. There are two parts, B and H. Part B requires participating states to furnish all children with disabilities a free, appropriate public education and part H addresses early intervention services for infants and toddlers ages birth to two years (Wallace & Gittler, 1997). The early intervention services are family centered where the pivotal role of the family is respected and supported (Ruppert, 1997). "Programs that foster a high degree of family participation enhance child development" (Ruppert, 1997, p. 344). Andy is enrolled in the early intervention program and is receiving services deemed necessary to maintain and/or increase his growth and development.

A child such as Andy with severe cognitive and physical impairments is not educable in terms of intelligence. However, he requires services such as physical and speech therapy to help him achieve his optimal level of growth and development. In Andy's case the use of the term "school" obscures the services that are actually being offered. However the term "school" decreases the focus on Andy's disabilities.

Euphemisms are used to humanize stigmas attributed to individuals who do not resemble the norms society is accustomed to. Society envisions that a child who attends school will receive an education that will provide knowledge to increase the child's intellectual capacity and capabilities so that s/he becomes a functional person.

According to Goffman (1963) persons who cannot conform to society's standards are not considered "normal". Persons who are different often become stigmatized. They fall into a social class with others bearing similar identifying differences. In order to desensitize issues that negatively impact the individual, society utilizes words that direct attention away from the individual's negative attributes. Society is constantly being challenged by the stigmatized to develop strategies that will help conceal a person's differentness and help them to develop their positive attributes acceptable by society, such as sending Andy to "school". Perhaps society needs to rethink the current use of language and formulate words that are not stigmatizing yet reveal the services that are actually being provided.

The states also have other agencies that come under the Maternal and Child Health Block Grant such as the Children with Special Health Care Needs (CSHCN) program. These programs were developed to meet the specific needs of children with special health care needs such as physical and developmental disabilities, sensory impairments and other chronic conditions. Interagency agreements are developing in response to the collaboration taking place between Medicaid and these other health care programs in order to "assure the effective and efficient delivery of health services to children, including children with special needs" (Hutchins & Hutchins, 1997, p. 37).

CHAPTER 5

SUMMARY, IMPLICATIONS and RECOMMENDATIONS

Summary

The purpose of this case study was to provide an inquiry into a mother's lived experience during an acute episodic hospitalization of her child with a chronic condition. Data were collected from 2 two hour interviews that were audiotaped, a 20 minute telephone interview, a 2 hour observation, and the researcher's recorded field notes. The data provide an emic perspective of the mother's relationship with nurses, other health care professionals, and family members, and the impact each one had as she experienced her child's hospitalization. The results of the study are based on one mother's lived experience. Therefore the findings are not generalizable.

The thematic analysis of data obtained from the three interviews and one observation revealed six primary categories with several themes clustering together under each. The 15 themes that emerged were:

Mother/Professional Relationship

Theme 1. The mother wants the health care professionals' approach to be individualized and caring.

Theme 2. The mother/professional relationship evolves slowly.

Theme 3. Health care professionals providing care for the handicapped child require a special understanding and compassion for the child's physical, emotional and psychological needs.

Theme 4. The mother needs the health care professionals to critically listen to what she relates about her child.

Theme 5. The mother perceives the hospital environment as discordant.

Theme 6. The constancy of nurses within the hospital and home is tantamount to good communication between the mother, nurses, and other health care professionals.

Mother's Ways of Dealing With Stress Is Related To The Hospitalization Of Her Child

Theme 7. Mother's ways of dealing with stress is related to how health care professionals perceive her and their expectations of her because she is a nurse.

Theme 8. Mother's ways of dealing with stress is related to her child's environment.

Mother/Child/Family Relationships

Theme 9. While the mother is very perceptive about her child's physical and mental capacities her acceptance of her child's chronic condition is difficult, sporadic, and transpires over time.

Theme 10. As the primary caregiver the mother assumes a multiplicity of roles .

Theme 11. Family relationships are impacted by the child's chronic condition.

Stress Related To Financial Deprivation And Inadequate Services

Theme 12. The family struggles because of insufficient finances, inadequate health care coverage, and constraints placed on the husband's employment opportunites.

Sources of Support That Are Acceptable And Helpful

Theme 13. A disparity emerges between the mother's and father's vision of supportive relationships.

Theme 14. Respite periods for the mother help decrease her stress levels and allow her some free time to address her own personal needs.

Ethical And Social Policy Issues

Theme 15. Ethical dilemmas and legislative policies confronting the mother.

The findings in this research study demonstrate difficulties experienced in the mother/nurse relationships and the mother/physician relationships during the acute episodic hospitalization of a child with a chronic condition. The findings also explicated how a child's chronic condition affected the mother, father, and siblings, and how the mother and the rest of the family handled the stress and uncertainty that dominated their lives.

The subject's six year old son's admission to the pediatric intensive care unit was unplanned. The mother perceived that many of the health care professionals used their power to maintain control over the child's care. She felt that the staff acted remote, were poor communicators and listeners, and failed to engage her in the decision making process concerning her son's care. This discordancy was disempowering and led to an asynchronous relationship. The mother felt that although the initial primary role of the health care professional was to address the immediate medical needs of the child, the health care providers should have remained cognizant of the mother's needs.

The mother was the primary care giver who provided for her son's physical necessities of life, his emotional support, and his mental stimulation. She acted as the spokesperson between the child and the outside world. It was important to the mother that her expertise be recognized and information provided in a timely manner so that her anxiety and stress levels could be decreased. This would have made her feel that she was part of the health care team supporting and caring for her child.

As a mother who has a child with a chronic condition and disabilities she faced many challenges, including a world of complex and often frightening emotions, multiple illness related encounters, involvement with numerous health care professionals, educational, and social service professionals, and at times difficult decisions about care and treatment of her son. The mother struggled as she attempted to coordinate the multiplicity of services her son received. The impact of her son's problems was also acutely felt by the other siblings and the husband. Each member of the family utilized different coping mechanisms to deal with the continuous unplanned turns of events. The husband had a difficult time communicating. The other children were beginning to show resentment towards the loss of their mother's attention. The mother was overwhelmed with her duties as the primary care giver for the family.

The mother elucidated how she struggled to obtain the multiplicity of services her son needed. She described the financial strain the family constantly had to deal with and the family's lack of health care insurance.

Home care for her son was another major problem the mother had to confront. She had to work with a number of different home care agencies that provided the nursing care for her son. The mother often found the home care nurses were ill prepared to work with a patient who required advanced technological care. Very often she would have to take over the care which impinged on her time that was allocated for the rest of her responsibilities.

Some important ethical and social policy issues were found embedded within this study such as society's responsibility to the child, mother and other family members after the health care professionals initiated costly medical interventions.

At times nurses are faced with ethical dilemmas and have to deal with issues that cause conflicts between a mother's wish for her child and a medical decision that is made against her wishes.

"Rapid advances in medical science and technology have created numerous new problems without legal and ethical precedents. Unfortunately, technical development is ahead of legal and ethical development" (Fjelland & Gjengedal, 1994, p. 23). Nurses need to understand that the essence of nursing ethics is dependent on at least four operatives that are interdependent, medical (includes all procedures that are medically indicated), therapeutic plan (that helps patients improve their health status and guides the medical plan), life plans (the patient's life goals which guide the therapeutic plan) and ultimate value (all of the above mentioned values guided by the person's ultimate value) (Thomasma, 1994). The unfolding of a caring relationship with the mother that nurses should strive to develop, is the essence of nursing ethics (Thomasma, 1994).

This reciprocity of mutual concern, understanding, and flexibility enables a mother to develop a higher level of self worth and self esteem, and provides opportunities for the mother to develop the necessary competencies needed to care for the child. A mother who experiences positive interactions with the nurses, and perceives being a part of the decision making process, will most likely perceive equality in the mother/nurse relationship.

Implications for Nursing

Child health nurses need to play an active role in supporting, encouraging, advocating and enhancing the strengths of mothers so that they can provide for the needs of their child with a chronic condition. The importance of nurses developing an understanding of the complexities of mothering a child with a chronic condition can not be over emphasized. Child health nurses face a tremendous challenge when working with mothers of children with a chronic condition.

The current trend in the new evolving health care system is early discharge home of patients with high level health care needs. Health care management that was previously thought to be highly technological and only capable of being provided by experienced professionals is now being entrusted to the mother. Therefore, it is important for nurses to become cognizant of a mother's coping skills, and knowledge base in order to provide her with the guidance and support she requires to care for her child at home. Being receptive to a mother's needs is essential.

Nurses need to utilize strategies that foster family centered care.

In order to achieve this, open honest communication between the mother and nurse must develop. The mother is the essential change agent who looks for support, encouragement and creation of opportunities that will help the child with a chronic condition reach his or her potential. Child health nurses must learn to value a mother's judgment and respect the unique contributions mothers make as they try to function as primary caregivers, decision makers, teachers and advocates for their child. It is efficacious for nurses to work at building up a mother's confidence in her ability to care for her child with a chronic condition who requires complex care at home as well as participating in the child's care during hospitalization. This helps strengthen and support the activities the mother already does well to nurture and promote the growth and development of the child, and creates additional opportunities that the mother can succeed at in meeting the child's needs. All mothers have strengths and capabilities. The mothering role is more likely to be successful if the nurse recognizes and focuses on the child's and mother's strengths and individuality.

Recently introduced federal legislation mandates "State Title V programs reflect the principles of family-centered care .... and part H of the Individuals with Disabilities Act of 1991 mandates state wide, comprehensive, family centered systems of early intervention for infants and toddlers with special needs and their families" (Thomas & Johnson, 1997 p. 107). Therefore, child health nurses need to become active participants on hospital committees that are involved in actualizing mission statements so that family centered care becomes clearly articulated on pediatric units.

Continuous quality improvement committees need to examine if family centered care outcomes are realized by both patients/families and staff. Satisfaction surveys of mothers and perception studies of staff need to be developed within a family centered framework.

Compassionate family centered policies for families of children with a chronic condition need to be developed and supported that promote optimal functioning in the multiplicity of roles that mothers assume both in their family and in their employment. Nurses need to make sure that access to services, standardized insurance forms and provision of services are threaded through the differentiated levels of care, home to hospital, hospital to home so that the flow of care feels non fragmented or "seamless" to the family.

Society is faced with many dilemmas within the current health care system, one being the allocation of funds for children with severe chronic conditions and/or disabilites. With the advent of managed care within the last few years everyone is feeling the impact of decreased access to services that were previously available. The burden is often placed on the medical profession to carefully evaluate the costly health care decisions they make and how these decisions impact the patient, family and society.

According to Callahan (1990)

> At the same time we desire to control costs, we want also to improve the quality and extent of, and access to health care. At the same time that we are trying to reduce the cost of entitlement programs, such as Medicare, we are bringing ... other forms of high-technology care under these programs. At the same time that we talk of death with dignity, we increase the budgets to cure all known causes of death. At the same time we talk

> about the need for justice and equal access, we work to preserve and extend individual choice and opportunity. At the same time that we try to contain costs, and avoid rationing, we continue to affirm those values that drive up costs. (pp. 78-79)

In addition Callahan (1990) articulates that our health care system is faulty because the ultimate goal is to meet individual needs rather than the needs of society. Unless we shift priorities and develop a new paradigm of health care, from an individual-centered to a community-centered view of health and human welfare, we will not be able to solve the problem of allocation of health care. If priority is to be given to caring instead of curing by firmly limiting the demands for individual cures, would more resources become available for the larger population?

Clinical decision making primarily focuses on the acute, often life threatening problems without considering the long term consequences. Questions have been posited regarding the beneficence and nonmaleficence of initiating aggressive treatment of these children who are so severely impaired (Jonsen, Siegler & Winslade, 1998). Controversy exists over who should decide when and if treatment should be given and terminated. Should the final decision be made by the physician or parents, or should it be a joint decision with all individuals involved with the care of the child? Before any decisions can be made all significant parties should be well informed. The mother and father need to be part of the decision making process (American Academy of Pediatrics, 1984; Jonsen, Siegler & Winslade, 1998). Information needs to be disseminated to the parent(s) concerning the level of function the child will be capable of achieving and the options of care available so that the parent(s) can make an informed decision (Magnet & Kluge, 1985). Clinicians as well need to become well informed of all health care options and resource allocations that are available that will help them arrive at an appropriate decision for all involved.

Recommendations for Further Study

Based upon this case study's findings that there are many factors that impact a mother's ability to cope with an acute episodic hospitalization of a child with a chronic condition, future researchers should consider conducting the following studies:

1. Replicate the design of this current study

using fathers to determine the father's lived experience during the acute episodic hospitalization of a child with a chronic condition.

2. Replicate the design of this current study using children of different age groups (younger than 3 years, older than 6 years) to determine if the mother's lived experience during the acute episodic hospitalization of a child with a chronic condition is different when the child is of a different age.

3. Replicate the design of this current study using children with a chronic psychiatric condition to determine if the mother's lived experience during the acute episodic hospitalization of a child with a chronic psychiatric condition yields different data.

3. Replicate the design of this current study with mothers who have no professional medical background.

4. Replicate the design of this current study with both the child's primary nurse and the child's mother to determine their perceptions of the mother/ professional relationship.

5. Design a qualitative study to determine mothers' perceptions of family centered care in pediatric intensive care units.

6. Design studies to determine which

differentiated practice levels, education levels and mix of nurses make a difference in providing non fragmented family centered care for mothers of children with a chronic condition admitted for an acute episodic hospitalization.

7. Design a study to determine the relationship of multiplicity of roles assumed by the mother, respite intervals for the mother, and levels of mother's stress.

8. It would be interesting to do an observational study that looked at nurses who are mothers versus nurse who aren't mothers and how they relate to the mothers of hospitalized children with a chronic condition.

In addition, research needs to be conducted that looks at nursing education. Nurse educators need to review both the undergraduate and graduate child health curriculum to be assured that a unit on family centered care is included. Introducing the student nurse to the family centered philosophy both theoretically and clinically will enable the student to become ingrained with each of the key elements of family centered care. Clinical instructors should expect to see the students implementing the concepts while caring for pediatric patients and their families.

Nursing educators should conduct research that evaluates the nursing students' knowledge about family centered care.

Nurse educators need to determine which educational strategies best prepare nurses to enable them to make the transition from hospital based care to home based care.

Nurse educators also need to critically examine the most appropriate strategies in teaching nurses communication skills that maximize concordant interpersonal relationships.

Finally, the advanced technologic procedures that have emerged have greatly increased the number of children who are born with genetic diseases, and congenital anomalies. Some children who develop serious chronic conditions after birth are also surviving for longer periods of time because of advanced medical interventions. Some are surviving into adulthood. Nurses, physicians, and other health care providers must critically examine the impact that initiated medical interventions have on family and society. Once treatment is started it is difficult to stop even if it is in the best interests of the child, family and society. Our health care system is at a cross road. Decisions have to be made that provide the best care for everyone without depleting private and public resources. Society needs to prepare itself for a paradigm change and health care professionals must be willing to change their ways without compromising their values and jeopordizing the lives of children.

Child health nurses have to become aware of the consequences inherent in the medical and therapeutic decisions made concerning children with a chronic condition and/or disabilities and their families. They need to be knowledgeable and have the skills necessary to articulate the needs of these children to legislators, health care professionals, hospital administrators and insurance company executives.

This study has elucidated one mother's lived experience as the primary care giver of a child with a chronic condition. Although the findings are not generalizeable, it is hoped that the knowledge gleaned through this mother's perceptions will have impact on the practice of child health nurses.

References

Ambert, A.M. (1992). The effects of children on parents. New York: Haworth Press.

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

American Academy of Pediatrics (1984). Joint policy statement: Principles of treatment of disabled infants. Pediatrics, 73(4), 559-560.

Ashburn, S. (1986). Psychosocial development of the toddler and preschooler. In C.S. Shuster & S.S. Ashburn. The process of human development (pp.233-253). Boston: Little Brown.

Ashburn, S. & Schuster, C.S. (1986). Cognitive development of the toddler and preschooler. In S.S. Ashburn & C.S. Schuster. The process of human development (pp.215-233). Boston: Little Brown.

Bandman, E.L. & Bandman B. (1995). Nursing ethics through the life span (3rd, ed.). Norwalk, Ct.: Appleton & Lange.

Bandman, E.L. & Bandman B. (1995). Ethical issues in the nursing care of infants. In E.L. Bandman & B. Bandman (3rd, ed.), Nursing ethics through the life span (pp. 165-184). Norwalk, Ct.: Appleton & Lange.

Beck, C.T. (1993). Qualitative research: The evaluation of its credibility, fittingness and auditability. Western Journal of Nursing Research, 15(2), 263-265.

Beckett, J.E. (1989). With a parent's eye. In R.E.k. Stein (Ed.), Caring for children with chronic illness, (pp.101-116). New York: Springer.

Benner, P. (1984). From novice to expert: Excellence and power in clinical nursing practice. Menlo Park, CA: Addison-Wesley.

Bergum, V, (1991). Being a phenomenologic Researcher. In J. Morse (Ed.). Qualitative nursing research (p. 55-71). Newbury Park, CA: Sage.

Berman, H. (1991). Nurses' beliefs about family involvement in a children's hospital. Issues in Comprehensive Pediatric Nursing, 14, 141-153.

Bogdan, R. & Biklen, S. (1992). Qualitative research for education: An introduction to theory and methods (2nd ed.). Boston: Allyn and Bacon.

Bohm, D. (1992). On dialogue. Noetic Sciences Review, 16-17.

Bond, N., Phillips, P. & Rollins, J.A (1994). Family centered care at home for families with children who are technology dependent. Pediatric Nursing,20(2), 123-130.

Bowlby, J.B. (1966). Deprivation of maternal care. New York: Shocken Books.

Bowlby, J. (1973). Attachment and loss: Separation Anxiety and anger. New York:Basics Books

Brown, J. & Ritchie, J. (1990). Nurses' perceptions of parent and nurses roles in caring for hospitalized children. Child Health Care, 19(1), 28-36.

Burke, S.O., Costello, E.A., & Handley-Derry, M.H. (1989). Maternal stress and repeated hospitalizations of children who are physically disabled. Child Health Care, 18(2), 82-90.

Burke, S.O., Kauffmann, E., Costello, E.A. & Dillon, M.C. (1991). Hazardous secrets and reluctantly taking charge: Parenting a child with repeated hospitalizations. Image, 23(1), 39-45.

Burns, N. & Grove, S. (1987). The practice of nursing research: Conduct, critique and utilization. Philadelphia: W.B. Saunders.

Breitmayer, B.J., Gallo, A.M., Knafl, K.A. & Zoeller, L.H. (1992). Social competence of school-age children with chronic illnesses. Journal of Pediatric Nursing, 7(3), 181-188.

Callery, P. (1997). Paying to participate: Financial, social and personal costs to parents of involvement in their children's care in hospital. Journal of Advanced Nursing, 25, 746-752.

Callahan, D. (1990). What kind of life: The limits of medical progress. New York, New York: Simon & Shuster.

Canam, C. (1993). Common adaptive tasks facing parents of children with chronic conditions. Journal of Advanced Nursing, 8(1), 46-53.

Cernoch, J.M. & Newhouse, E.E. (1997). Respite care: Support for families in the community. In H.M. Wallace, R.F. Biehl, J.C. MacQueen & J.A. Blackman (Eds.), Mosby's resource guide to children with disabilities and chronic illness (pp. 402-411). St. Louis: Mosby.

Chesla, C.A. (1996). Reconciling technologic and fmily care in critical-care nursing. Image, 28(3), 199-203.

Chesla, C.A. & Stannard, D. (1997). Breakdown in the nursing care of families in the ICU. American Journal of Critical Care, 6(1), 64-71.

Chesler, M. (1985). Active roles for parents in the care of chronically ill children. Child Health Care, 14(1), 4-5.

Clark, C.L. (1991). Parenting the hospitalized child. Michigan: U.M.I Dissertation Services.

Clements, D.B., Copeland, L.G. & Loftus, M. (1990). Critically ill times for families with a chronically ill child. Pediatric Nursing, 16(2), 157-161.

Cohen, M.H. (1995). The triggers of heightened parental uncertainty in chronic, life-threatening childhood illness. Qualitative Health Research, 5(1), 63-67.

Copeland, L.G. (1993). Caring for children with chronic conditions: Model of critical times. Holistic Nurse Practice, (1), 45-55.

Copeland, L.G. & Clements, D.B. (1993). Parental perceptions and support strategies in caring for a child with a chronic condition. Issues in Comprehensive Pediatric Nursing, 16, 109-121.

Corbin, J.M. & Strauss, A. (1992) A nursing model for chronic illness management based upon the trajectory framework. In Pierre Woog (Ed.), The chronic illness trajectory framework: The Corbin & Strauss Nursing model (pp. 9-28). New York: Springer.

Coyne, I.T. (1996). Parent participation: A concept analysis. Journal of Advanced Nursing, 23, 733-740.

Coyne, I.T. (1995). Partnership in care: Parents' views of participation in their hospitalized child's care. Journal of Clinical Nursing, 4, 71-79.

Coyne, I.T. (1995). Parental participation in care: A critical review of the literature. Journal of Advanced Nursing, 21, 716-722.

Curley, M.A.Q. & Wallace, J. (1992). Effects of the nursing mutual participation model of care on parental stress in the pediatric intensive care unit-A replication. Journal of Pediatric Nursing, 7(6), 377-385.

Danielson, C.B., Hamel-Bissell, B. & Winsted-Fry. (1993). Families health and illness: Perspectives on coping and intervention. St. Louis: C.V. Mosby.

Darbyshire, P. (1994). Parental participation and involvement in the care of their hospitalized child. In P. Benner (Ed.), Interpretive phenomenology: Embodiment, caring and ethics in health and illness, (pp. 185-210). London: Sage.

Denzin, N.K. & Lincoln, Y.S. (Eds.).(1994). Handbook of qualitative research. Thousand Oaks, CA: Sage.

Drotar, D., Crawford, P. & Bush, M. (1984) The family context of childhood chronic illness: Implications for psychosocial intervention. In M. Eisenberg, L. Sutkin, & M. Jansen (Eds.), Chronic illness and disability through the life span: Effects on self and family (pp.103-129). New York: Springer.

Dunst, C. & Trivette, C. (1987). Enabling and empowering families: Conceptual and intervention issues. School Psychology Review, 16(4), 443-456.

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

Dunst, C., Trivette, C., & Deal, A. (Eds.) (1994). Supporting & strengthening families. Cambridge, MA: Brookline Books.

Dunst, C., Trivette, C., & Deal, A. (1988). Enabling and empowering families:Principles and guidelines for practice. Cambridge, MA: Brookline Books.

Eakes, G.G., Burke, M.L. & Hainsworth, M.A. (1998). Middle range theory of chronic sorrow. Image, 30(2), 179-184.

Erikson, E. (1963). Childhood and society. New York: W.W. Norton.

Evans, M.A. (1994). An investigation into the feasibility of parental participation in the nursing care of their children. Journal of Advanced Nursing, 20, 477-482.

Evans, R.I. (1973). Jean Piaget: The man and his ideas. New York: E.P. Dutton.

Ferraro, A.R. & Longo, D.C. (1985). Nursing care of a family with a chronically ill hospitalized child: An alternative approach. Image, 27(3), 77-81.

Field, P. & Morse, J. (1985). Nursing research: The application of qualitative approaches. Rockville, MD: Aspen.

Fjelland, R. & Gjengedal, E. (1994). A theoretical foundation for nursing as a science. In P. Benner (Ed.), Interpretive phenomenology: Embodiment, caring and ethics in health and illness, (pp. 3-25). London: Sage.

Freiberg, K.L. (1987). Human development: A lifespan approach. Boston: Jones & Bartlett.

Gibson, C.H. (1995). The process of empowerment in mothers of chronically ill children. Journal of Advanced Nursing, 21, 1201-1210.

Gittler, J. (1997). Legal rights of children with disabilities. In H.M. Wallace, R.F. Biehl, J.C. MacQueen & J.A. Blackman (Eds.), Mosby's resource guide to children with disabilities and chronic illness (pp. 97-105). St. Louis: Mosby.

Goffman, E. (1963). Stigma: Notes on the management of spoiled identity. New York: Simon & Shuster.

Gravelle, A.M. (1997). Caring for a child with a progressive illness during the complex chronic phase: Parents' experience of facing adversity. Journal of Advanced Nursing, 25, 738-745.

Guba, E.G. & Lincoln, Y.S. (1989). Fourth generation evaluation. Newbury Park, CA: Sage.

Haas, D., Gray, H. & McConnell, B. (1992). Parent/professional partnerships for children with special health care needs. <u>Issues in Comprehensive Pediatric Nursing, 15</u>, 39-53.

Haslam, R.H.A.. (1996). Cerebral palsy. In R.E. Behrman, R.M. Kliegman, & A.M. Arvin (Eds.), <u>Nelson: Textbook of pediatrics</u> (pp. 1713-1715). Philadelphia: W.B. Saunders.

Haslam, R.H.A.. (1996). Microcephaly. In R.E. Behrman, R.M. Kliegman, & A.M. Arvin (Eds.), <u>Nelson: Textbook of pediatrics</u> (pp. 1681-1683). Philadelphia: W.B. Saunders.

Haslam, R.H.A.. (1996). Neurologic evaluation. In R.E. Behrman, R.M. Kliegman, & A.M. Arvin (Eds.), <u>Nelson: Textbook of pediatrics.</u> (pp. 1667-1677). Philadelphia: W.B. Saunders.

Haslam, R.H.A.. (1996). Seizures in childhood. In R.E. Behrman, R.M. Kliegman, & A.M. Arvin (Eds.), <u>Nelson: Textbook of pediatrics.</u> (pp. 1686-1687). Philadelphia: W.B. Saunders.

Hayes, V. & Knox, J. (1983). Reducing hospital-related stress in parents of children with cancer. <u>The Canadian Nurse, 79</u>(10), 24-28.

Hayes, V. & Knox, J. (1984). The experience of stress in parents of children hospitalized with long-term disabilities. Journal of Advanced Nursing, 9, 333-341.

Hobbs, N. (1975). The futures of children. San Francisco: Josey-Bass.

Hobbs, N. (1976). Issues in the classification of children. San Francisco: Jossey-Bass.

Hobbs, N. (1978). Classification options: A Conversation with Nicholas Hobbs on Exceptional Child Education. Exceptional Children, 44, 494-497.

Hobbs, N., Perrin, J.M. & Ireys, H.T. (1985). Chronically ill children and their families. San Francisco: Jossey-Bass.

Horner, M., Rawlins, P. & Giles, K. (1987). How parents of children with chronic conditions perceive their own needs. Maternal Child Nursing, 12, 40-43.

Hostler, S.L. (1991). Family centered care. Pediatric clinics of North America, 38(6), 1545-1560.

Hutchins, V.L., & Hutchins, J.E. (1997). Public sector health services for children with special health care needs. In H.M. Wallace, R.F. Biehl, J.C. MacQueen & J.A. Blackman (Eds.), Mosby's resource guide to children with disabilities and chronic illness (pp. 30-41). St. Louis: Mosby.

Hymovich, D.B. & Baker, C.D. (1991). The needs, concerns and coping of parents of children with cystic fibrosis. In A.L. Whall & J. Fawcett (Eds.), Family theory development in nursing:State of the science and art (pp.375-388). Philadelphia: F.A. Davis.

Hymovich, D., & Hagopian, G. (1992). Chronic illness in children and adults: A psychosocial approach. Philadelphia: W.B. Saunders.

Jackson, P.L. & Vessey, J.A. (1992). Primary care of a child with a chronic condition. St. Louis:C.V. Mosby.

Janesick, V.J. (1994). The dance of qualitative research design: Methapor, methodolatry, and meaning. In N.K. Denzin & Y.S. Lincoln (Eds.), Handbook of qualitative research (pp.209-220). Thousand Oaks, CA: Sage.

Jessop, J & Stein, R. (1989). Meeting the needs of individuals and families. In R. Stein (Ed.), Caring for children with chronic illness: Issues and strategies (pp. 63-74). New York: Springer.

Johnson, B.H. (Fall, 1990). The changing roles of family in health care. Child Health Care,19(4), 234-241.

Jonsen, A.R., Siegler, M. & Winslade, W.J. (1998). Clinical ethics (4th. ed.). New York: McGraw-Hill.

Kasper, J.W. & Nyamathi, A.M. (1988). Parents of children in the pediatric intensive care unit: What are their needs? Heart & Lung, 17(5), 574-581.

Kirschbaum, M.S. (1990). Needs of parents of critically ill children. Dimensions of Critical Care Nursing, 9(6), 344-352.

Knafl, K., Breitmayer, B., Gallo, A. & Zoeller, L. (1992). Parents' views of health care providers: An exploration of the components of a positive working relationship. Child Health Care, 21(2), 90-95.

Knafl, K.A., Cavallari, K.A. & Dixon, D.M. (1988). Pediatric hospitalization: Family and nurse perspectives. Glenview, IL: Scott, Foresman and Company.

Knox, J. & Hayes, V. (1983). Hospitalization of a chronically ill child: A stressful time for parents. Issues in Comprehensive Pediatric Nursing, 6, 217-226.

Kohrman, A.F. (1991).Medical technology: Implications for health care and social service. In N.J. Hochstadt & D.M. Yost (Eds.), The medically complex child : The transition to home care (pp. 3-13). New York: Harwood Academic.

Kohrman, A.F. & Kaufman, J. (1997). Home care for children with technological needs. In H.M. Wallace, R.F. Biehl, J.C. MacQueen & J.A. Blackman (Eds.), Mosby's resource guide to children with disabilities and chronic illness (pp. 411-419). St. Louis: Mosby.

Kristjansdottir, G. (1991). A study of the needs of parents of hospitalized 2-to 6-year-old children. Issues in Comprehensive Pediatric Nursing, 14, 49-64.

Kuhse, H. & Singer, P. (1985). Should the baby live: The problem of handicapped infants. New York: Oxford University.

Leff, P.T. & Walizer, E.H. (1992). Building the Healing Partnership. Bethesda, MA: Brookline Books.

Leff, P.T., Chan, J.M. & Walizer, E.H. (1989). Talking to parents: Enhancing parent-professional relationships. Children's Hospital Quarterly, 1(2), 171-174.

Lincoln, Y.S. & Guba, E.G. (1985). Naturalistic inquiry. Newbury Park, CA: Sage.

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

Magnet, J.E. & Kluge, E.W. (1985). Withholding treatment from defective newborn children. Cowansville, Quebec: Brown Legal.

Mahon, M. (1992). Chronic conditions and the family. In P.L. Jackson & J. Vessey (Eds.), Primary care of the child with a chronic condition (pp.12-25). St Louis: C.V. Mosby.

Mason, J.K. (1998). Human life and medical practice. Edinburgh: Edinburgh University Press.

Maxwell, J.A. (1992). Understanding and validity in qualitative research. Harvard Educational Review, 62(3). 279-300.

Melnyk, B.M. (1994). Coping with unplanned childhood hospitalization: Effects of informational interventions on mothers and children. Nursing Research, 43(1), 50-55.

Mezirow, J. (Fall, 1981). A critical theory of adult learning and education. Adult Education, 32(1), 3-24.

Mezirow, J. (1985). A critical theory of self-directed learning. In S.Brookfield (Ed.), Self directed learning: From theory to practice. New directions for continuing education (pp. 17-30). San Francisco: Jossey-Bass.

Meier, P. & Pugh, E.J. (1986). The case study: A viable approach to clinical research. Research in Nursing & Health, 9, 195-202.

Morse, J.M. (1994). Designing funded qualitative research. In N.K. Denzin & Y.S. Lincoln (Eds.), Handbook of qualitative research (pp.220-235). Thousand Oaks, CA: Sage.

Mundinger, M.O. (1994). Health care reform: Will nursing respond? Nursing & Health care, 15(1), 28-33.

Munhall, P. (1989). Philosophical ponderings on qualitative research methods in nursing. Nursing Science Quarterly, 20-27.

Munhall P. & Oiler, C. (1986). Nursing research: A qualitative perspective. Norwalk, CT: Appleton-Century-Crofts.

Newacheck, P.W. Stoddard, J. & McManus, M. (1993). Ethnocultural variations in the prevalence and impact of childhood chronic conditions. Pediatrics, 91(5), (Suppl.), 1031-1039.

Newacheck, P.W. & Taylor, W.R. (1992). Childhood chronic illness: Prevalence, severity and impact. American Journal of Public Health, 82(3), 364-371.

Ogilivie, L. (1990). Hospitalization for children for Surgery: The parents view. Child Health Care, 19(1), 49-56.

Omery, A. (1983). Phenomenology: A method for nursing research. Advances in Nursing Science, 49-63.

Palmer, S.J. (1993). Care of sick children by parents: A meaningful role. Journal of Advanced Nursing, 18, 185-191.

Park, C.L. (1991). Parenting the hospitalized child. Dissertation Abstracts International, 53(10), 1-161.

Patterson, J.M. (1991). Family resilience to the challenge of a child's disability. Pediatric Annals, 20(9), 491-499.

Patterson, L.M., Jernell, J., Leonard, B.J. & Titus, J.C. (1994). Caring for medically fragile children at home: The parent-professional relationship. <u>Journal of Pediatric Nursing, 9</u>(2), 98-106.

Perkins, M.T. (1993). Parent-nurse collaboration: Using the caregiver identity emergence phases to assist parents of hospitalized children with disabilities. <u>Journal of Pediatric Nursing, 16</u>(1), 2-9.

Perrin, J.M. (1996). Issues common to diverse chronic conditions. In R.E. Behrman, R.M. Kliegman, & A.M. Arvin (Eds.), <u>Nelson: Textbook of pediatrics,</u> (pp. 124-128). Philadelphia: W.B. Saunders.

Perrin, J.M. (1985) Clinical ethics and resource allocation: The problem of chronic illness in childhood. In J.C. Moskop & L. Kopelman (Eds.), <u>Ethics and critical care medicine</u> (pp.105-116). Hingham, MA.: Kluwer Academic.

Perrin, J.M. & MacLean, W.E. (1988). Children with chronic illness: The prevention of dysfunction. <u>Pediatric Clinics of North America, 35</u>(6), 1335-1337.

Perrin, J.M., Shayne, M.W. & Bloom, S.R. (1993). <u>Home and community care for chronically ill children.</u> New York: Oxford University Press.

Peterson, L.J. & Mori, L. (1988). Preparation for hospitalization. In D.K. Routh, (Ed.), Handbook of pediatric psychology (pp.460-487). New York: Guilford Press.

Piaget, J. (1962). Play, dreams and imitation in childhood (C. Gattegno & F.M. Hodgson, Trans.). New York: W.W. Norton.

Polanyi, M. (1966). The tacit dimension. New York: Doubleday.

Polit, D. & Hungler, B. (1991). Nursing research: Principles and methods. Philadelphia: J.B. Lippincott.

Price, P.J. (1993). Parents' perceptions of the meaning of quality nursing care. Advanced Nursing Science, 16(1), 33-41.

Pulaski, M. (1980). Understanding Piaget: An introduction to childrens cognitive development. New York: Harper & Row.

Rappaport, J. (1985). The power of empowerment language. Social Policy, 15-21.

Ray, L.D. & Ritchie, J.A. (1993). Caring for chronically ill children at home: Factors that influence the parents' coping. Journal of Pediatric Nursing, 8(4), 217-224.

Rennick, J.E. (1995). The changing profile of acute childhood illness: A need for the development of family nursing knowledge. Journal of Advance Nursing, 22, 258-266.

Robinson, C.A. (1987). Roadblocks to family centered care when a chronically ill child is hospitalized. Journal of Pediatric Nursing, 1(4), 274-277.

Rose, M. & Thomas, R. (Eds.) (1987). Children with chronic conditions: Nursing in a family and community context. New York: Grune & Stratton.

Rose, P., Beeby, J. & Parker, D. (1995). Academic rigour in the lived experience of researchers using phenomenological methods in nursing. Journal of Advanced Nursing, 21, 1123-1129.

Roy, C. (1988). An explication of the philosophical assumptions of the Roy adaptation model. Nursing Science Quarterly, 1(1), 26-34.

Ruppert, E.S. (1997). Early intervention. In H.M. Wallace, R.F. Biehl, J.C. MacQueen & J.A. Blackman (Eds.), Mosby's resource guide to children with disabilities and chronic illness (pp. 338-345). St. Louis: Mosby.

Rushton, C.H. (1990). Family-centered care in the critical care setting: Myth or reality? Children's Health Care, 19(2), 69-78.

Sandelowski, M. (1986). The problem of rigor in qualitative research. Advances in Nursing Science, 27-37.

Sandelowski, M. (1996). One is the liveliest number: The case orientation of qualitative research. Research in Nursing & Health, 19, 525-529.

Schepp, K.G. (1991). Factors influencing the coping effort of mothers of hospitalized children. Nursing Research, 40(1), 42-46.

Schön, D.A. (1983). The reflective practitioner. New York: Basic Books.

Schuster, C.S. (1986). Development of a concept of death. In C. Schuster and S. Ashburn. The process of human development (pp.405-418). Boston: Little Brown.

Servonsky, J. & Opas, S.R. (1987). Nursing management of children. Boston, MA: Jones & Bartlett.

Shelton, T., Jeppson, E., & Johnson, B. (Sept.,1987). Family-centered care for children with special health care needs (2nd. ed.). Washington, DC: Association For the Care of Childrens Health.

Shelton. T.L. & Stepanek, J.S. (1994). Family-centered care for children needing specialized health and developmental services. Bethesda, MA:Association for the Care of Children's Health.

Shonkoff, J.P. (1996). Mental retardation. In R.E. Behrman, R.M. Kliegman, & A.M. Arvin (Eds.), Nelson: Textbook of pediatrics (pp. 128-131) Philadelphia: W.B. Saunders.

Stake, R.E. (1994). Case studies. In N.K. Denzin & Y.S. Lincoln (Eds.), Handbook of qualitative research (pp.236-247). Thousand Oaks, CA: Sage.

Stein, E.K. (ed.) (1989). Caring for children with chronic illness. New York: Springer.

Stein, E.K. & Jessop, J.J. (1984). General issues in the care of children with chronic physical conditions. Pediatric Clinics of North America, 31(1), 189-198.

Stein, R.E. & Jessop.D.J. (1982). A noncategorical approach to chronic childhood illness. Public Health Reports, 97(4), 354-362.

Stein, R.E., Jessop, D.J. & Riessman, C.K. (1983). Health care services received by children with chronic illness. American Journal Diseases in Children, 137, 225-230.

Surrey, J. (1991). Relationship and Empowerment. In J. Jordan, A. Kaplan, J.B. Miller, I. Stiver & J.Surrey, Women's growth in connection (pp.162-180). New York: Guilford Press.

Swanson-Kauffman, K. & Schonwald, E. (1988). Phenomenology. In B. Sarter (Ed.). Paths to knowledge: Innovative methods for nursing. New York: National League for Nursing.

Tanner, C.A., Benner, P,, Chesla, C. & Gordon, D. (1993). The phenomenology of knowing the patient. Image, 25(4), 273-280.

Taylor, C. (1971). Interpretation and the sciences of man. The Review of Metaphysics, 25(1), 3-51.

Taylor, S. & Bogdan, R. (1984). Introduction to qualitative research methods: The search for meanings (2nd ed.). New York: John Wiley & Sons.

Thomas, C.L. (Ed.). (1989). Taber's cyclopedic dictionary (16th ed.). Philadelphia: F.A. Davis.

Thomas, R.B. (1987). Family adaptation to a child with a chronic condition. In M.H. Rose & R.B. Thomas (Eds.), Children with chronic conditions: Nursing in a family and community context (pp. 29-54). New York: Grune & Stratton.

Thomas, R.B. (Fall, 1990). Research commentary: A foundation for clinical family assessment. Children's Health Care, 19(4), 244-250.

Thomas, J. & Johnson, B.H. (1997). Family roles: The most relevant aspect of family-centered care. In H.M. Wallace, R.F. Biehl, J.C. MacQueen & J.A. Blackman (Eds.), Mosby's resource guide to children with disabilities and chronic illness (pp. 411-419). St. Louis: Mosby.

Thomasma, D. C. (1994). Toward a new medical ethics: Implications for ethics in nursing. In P. Benner (Ed.), Interpretive phenomenology: Embodiment, caring and ethics in health and illness, (pp. 85-98). London: Sage.

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

Thorne, S.E. & Robinson, C.A. (Fall, 1989). Guarded alliance: Health care relationships in chronic illness. Image, 21(3), 153-157.

United States Congress, Office of Technology Assessment (1987). Technology -dependent children: Hospital v. home care-A technical memorandum, OTA-TM-H-38. Washington, DC: U.S. Government Printing Office.

Wallace, H. M. & Gittler, J. (1997) Federal ledgislation for children with special health care needs and their families: Past, present and future. In H.M. Wallace, R.F. Biehl, J.C. MacQueen & J.A. Blackman (Eds.), Mosby's resource guide to children with disabilities and chronic illness (pp. 81-93). St. Louis: Mosby.

Wallerstein, N. & Bernstein, E. (Winter, 1988). Empowerment education: Freire's ideas adapted to health education. Health Education Quarterly, 15(4), 379-394.

Wolfer, J.A. & Visintainer, M.A. (1975). Pediatric surgical patients' and parents' stress responses and adjustment. Nursing Research, 24(4), 244-255.

Wolfer, J.A. & Visintainer, M.A. (1979). Prehospital psychological preparation for tonsillectomy patients: Effects on children's and parents' adjustment. Pediatrics, 64(5), 646-655.

Worthington, R.C. (1992). Family support networks: Help for families of children with special needs. Family Medicine,24(1), 41-44.

Wright, L.M. & Leahy, M. (1987). _Families and chronic illness._ Springhouse, Pa: Springhouse.

Appendix A

Informed Consent Form

Project Title: The Mother's Lived Experience During an Episodic Hospitalization of a Child with a Chronic Condition.

Investigator: Arleen J. Steckel, MS, RN, CPNP
Telephone #:

The purpose of this research project is to find out what your experience was when your child with a chronic condition was hospitalized for an acute episodic problem. The information obtained may provide nurses with a better understanding of what mothers experience during their child's hospitalization. The information may contribute to developing improved interventions and may improve child and family care. If you decide to participate, your part in the research project will involve participating in at least two audiotaped interviews that will last approximately 1-2 hours. You will be asked to describe your experience during the hospitalization of your child. The data will be analyzed and kept in strict confidence, though the data in the final report may contain anonymous quotes. The final report will be available to you at the end of the study if desired. All information obtained, including your identity will be kept confidential. There may be no direct benefit to you as a participant of this study, but nurses and other health care professionals may gain a better understanding of what mothers experience during their child's hospitalization. There will be no health risks resulting from your participation in the research.

THIS IS TO CERTIFY THAT I,______________________________________,
(print name)

HEREBY agree to participate as a volunteer in the above named project.

I hereby give permission to be interviewed and to be audiotaped.

My name will be held in confidence, and the coded tapes will not be used for any other purpose.

My name will not be associated with the research information that may be published.

I am free to deny any answer to any specific question in the interview or demographic data form.

I am free to withdraw my consent and end my participation at any time, without penalty.

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

If you have any questions about this [redacted]y contact Dr. Pierre Woog, at Adelphi University @ .

If you sign below, it means you have ad read to you) the information given in this consent form, and you would like to be a volunteer in this study.

You will given a copy of this consent form to keep.

Participant	Date	Researcher	Date

Appendix B

Flier

VOLUNTEERS NEEDED TO PARTICIPATE IN A DOCTORAL RESEARCH STUDY

ADELPHI UNIVERSITY
SCHOOL OF NURSING

Arleen Steckel, MS,RN,CPNP and Ph.D Candidate, is seeking volunteers to participate in a doctoral research study.

Volunteer Mothers needed who have a child ages 3-6 years old with a chronic condition who has been hospitalized within the past year for an acute episodic problem.

If you have had this experience and are willing to participate in t[redacted]ease contact Arleen Steckel at (If Arleen is not home leave her tape-machine and she will return your call.

Appendix C

Recruitment Letter For Participation In Research Study

Dear Potential Participant:

I am a doctoral candidate at Adelphi University in the School of Nursing. I am seeking volunteers to participate in a doctoral research study. I need to interview mothers who have a child with a chronic condition who was hospitalized within the past year for an acute episodic (unexpected) problem.

The purpose of the study is to learn about what mothers' experience during the hospitalization of their child. The information gained can help maintain and/or establish a relationship between nurses and other health care professionals that can support the continuity and emotional stability of the mother/child relationship.

The project will consist of 1-2 interviews lasting approximately one hour each. The interviews will be scheduled at a time and place that is convenient for you. Each interview will be tape recorded and all names and information will be kept confidential. You will be asked to sign a consent form stating you understand the reason for the study and that you understand that you can withdraw from the study at any time. This study will not pose any risks to you or your child.

If you have a child aged 3-6 years with a chronic condition who has been hospitalized unexpectedly within the last year, and you are willing to participate in this study, please call me at my home number [redacted]-[redacted] or at my work number [redacted]

Sincerely,

Arleen Steckel, MS,RNC,CPNP
PhD Candidate

Appendix D

Demographic Data Sheet

Code Number:

Directions: Please complete the following questions.

Name:____

Age:____

Address:____
____
____

Telephone Number:_____________________________________

Marital Status:	Children:
Single______________	Male ____ Age of each ________
Married_____________	Female ___ Age of each ________

Separated___________
Divorced____________
Widowed_____________
Never Married______

Race:

American Indian_____
Black________________
Caucasian_____________
Latino American________
Asian___________________
Other____________________

Occupation______________________________

Employment:

Full-Time_____

Part-Time_____

Unemployed_____

Income:

Less than $ 8,000___________

$ 8,000 - $ 15,000___________

$16,000 - $ 20,000___________

$21,000 - $ 30,000___________

$31,000 - $ 40,000___________

$41,000 - $ 50,000___________

Greater than $ 50,000___________

Education (Check highest level):

Grade School_______________

High School Graduate_______

Vocational School Graduate_______

College Graduate_______

Associate Degree___ Bachelor's

Degree___ Master's Degree____

Biographical Data on child with a chronic condition:

Name_______________

Age_________________ Date of Birth_________________

Male________________ Female_________________________

Diagnosis____

____

Date of last acute episodic hospitalization______________

Reason for this hospitalization___________________________

____

Number of days spent in hospital for the above hospitalization___

Type of hospital: City_________ State____________ Private______

Are you the primary caregiver for your child?_________ If not who is?____

Appendix E

Additional Probes

1. Tell me about your experiences with the nurses who cared for your child during the hospitalization?

2. Describe your relationship with nurses and other health care providers.

3. Did you find you interacted with certain nurses and health care providers better than others? Can you explain why?

4. Describe how the nurses and other health care providers made you feel.

5. Describe ways in which nurses and other health care providers communicated with you.

6. Did the nurses and health care providers listen to your concerns about your child's needs? Can you give examples?

7. Did the nurses and health care providers answer your questions in a way that made you feel they understood what you wanted to know? Can you give some examples?

8. Describe how the nurses and health care providers showed they respected the decisions you made concerning aspects of your child's care that you considered important.

9. Describe instances where they didn't respect your wishes.

10. Describe instances where the nurses and health care providers made you feel you were the ultimate decision maker.

11. Describe ways nurses and health care providers let you know you had a choice in how much you wished to participate in the care of your child.

12. Describe ways nurses and health care providers supplied the information you needed so that you could provide appropriate care for your child.

13. Were you satisfied with the amount of time the nurses allowed you to care for your child?

14. Can you describe how nurses and health care providers showed that they trusted or didn't trust your care giving skills?

Appendix F

Interview #1

Q Describe what your experience was during the time your child was hospitalized last time.

S It was a very stressful experience. Andy was really very sick that time, he had pneumonia and um---it's just completely stressful because you don't really feel like you know what's going on at all and um he was in the ICU and it seems like it is very secretive. People, they don't volunteer information, and um---especially when there's rounds and stuff like that, I find it very hard, they ask you to go outside and my first thought is what are they hiding? You know----I don't like that at all.

Q Did you ever ask them if you could stay?

S Yes, and they say No. Very direct No you can't so that's it and um---------

Q Who do you ask? Do you ask the physicians or the nurses?

S I'll ask the nurses and they will direct me to the physicians and the director of the ICU and I guess it's Dr. Wong, she's very um strict about these topics and she just says no. Usually when they do any kind of procedures I'm asked to leave, this is not Andy's first hospitalization so this time actually was a better one as far as the relationship went with Dr. A. and Dr. B. He actually let me stay when they were putting in a central line and things like that which never happens, never never happens. So I was very surprised. But it has taken me many hospitalizations to get to the point. You know I think that they really don't like to give you a whole lot of information and um I think that they feel threatened by parents, so it almost feels as if it's them against you and I've known Dr. A. actually for a longer time than at Corner we met when she was a resident at Newland Hospital. So I've know her a long time and she knows Andy and sometimes she has preconceived ideas. Her um----She always thinks that Andy's difficulties wide up being from reflux and they are not. And he doesn't have reflux and she always thinks that pneumonia is from that so it's very hard to get past that mental block. But I think that we did this time so---

Q Did you ever do the testing?

S Yes, yes we did.

Q To rule out reflux.

S Yes, with Dr. H., he had one of those I don't know what you call it.

Q Endoscopic?

S Yeah, you come home with a monitor and a filament--a pH probe. That whole, thing, and it was negative.

Q That was good. Why do you think they let you stay this time when they did a central line?

S I actually think she stayed because----she let me stay because I think that after all of this time I think she is beginning to realize that I am not a strange mother that gets in the way and that doesn't listen, you know, but it has taken this long--------its actually taken this long.

Q How long has it taken?

S Since Andy was born, since maybe he was three months old.

Q She knew from Andy TFC? Was that where he was born?

S No he was actually born in Randal, he was transferred over to Corner in their neonatal ICU and he had vocal chord paralysis and they didn't realize that he had any other problems. Nothing else had come into evidence at that point. And um----there were no pediatric ENTS at that time so Dr. S. has suggested that we go into TFC hospital to see Dr. W, who's the ENT there, a pediatric ENT. So that's where we wound up and that's how I wound up meeting Dr. Um, what's her name. I get the wrong name(pause).

Q She's Asian?

S Yeah, It's not Dr----

Q A.?

S Dr. A., that's right. Dr. G. is the pediatrician who is on call for other things but it's not Dr. G., it's Dr. A., so she met him as a resident there. I think as a resident, and um. Then she wound up as being in the ICU, she wound up being the director here at Corner and that's how we met again. But I just think that parents um----their opinions don't really count. I think that the doctors they're trained a certain way, I don't even know how, but they are certainly not trained as nurses are trained and I think they are trained, and they are here (pointing up) and the parents are here (pointing down) and their ideas and their opinions are gold and they don't really ask the opinion of the parents and um-----they also have this assumption that you are going to overreact to everything because you are in a stressful situation. And that may be true for a lot of people but it's not true for everybody and I resent that they come with that immediate assumption without feeling you out to see how you are. And I think that it has taken a couple of years-----dealing with any one of the doctors that we wind up dealing with in Corner----to change that feeling just in myself, just with me, it's always very hard so I actually think that she let me stay because after so many time meeting her she knows that I'm, not going to get in her way and I actually can be a help, so, I wound up staying and assisting her-----when nobody else was available, and that's my child. It's not something that I want to do but, the poor thing, how many times can you be poked and I think that he needs somebody to stay with him besides people that he doesn't know. Why should I have to leave?

Q When you approach her, or any of the physicians, do they ever give you a reason why you can't stay?

S Because they will say that they are doing their rounds, and it's for educational purpose and it's not that I want to stay and listen to somebody else's child's rounds, but this is my child and I feel that I have every right to listen to what they are discussing. This is about my child. You're learning about my child. And so I should be, I should be allowed or permitted to sit there and listen. And maybe I'll learn something about him that you haven't told me. So that's the other thing, I don't think they tell you everything and even if I hear stuff I can't remember a particular incident, but um--I wound up, this was on the regular pediatric floor when he hadn't been in ICU yet, but they were making rounds and they were outside his door and I heard a couple of things being said about him when I went in afterwards and I asked and they got very indignant that I had even heard that and they tried not to answer those questions, so that's I always feel like they are hiding something. You know they were questioning things, they hadn't come up with a complete diagnosis, or all of their answers but, but they were still questioning and I don't think that even like you to hear what they are thinking about or questioning. Um--, I think, that they think that you'll get carried away with something. I'm not really sure. But they weren't very happy that I heard it anyway and it's about my child. How can you say that? They make sure the doors are closed. They will try to do rounds when a parent is not around and if you are in the ICU they completely ask you to leave, so I don't think that that is really good. You know.

Q Did you ever refuse to leave?

S Actually I probably haven't. I um---I don't think that I have. Because I don't think that's going to benefit anything. If it was a procedure that they were doing and I intended to stay, they are not going to get me out of the room , but if they are doing rounds I just don't want anyone resenting my child. Because then it's like a block. They'll never tell you anything then. They'll never tell you anything, they'll never help you, it will just be an attitude thing and I don't want that either, so you have to try to do what's best-----for the child involved. So I find that hard.

Q Do you stay when they do the procedures or was this the first time that they allowed you to stay when they did the central line?

S That was the first time they allowed me to stay in the ICU. On the regular floor I'll stay. Most of the time they don't ask me to leave, because it's a resident, but um--but in the ICU you are pretty much asked to leave. And it's hard you don't want to leave, he's already upset and not in a good way, so---I can understand I guess that they are worried about the emotions of the family person, but I wish that they wouldn't assume that about everybody. So that's what I find difficult.

Q Have you ever said to them that you just want to be there to comfort--?

S Yeah, but it's their policy, you can say it, but that's their policy and I guess that they feel if they switch it for somebody then they would have to switch it for everybody. I just don't know what their reasoning is. It's just my opinion, but I always think that when they say no it's really because they don't want you to hear anything that is going on. I really think that's it. You know you have a hard time. And they are going to do to your child whatever they want to, when you're not there. You know if they are having a hard time doing a stick or whatever, and you are not there to say no stop or get somebody else. So that I find hard. I also find it hard another thing that wasn't good when I was there, and these are just little things. These have nothing to do with the big large things. Dr. A. came in with a resident. The resident never introduced himself, just started working on my child and I stopped him and said you didn't tell me who you were. And I think that is very rude. And it wasn't an emergency situation, it wasn't anything like oh boy something's happened, everybody better come. This was he was coming in I don't even know if he was doing a blood draw or, but that sticks in my mind. It happens all the time people come in and they do not introduce themselves and I'm the parent and this is my child and you want me to have trust in who you are, but I don't even know who you are, I don't know what you're doing here and what you plan on doing to my son. You know he is still mine and I still give consent.

Q What did the resident say----?

S He apologized and then he introduced himself. So. I even find that hard. Why should I have to do that? You're already in a stressful situation and I shouldn't have to ask. I don't know if it's his personality or the way they are trained or if they just assume that they are the almighty doctor and they can come in and do what they want. It's not true, it's really not true.

Q What about the nurses? Um, what type of relationship did you have with them?

S For the most part it's very good. Some of them I've known for a while and some of them are new and for the most part they really try to be very helpful and try to answer your questions. They don't really know what the residents or anybody else thinks either. They only know what goes on from day to day. And it's an acute care setting so they don't follow your son, my son, sometimes not even the same ones take care of him everyday. So I think that's hard too, especially if your child is in there for 21 days, you would like to have one person take care of him but they all take their rounds. They aren't able to always answer specific questions. Then you have to wait for the residents--- that's a little hard. But for the most part they're willing to try to give you any answers. In the ICU, only there's always somebody available. On the regular pediatric ward in Corner it's terrible. You can't leave your child. I wouldn't leave anybody there. There is not enough staff. Not for this hospitalization, but these are experiences that lead me to feel the way I feel particularly about Corner and the hospitals and things like that. He had been in there for uncontrolled seizures and he was on a regular pediatric floor and he was in an isolated room I think because they didn't quite know what his problem was. So at the time they put him in an isolated room with a child with a trach, a handicapped child, he can't call out, he can't even express his needs and he had also had I think pneumonia so he was in a mist tent in an isolated room way up the hall away from the nurses stations. I went out and told them that I was going to go downstairs and grab a cup of tea. I went downstairs, got the tea brought it back upstairs, he was in an uncontrolled seizure in the bed and the plastic bag from the mist tent was wrapped around his head-----Now that's not good, that's not good at all. I mean something could have happened to him.

Q How long ago was this?

S About 2 years ago. He was two or four actually he was four. And actually he had even turned himself upside down in the bed. I don't know how he did it, but his head was now at the bottom of the bed, his mist tent was around his head, and there was nobody there and the monitors were going off. So I don't think that that was so good either. Nobody is available. I think he gets better care when he is in the ICU only because of the better staffing---but that's the budgetary system so-----

Q This last admission, was he only in the ICU?

S This last admission he was only in the ICU. I think that this last admission and the one that was immediately before it, really are related because I don't think that he was really ever better. And so I think they discharged him the first time too soon out of the ICU. And that's another thing that I don't like about the ICU.

These doctors only treat acute illness. They make that acute illness okay and then discharge. But when you are dealing with a handicapped child who does not respond the same way that a usual healthy child responds you can't treat them the same way. So okay, pneumonia may have looked like it was resolved, but I'm telling you, he's not okay. I'm telling you he is not fine. But you sent him home anyway and he is back in two weeks. So that's really another thing that was very frustrating about this last admission. He was never really fine the two weeks in between. And they discharged him anyway. And although I'm a nurse and although he has nursing care at home, I don't want him home when I know he has pneumonia because I know how bad he gets very quickly. So it's these kinds of things that they don't listen to you about and that's frustrating.

Q What did you tell, what did you say to the physician the admission before, that you just knew that your child wasn't well?

S I just said to them that his Sat's are not really right, he doesn't look well, and they look at the x-rays and that kind of thing and they only see him also when he is acutely ill, they don't see him on a normal basis. On a normal basis he sits up, and he's active and he's responsive and he's playful and although he's very handicapped and can't do a whole lot, his personality is very alive, he's very smiley, enjoys people, enjoys social things. So when he is in an acute setting and he has an acute illness, all they see is a lump in the bed. And so they don't understand that there is more to him. They also have assumptions about handicapped children and um---

Q Such as?

S Such as this is the way they are, you know, they can't do much more. You know, so if that's how he looks well that's the way he is anyway.

Q What can he do, what's he capable of doing?

S Um well he has OT and PT at this point and he is able to stand in a prone stander. He is able to manipulate with gross motor skills toys on a tray. He likes music, he likes sounds, he likes light and he makes purposeful movements now in trying to activate cause and effect toys that have music or sound or whatever um----and those are the kind of things that he enjoys. I know he recognizes everybody in my house including the nurses and he responds to people very differently.

Q What type of responses does he have?

S Um, as far as my children, probably are the best ones. And my husband. I treat him-----I'm the one that grabs him and hugs him and loves him and squishes him. My husband will be more rough. Playful and he anticipates the roughness, the little toss or whatever and he'll either like look sideways at my husband and kinda give a laugh and wait for something to happen. With my children, my older children, my older son is a very gentle kid as far as Andy is concerned. And he'll come up to Andy and he'll gently hug him and give him a light squeeze or whatever. My younger ones are much more rough. And they're just zooming around all the time, so when they approach Andy it's much more rough and he knows that he might get clucked. Not on purpose but he might get a bump or whatever and so he flinches a little when they're around, you know like when they come up to him, but he's still laughing, he's wanting this. But he knows like to duck a little bit. So these are the kinds of things that you know he knows the difference between each one and when there is new people that come in he becomes very quiet and just listens if it's a new nurse or new caregiver. He isn't, he isn't as vocal---as he is when he knows people.

Q When you say vocal. Does he babble? Can he say anything?

S He just makes noise. He has a passeur valve. He doesn't make any purposeful verbal response, like he doesn't communicate verbally at all except for sounds, like when he cries, so you know that something is wrong and doesn't cry unless there is something wrong. Um, he usually is very happy. He'll crank at you if you are doing something like washing his face, but it's immediately resolved. If you are doing something to him that he doesn't like, he will give you a crank. There's no tears, there's no sobbing. If there is something wrong, he completely cries and you know that there is a difference. Most of the time he is just very happy, so and he'll make like noises. He likes to make noises, but he's not saying anything purposeful. Just a lot of noise.

Q Well, he's not saying words that we can normally understand but in his own way he communicates. I mean you obviously understand his needs. Now when he is in the hospital when new people come in, how does he react?

S Most of the time he is so sick that there's no ability to even react anyway. You know he's either crying because he is so miserable or he's just very lethargic, that's pretty much the whole experience at this point. He's so sick by the time he gets there. I mean he has nursing care at home so he's not immediately hospitalized for certain things. And then by the time he needs to be hospitalized he's really, really sick so he's lethargic, so they never see---him healthy and happy and awake. They only see him when he's so sick so then they assume every time they see him that that's the way he is and he's really not that way.

Q Now when he was admitted for this last admission or since he has so many frequent admissions, do they sit down and take a history again.

S Every time they take a history. But they don't get into that kind of stuff. They ask the same, I wish they could just take it out of the computer. They ask the same questions about birth and up until this time health wise, but they never ask anything as far as day to day living, they never ask that kind of stuff. They'll ask what he eats, no big deal. And they are so concerned about his nutrition that it drives you crazy. But they don't ask about how he responds to certain things. They never ask things like that.

Q Have you ever tried to volunteer the information?

S Yeah, but it's usually the nurses who'll get that information you know I'll volunteer that, you know, don't do it this way or approach him from a different angle or whatever it is. The doctors don't even come in long enough and they are not interested in that kind of stuff, they're not.

Q Do the nurses ask you know what he is usually like? Is there any way we should approach him? Do they ask those types of questions?

S They will yeah. On this last hospitalization again he was so sick and he was on a respirator and they had him medicated so of course he couldn't move or anything, but they'll ask things about---just simple things. I mean just simple things even about approaching his trach or he's had so many miserable things happening to his face, and his neck area. Before he had the trach he couldn't breath. Now I think this last visit and this whole feeling of suffocation with him um--I assume that that's how he felt. When he was a baby he couldn't suck, he couldn't cry his Sats would bottom very low into the 50's, um everything exhausted him before he had a trach and so I think he must have had this feeling of----like being suffocated all the time, so when anybody would approach him face on, he really backs away and it's very distressful to him. He also had, before he had a g-tube he had a lot of N-G tubes so that's miserable all the time. And so when you approach him you kinda have to come from the side. And you have to---even if you are just washing his face or you want to comb his hair or do anything to him, or you know brush his teeth, you kinda have to come to the side and you have to approach him as if you are playing. Make it a pleasant thing, you know. It doesn't have to be my way, but whatever your relationship with him it is, you just have to make it play. He has to understand that you are not doing anything bad to him. And so the way that you have to approach him is that way. And um--the nurses will listen, but I don't think doctors listen. You know even if they go to put an IV into him they go over his face. You don't have to be over his face. Your arm can't be there. Because he won't stay relaxed, because you are in his face. He doesn't know you are trying to access his arm or his leg or whatever. If you are near his face he assumes you are going to do something bad to him and he starts flinging himself around so these are the kinds of things that they don't listen to, they don't hear.

Q Does the nursing staff ever try to communicate what you have communicated to them to the physicians?

S I really don't think that they do. I don't think that they are they're that comfortable either with it. I think they have a different relationship with Dr. B. who is another attending and then there is another doctor a Dr. M. who we only met after this last hospitalization. Most of the time we see Dr. A. and I think that's because we wind up being there when her rotation is on. And um just the way the cards fall. I don't think they are that uncomfortable telling her these things.

Um Dr. B. is someone that will listen a little bit more. And I have to say this and maybe after Dr. A. had children of her own she is very different. She had children of her own since Andy was born within the last couple of years and um ever since then she's a little bit different and I think that that has affected her. You asked me why you thought she let me stay when she was putting the central line in I think that has a lot to do with it. I do.

Q How has she changed? What changes have you seen over the years?

S She's not so clinical, she's a little bit more personal. I mean her personality, is her personality but she will listen and she is a little bit more motherly, I think that doctors whether they are male or female have to have a little bit of a mother and a father in them and that is not something that is taught to them when they are in medical school. Nurses have it for the most part. Whether they are male or female they have it and I think it's the way they are trained. I don't know what the difference is. I think that physicians are trained very clinically and their approach to a patient or a family is very different---I think that she has changed after she's had children. She allows a little bit more of her personal feelings to come in. I don't know if it's just with her or that would be with anybody.

Q I think a lot of people change when they have their own children. I think it's a whole different concept. I think they realize the difference. Do you see a difference in nurses as far as young nurses who do not have children and may not have a family and the nurses that you know have children and a family?

S Not always, not always. Um, Andy had a nurse that is, she's not a real young nurse I think that she may be in her 30's but she doesn't have children, but you would think that she did you know the way that she responded to Andy. And some of them that are fresh out of school-----they may not have the experience with children yet, but their approach is they try, it's very different, they may not know children they may not know that kind of thing, but they are not so clinical. They are just not. You know they have to have a certain amount of clinical, you have to be clinical, but in a homecare setting or even in a hospital they're working with children and their approach is very different if they're on peds it's just a very different approach.

Q Now when you are there do you stay 24 hours or did you leave in between?

S You are not allowed to stay 24 hours in the ICU. They make no accommodations for you at all. Um, you are lucky if you get a chair----and so they really don't want you, they really don't encourage it. And I don't really understand that, it's one of the only hospitals that I find like that. Um. Even on the regular floors now Andy was of course in the ICU this last admission but um on the regular floors they don't make accommodations for you either. They have a chair, you can get a hospital chair if you can find it. There's no way to get coffee anywhere. They just don't make it comfortable at all. You know I think since I was there they have a coffee machine. There really is no facilities. The cafeteria closes by 8 o'clock. Um--they just don't encourage family participation or families to stay. I don't know why. And the ICU doesn't allow it, so forget it.

Q Did you ever question them about it?

S Yeah and they just say that's the policy----you know. Some of the nurses---the doctors will say that, the doctors will say that's the policy. The nurses say that there are some families that just abuse it. And so you can understand that too. But then the hospital should deal with that. That shouldn't affect every family. You know if there is a family that comes in, you know I think that there are times that they have families that come from maybe other areas or other countries that have special surgery for their children and maybe they bring along all their equipment and everything they have and they bring it in, but that should be dealt with a social worker on an individual basis. It shouldn't affect every single family that's there. That's not fair to my family, to my child. I don't bring in and cart in kinds of stuff. And I find the need to stay with him, he's my child, he's in a very scary setting and I don't get in the way and I leave when I have to leave, so why can't I stay?

Q How long did you stay on an average each day?

S Each day. I would take care of what I had to deal with at home. I have 5 children as you know, get everybody off to school, I'd go in probably by 10 and I would stay well into the night. I would leave maybe 1 or 2 in the morning. And that's how, I would wait until he was asleep. As far as I knew. I knew he would wake up in the middle of the night and I would stay. And that was pretty much every day. And if I couldn't be there then someone else would be there. There were hours. And of course this was Christmas also. Christmas season that I had to deal with getting gifts for my other children, finish dealing with that kind of stuff. So there were times that I couldn't stay so I would have somebody else go in. And that I have to say was something that was good about Lynwood and this admission. If I let the nursing staff know and they would relate it to I guess to the resident or the attending on. It didn't necessarily have to be my immediate family. Nurses that cared for Andy were able to stay with him. They didn't do the nursing duties that Corner nurses are responsible for. But they could stay with him and be with him because that was somebody he recognized. We have long term nurses with Andy. They have become part of Andy's family. So I have to say that yes they did allow that and that was good. They understood that at least. Yeah that was good.

Q Now the hours that you spent there. Did they ever come in to see you to speak to you to see how you were doing, if you needed anything?

S The nurses did. The nurses would ask. Physicians don't ask. Physicians don't do that. The Attendings anyway. There are some doctors there that know us. Long term again, Dr. H. who is a Gastroenterologist, Dr. H. who does Infectious Diseases. They know Andy and they will come in and just say hello. And I find that that's good even if they have no reason to see him. They'll come in and just check to make sure that everything is okay so if I have any questions in their area, that's what I find good. And Dr. H. has a nurse practitioner and she actually, she'll come in and say Hi. So I think that when a doctor has somebody that works that closely with him, like a nurse practitioner there is a change also. They are not so clinical.

Q Does the nursing staff make sure that there is a chair to sit on? Or that you know they will come in and say you know do you want to go get a cup of coffee, I'll watch Andy for you?

S Um, in the ICU it's very different because they are there all the time and he had a nurse that had only him or maybe another patient so he was pretty acute at the time. So I knew that I was able to. I could leave pretty much when I needed to and wanted to. The chair situation is another story. You know if I'm sitting on the radiator and things like that there were no, there are no accommodations there. And this was a year ago. I don't know if it's changed but that was my experience at the time, so I find that very very frustrating.

Q Did you ask someone to get you a chair?

S I would. You know I would ask. There's no comfortable chairs, you'd get you know some old rickety old chair and if you ever did get a comfortable chair some resident would come in and get it, swipe it from you. You know it happens, it's true, so what can you do? You know bring your own chair (laughs).

Q Can you think of any, you know, specific incidents that occurred during this hospitalization that you were either happy with or unhappy with, unhappy about?

S We talked about my being allowed to stay with Dr. A. when she did that procedure. Uh that gave me a better feeling. This has not been the most negative hospital experience, this last one. It was one of the more positive ones and as I said it has taken years for the doctors to get, Andy is going to be 6 now. It's taken, at that point it was 5 years that they got to know me and to know him. And um, I thought that it was a major step that she even allowed me to stay. That was really very very good. And she actually did call a few times when she knew I couldn't, I had also gotten the flu now in this whole thing. I had gotten the flu, it's Christmas time, my child is in the hospital for his birthday, Thanksgiving, Christmas, New Years, you know the whole bit. In that I finally ended up getting the flu very badly. And at that particular time was when Andy was the most acute and she did call and, quite a number of times and she knew she couldn't speak to me because I had 103 fever so she'd call my husband and then there would be a 3-way conversation. So these are things that she didn't do before and I don't know if it's because she now has gotten to know us a little bit better, or if it's because she's actually had children of her own, or because she has more experience now as a doctor----you know treating families in an acute setting I don't know. But that was a much more positive experience, but it didn't happen before.

Q When she did do these few things did you mention to her how glad you were that she did it?

S Yes as we were standing in the room, and she was doing her thing with this um--femoral line. I said to her you know this is the first time that you've allowed me to stay. She said something like well yeah I guess so. You know that kind of thing. Just the little acknowledgement was very good and um----that time also, the second time that was he was in, this was the second admission, he was admitted again December. November he was very sick, the second admission when I brought him in on the first day that was a Thursday, I'm pretty sure he didn't look that bad. And I knew he was getting sick and um she actually did listen to me. We brought him in, he was sitting a stroller, he was up and he was smiling and he was happy. I knew he was sick and they took him right into the ICU, they didn't make him go onto the regular floor and um they did all of their testing now this was Thursday night and she listens to me. He didn't look like he needed to be in the ICU but by Friday night, actually by Friday afternoon all of a sudden he bottomed out, his SATS went down to 9 and they had a very hard time getting them up. And I appreciated the fact that she listened to me that I knew that he was going to get that bad. I didn't know that he was going to get that bad but I knew that he belonged in the ICU. So I found that that was a very positive thing. So this admission again was not as bad----but why does it take 5 years---to get to that point? The previous one which only was only two weeks prior was a little bit more difficult because they didn't listen right away and so when you don't listen right away and then the child winds up being in a bad way it's very frustrating.

Q So the admission two weeks before, he was admitted also for pneumonia?

S Yes, he was admitted on a regular floor and uh-----he was on a regular floor and you had to deal with the residents and they really don't listen. Residents do not listen at all, and um, I knew what was happening was, I um, his SATS would go way down, I'd do a lot of chest PT, now there is nobody around, I'm the mother, I'm not supposed to be doing this, um, but since I'm the only one around, nobody else comes in, also like I guess I'm scattered a little bit, but when you have respiratory therapy they come in they plug the medicine on and they leave. They do no chest PT, they do nothing, what is that? What good is that you know you plug albuterol in, aren't you supposed to do chest PT or something with this kid? They don't, nobody does, they put the medicine in, they listen with the stethoscope and they leave. That's not good either and I know it's supposed to be done another way. So now the child is in the bed there's no nurses around his sats keep going down, I kept calling. I called a resident three times in one night and she probably thought I was nuts, she would come in she would look at him, she only came in twice she didn't come in the third time. Finally the kid bottoms out so badly that they almost called---they actually did call a respiratory code although he hadn't stopped breathing and then he wound up in the ICU. This is what makes families crazy. I know he's not good. I know that his stats are going down. I'm doing a lot more chest PT, more than I should be doing. His sats keep going down, I suction him, he's fine for 15 20 minutes and they keep going down, he also had apnea, but they don't listen. They don't listen because he's a handicapped kid, they think he's that way, does he have apnea at home, yeah, but its central apnea it has nothing to do with being all clogged up. But they don't listen. And so that's what I find very very frustrating. So then a big thing has to happen before they listen to you. Now he's almost in respiratory arrest, he didn't really code, but they called a code anyway. Everybody comes flying out of the walls and now you listen to me.

Q Did you say anything to them after this occurred?

S Yes I did, I did---

Q What did you say?

S You know I said to the nursing staff and I said to the doctors, it doesn't have to come to this, I told you he wasn't good and why didn't that doctor come in who was on call and listen to me. It didn't have to come to this. But that's the way it happened. And you don't get really a response. It's all that kinda like they pat you on the head and you don't get a direct response. Yes it should have been different, or anything. That's the way it is.

Q When you told the nursing staff about how you felt about the changes and that you felt that Andy was getting worse did they try to contact anyone?

S Yeah they did. One particular nurse, I guess Andy had her she was the one that would listen to me. She didn't really see what I was talking about either, but this is my child I've known him a long time, I take care of him at home I know him. She's the one that kept calling the resident and the resident only responded two times and would not come in the third time and so I think that that's not right. That's unfortunate.

Q Why wouldn't the resident come in?

S Because he came in two times before and he didn't change any the resident said. He looks perfectly fine, he's you know----So those are the kind of things that I find extremely frustrating.

Q When they say Andy was perfectly fine do you explain to him that you know he has this he has that?

S Yeah I do. When the resident came in the second time she seemed a little bit put off. And I guess I disturbed her sleep----too bad and I said to her you know he is desatting, I keep doing chest PT I keep suctioning him, sats are fine right now because I just did it and now you are walking in when they are fine. They keep going down into the 80's. It's not good, his respirations are very very high, his heart rate is going very high, but this is how he came in. But he was getting worse and it was happening more frequently, the times between when I could get a sat stable and his heart rate kept progressively going up. And it didn't make a difference. She just assumed that I was another wacko mother who is overreacting to the situation. And she assessed him and that was the end of it and she went away. The next thing you know, I guess it was the following morning, he wasn't so acute during the night, but I saw it coming, I knew this was coming, but nobody was really listening to me. All of a sudden now and it happened in a flash, all of a sudden his heart rate went way over 200, his respirations were well over 80 and that's when they started calling the code and his sats were going down, down, down. That's when they called the code. But why did it have to get to that? Maybe if they had listened to me he wouldn't be in that situation so badly, so quickly. But they don't listen to you so---

Q Do they know that you are a nurse?

S I try not to tell them that, because that can work against you,but they know it now.

Q Why do you feel that way?

S Because then they really don't tell you, they really really don't tell you anything then. They don't volunteer anything because they know that you know a lot more than a regular parent does and they can't snow you and they can't put you off. So I try very hard not to say anything and if its new residents I don't. But it gets around. The nursing staff knows I'm a nurse. The attendings that are there all the time know I'm a nurse so if a resident comes in he will find out or she will find out that I'm a nurse so the approach is then a little different. Sometimes its positive, but a lot of times it's very negative. They become more secretive. I guess it's because maybe they think I'm watching every move they make which of course I am (laughs). Another thing that I find very distressing at Corner is cleanliness there. They don't come in and they don't wash their hands before they treat your child so I have to put signs up all over the room. I don't think that's right. They are taking from one child and passing it to another. And um---that's not good, Andy now has, he's colonized with stuff, he wasn't colonized before certain hospitalizations, after a certain hospitalization he was colonized. That's because they don't wash their hands. Now he's got, whatever he's got. But I don't know what it is.

Q What do you put on the signs?

S Did you wash your hands first? Would you please wash your hands before you touch me? I put all kinds of stuff all around. And it helps sometimes----and sometimes it doesn't. I think they need a good infection control person over there but I don't know who would handle that but I think they do and I think somebody has to be much much more like more like a policing this.

Q Do you find that both from the nursing staff and the medical staff?

S Yes, that I find both.

Q The nurses don't wash their hands either?

S There are some that do and some that don't. For the most part I find residents don't. Attendings will---but not all the time.

Q Do they ever say to you who put up those signs?

S They know it's me. Or I'll sign Andy's name on the bottom. Please wash your hands before you touch me. You know. That kind of stuff.

Q When they are taking care of Andy do they interact with him?

S Um----Some do. Nurses will. This last hospitalization he was really sedated a lot. So they didn't really. I would think that they should talk to him. Even though you don't know if he's awake or not with the medications that they were giving him. They don't really. They come in and do their thing. They come check the respirator, switch the buttons and that kind of thing but they don't really interact. If they are getting lab stuff they don't really interact. And I don't think that's so good. The nurses do. They care for him, they give him baths and they get to be more personal. I don't know if physicians are afraid of becoming more personal, I don't know.

Q If you are sitting in the room and the nurses come in to do a procedure do they they talk to you and tell you what they are going to do or do they just come in and do it?

S The nurses do. Or I ask. Nurses pretty much will.

Q Do you have to ask them?

S Sometimes I do. If they come in and hang another bag or whatever they are hanging you know I will have to ask. But it's not always. I guess it depends upon the individual, you've got personalities involved.

Q Now when you come in do you see other health care providers besides the nurses and physicians that were in the unit?

S As far as what?

Q Social workers, dietitions, physical therapists, respiratory therapists ?

S Respiratory comes in and they don't really do what I think they are supposed to do. I don't know what their um, I don't know what their job description is there, but I think that a respiratory therapist isn't just supposed to put medicine in and then take blood gases and things like that. If you do respiratory treatment I was taught in nursing school that you also have to do some kind of chest therapy. They don't, nobody knows that kind of stuff. It's left to either the nurses or the mom, so I think that that's unfortunate too, um. PT would come in----because I had requested it. That's another thing that they don't do. This is a handicapped child. He's already going to be so behind and um----what happens with handicapped children and especially with Andy is they regress. Instead of just staying where they are they regress and so when they are acutely ill and you have PT and OT available even if you can only do passive range of motion don't you think we should put that on the chart right away? You know for whatever the child can tolerate at least he can do that much and they don't unless I ask. And I think that is something that I think they maybe have to get a better history for or something. To know it's available. And if the child can tolerate it even just passively.

Q When they come in do they do a thorough history?

S They do a history as far as clinical stuff but they don't really do a thorough history as far as his day to day stuff and that's what I really think they need more to do. They have all this information. Go plug it in the computer. Ask me what he's doing today, ask me what he's doing as far as therapy and schooling and that kind of thing. Then they'll get a picture of what he is like on a regular basis. So I think that's something that's lacking in the history. Who cares about how my pregnancy went at this point--you know.

Q Now do you try to give them this information. Do you ever say to them let me tell you how Andy interacts, things that he doesn't like, things that he does like?

S I will eventually to the nurses. It's not when---

when I bring Andy in he's sick and um like I don't think about that right away and it takes me a couple of days to realize he's not getting PT let me go ask them to put in an order you know then I'll start telling them but it doesn't happen right away. It's not something that I can keep track of when he's so ill. It's not the thing that's uppermost in your mind. So I will eventually, especially, when he's there that long I will eventually say wait a minute you forgot about this aspect. You know.

Q When the physical, when the respiratory therapist comes in and does the treatments, do they ever ask you if you've seen a change if the respiratory therapy is helping?

S No, no, they don't really ever ask anything. Those if I ask they will tell me what they are doing. And they become personal like after a three week period of time they begin to become, if you see the same one, they'll become a little bit more friendly and they'll talk to you and they'll tell you the changes in the setting of the respirator or why they are doing certain things and why they put it, it's not right away and that's difficult I think. Especially if you are there not such a long time, you know you don't get to have that interaction with people.

Q You were there how long, two weeks?

S This time it was 3 weeks. And the time before that it was probably 2 weeks.

Q So you were 3 weeks in the ICU and you spent most of your time there.

S Pretty much, um--------pretty much I did but with the holidays it changed a bit because of what I had to deal with. My other children had concerts and this and that and then I have to deal with gifts for them, you know, I'm never ready. On a regular basis I'm never ready, and then when something like this gets thrown in that really put me behind and then I was also sick with the flu. So when I was well I was there most of the time.

Q Now if you want Andy to be cared for in a certain way, as far as positioning or changing clothing or feeding and you tell them this. Do you find they respect your wishes?

S When you are there (laughs). When you're there. They will but they don't pass it along either. I think that's another um problem. If I tell something to a nurse that's taking care of Andy on 7 to 3 it doesn't necessarily reach the next shift or the shift after so I find that a lack of communication sometimes is a little difficult too. They also deal with the clinical part of it, they don't really always remember the stuff that to them is not quite as important. But it would make his stay easier you know, that kind of thing.

Q How do you know that when you're not there they are not doing what you ask them to do versus what you are seeing?

S If someone else goes in and I'll ask them did they do such and such. Then they'll tell me no or if I go in and find him a certain way, you know, now finally after awhile---you see one of the things with Andy also and this may sound like it's not a big thing but Andy has a lot of distress from abdominal gas, he has so much air and I think it's because of his trach, he swallows a lot of air they don't listen--------that sometimes he's crying and all you have to do is vent him, all you have to do is vent him but they don't listen to that. And they didn't for quite a while and they took another chest x-ray and they saw a monumental amount of air in this chest x-ray that the physicians came in and told the nurses they had to vent him. So it's kind of like these little things that you say like this if they would just do this---but they don't listen. These are even little things you are talking about positioning, but this to me is like daily care with Andy you just vent him and you have to do it and if you don't he's going to have a bellyache and you'd better vent him before you feed him, because if you feed him first then it gets all clogged up and---they didn't until finally now they have it on an x-ray, monumental amount of air and the physicians actually come in and say look at this you've got to get this out. So they really don't put credence into what you say. So I find that hard.

Q Is he fed through the gastrostomy tube or does he suck?

S He'll suck on a bottle and he'll also eat pureed food. Not always great, but he does. Right now today he has a great appetite, but at that point when he's sick you don't feed him by mouth everything goes in a tube. So they had him on a pump which was okay but he was still getting a lot of air in his belly and um---they had to vent him. And they didn't get it, they just didn't get it.

Q Now your hospitalizations were so close two weeks apart---when he's out on other units, which is not the ICU and it's not that clinically---as clinically oriented as being in the ICU, do you find that the nurses ask you what's the best way to feed Andy, what's the best way to position him?

S It's less, it's even less helpful there because there is not enough staff. They are just happy that you are there. They're hoping that you stay because they can't do any of that. They'll come in and they might put up the IV bag or give him whatever medication, but for the rest of the time they are barely there. There's not enough people there.

Q Do they ask you for help?

S Yeah they do. They have to. There's nobody else there.

Q What do they ask you to do?

S Um, if they're doing um---beds and changes like that, a lot of times I'll do that. Sometimes they'll even leave a mess there which I don't think is so hot, because they know I'm a nurse. I'll do it, because I know what's in the thing and it's labeled but legally they're not supposed to do that, you're not. But that's what they do.

Q Do you ever give treatments?

S I have to. I haven't done like albuterol a respiratory therapist will do that, but as far as suctioning and chest PT I have to do it, because they don't do it.

Q Do you resent having to do it?

S Um, when he is in the hospital yeah I resent it, yeah I do. I do it at home and he's home and it's fine and it's my child and I do it, but I don't think that I should be the sole person doing it in the hospital because who's assessing him then--you know of course I'll do it there but I don't think I should be the only one doing it.

Q Do you find that nurses just assume that you are going to take on this role or did they ask if you if you mind doing it?

S Some will assume, some ask. Um some have no time. Some have no time. I think it's not because they don't want to, I think that maybe it's because there is one nurse to maybe half a floor. That's not good and so I think that part of this is because of staffing. And it's administrative problems. But it affects the family. There should be more people there. I should not be afraid to leave Andy. I shouldn't be afraid to. But a lot of times I can't leave him because there's not enough monitors around. He's on an apnea monitor and an oximeter at home. When I go there, there's not enough and I then certainly can't leave him. Because even if, even if he's hooked up to that at least the alarm would go off and somebody can look in maybe he's moving but at least you know that, if that's the only reason why it's going off. But then as I said before there are times the alarms will go off and nobody will go in because nobody hears it because there is nobody out on the floor. There's nobody there.

Q When you do leave, how do you feel about leaving? Do you leave him alone or do you leave someone there if you are going home to take a shower, or to eat.

S Sometimes I have to leave him alone. I have high anxiety over that. Not particularly when he's in the ICU because he's hooked up to every kind of monitor. I'm treating these last two admissions pretty much the same because they were just so close and the very last one I was solely in the ICU I could leave comfortably because I knew that there was always somebody there and he was hooked up to so many things and if an alarm goes off there is somebody there. When he's on a regular acute floor there isn't anybody there and the anxiety that I have, like I go home and do whatever I have to do right away and either I make sure somebody's going to get there or I try to fly back. Because I don't think that he's safe. I really don't think that he's safe there on a regular floor.

Q It must be frustrating.

S It's very frustrating and it gives you such high anxiety. You then and to have these feelings, my approach to the physicians isn't always as good as I want it to be. Because I'm so stressed out and I have such anxiety that I'm already mad that it's this way. And so then my relationship with the doctors maybe isn't what I would rather it be because then it's going to affect Andy and their approach to me is like I'm a lunatic. So and I find, what I find also very stressful is that I always have to be aware of how they are perceiving me. I cannot just have emotions. I have to be very controlled. Because if I'm not controlled then their assumption of me is going to be true and so then well, you see she's a nut and she overreacts and then they really won't listen to you. So when you are already in a stressful situation and your child is already sick you have to be very guarded on how you approach anyway. And um, that's extremely frustrating because you can't always be very um--calm when your child is sick-------and you can't always be um, I don't know, you try to be, you need something you are trying to be not aggressive but you wind up being aggressive and um that's not good either.

Q So what you are saying is that unless you're aggressive and you start yelling or demanding things you are not getting what you need?

S A lot of times that's true, but that also has a negative effect. Um. My approach, I try to be what is the term not aggressive but, it's um--------------

Q Passive?

S No, it's when you are try to get something that you need but not be aggressive about it you are trying to do it the right way. The word is like I had a patient today what is that word, um

Q Diplomatic

S No diplomatic. Assertive, that's the word. I try to be assertive, but when you are in a very acute situation you don't have control over your emotions all the time, that's why sometimes it turns aggressive when they are not listening to you which has a negative affect then their feelings about you already-----which I think are ingrained the way they are trained, physicians, they think a family is going to be aggressive or they are going to be um--overreacting. It's like a Catch 22, they don't listen as it is and then you become aggressive and they say ahah she is and so then you don't get anywhere.

Q Do you find that when you are asking for these things and you start being a little aggressive that, do you get what you want or do you just, they just do what they want to do anyway.

S Um---it's a little bit of both. Sometimes it works, sometimes you get what you need but then after that it backfires because then nobody comes around. You know in the situation where you are aggressive they have to do something because then you're going to become a lunatic. Then they may stop. It's always over IV's and blood draws. And a lot of times that is what my aggression is over. Um, I tell them that he is a hard stick and I tell them that they better get somebody that has experience and don't let somebody try who is still learning and that in one area they never listen. So then this particular person will come in and stick him two or three times and then they will get the next person. So each person thinks they are only sticking him 2 or 3 times but it winds up being 2, 3, 4, 5 people. Now I'm mad up to here and then I get aggressive and then they wonder what's wrong with me. So it's almost always, anything that I get angry about is because it causes pain to my son. I don't usually get angry um--about anything else. But if it's causing pain to him and they are not listening to me and I know that they could change it---then I become very aggressive, very angry.

Q Now when you become aggressive and angry like that, what is it that you do?

S I become very aggressive when it comes to that because I don't want Andy to be hurt anymore than he has to be. He is already going to hurt in whatever they do to him. So I feel that if they need to start any kind of a line or draw any kind of blood they should get somebody that is very very experienced with children who have very poor veins. And Andy has been stuck so many times that of course his veins are not the greatest anymore. And I tell them that from the start and I don't feel that they listen to me at all. A lot of times the resident will march in just to get his practice and that makes me a lunatic from the very start and I'm pretty passive. I'm a passive person and I've only learn to become more assertive because of Andy and so I'll ask them and they'll kind of ignore you, you know we really have to get this IV going, well you know I've only tried three times. By the second person I've had it and I just tell them to stop. Just stop! And I've become this way because on a previous hospitalization, it wasn't either one of these two, but one time Andy was on an acute floor and again it was for pneumonia. They needed to again start some kind of an IV. They were just trying to do an IV and they had four people in there sticking him so many times, everyone had a foot, an arm and I asked them to stop and nobody stopped. I was so angry after I would say 15 minutes they were working on this child and I couldn't tell you how many sticks they made. I ran out to the nurses station, his bed was in a room by the nurses station, I ripped the phone out of somebody's hand and I called my regular pediatrician. And I told him what was going on and I asked them to stop. And that's not right. I dragged the phone into these people that are in the room taking care of my kid and I'm asking them to stop and they wouldn't stop. So that's why you become crazy. They don't listen to you. This is not a doll, this is not a piece of meat, this is my child. An you're causing him pain. So if you are not skilled at doing this go get somebody else. Go practice on your own kid. You know that's how I feel, and they don't listen. And so I've become very very aggressive. For me and I'm not a lunatic (laughs). I just become very that's it, stop! You know you have to stop, now go get somebody, you know I've learned this person isn't there anymore but I would learn names and say no, no get this person I don't care what floor they're on, I don't care where they're working. And I don't care if the person resents it I don't care, this my child and I know I don't want him stuck 100 times so you go get that person who has had numerous successes. And I think they really have to respect that. Especially in peds. And adults can tell you to stop, but a child can't, and a handicapped child. That's not right, so that I find extremely frustrating. And it is a teaching hospital and they need experience but don't practice on mine when you know that he is going to give you a hard time. So that's something that I find extremely difficult there.

Q Do you have any ideas what would help the communication process?

S Um--I think that the only thing that can be done if physicians really try to understand. Um--I think that they don't think it's a very big deal they see so much and they do so much as far as treatments go but I just of course went to an IV course recently and they have a new medication and I'm not even sure of the name of it. I wrote it down, but if they are not in an acute thing and it's not an emergency situation there is this certain kind of cream, why don't they use it on a regular basis at Corner. Why isn't that used and why did I have to learn about it through a chemotherapy tape in this IV course. I think that should be a standard thing on peds. Especially if it's not an emergency. You know you are going to start an IV, you know it's going to be miserable for the kid or you know you are going to have to do certain blood draws and I really don't care about the time, I don't care if it's inconveniencing the staff. I really don't care, I think that they should especially on the peds floor be more concerned about how all of these treatments affect kids and their own psychological feelings about being in a medical setting. If it's not going to be so painful, they are going to get calmer children. Calmer parents and they are going to have more cooperation. So why don't you make this available on a regular basis?

Q Why do you think they don't. Why do you think it's inconveniencing them?

S Because they have to put it on and it has to stay on the child for an hour. They also don't have enough staff-----to time these things the right way. Once you remove the cream, I think you have start the IV say within 15 minutes, so maybe they can't time themselves or they don't want to be bothered timing themselves to this. They can come in and start the IV whenever they're ready. And so that's what they want to do. But if they have to time it around a certain medication, they don't want to be bothered doing that and I think that's why it's not available. They don't have enough staff as it is.

Q What about if you ask them---?

S To do what?

Q Do you think you would be able to put the cream on? Say you weren't a nurse.

S I think it's very easy. As long it's the parents that can understand they would have to access that. But I think it's very very easy. Just explain how it has to be done and that's it. Maybe the first time, maybe if the child is going to be stuck or you know that you are going to have to rotate the site okay the first time a nurse that's very good at teaching can come in and show the parent directly how to put it on and do the whole thing the first time. And then the second time around let the parent do it. Alright we have to start another IV we have to change the site. We'd like to do it at such and such a time, um, we know we've taught you how to do this would you do it so we can start the IV at whatever time it is and it won't be so painful. I don't think that there's anything wrong with that. But they don't----I never even heard of it. I'm only beginning to hear about it because I'm back to work---now

Q It's relatively new, it's out about at least two years already. And they have started doing it.

S I know they use it with chemo patients.

Q And it lasts longer than 15 minutes.

S I figured it did. But that's what they told me. They would have so much more cooperation from the child and from the family if they knew it wasn't going to be so painful. And it would be easier. They probably would not have such a difficult time finding a spot because a child would be relatively steady. I think half the battle is with the child fighting. And so then the child wouldn't have to be stuck so many times.

Q Did they ever ask you to stay and hold the child so that it would make the procedure easier?

S I don't leave when they do IV's that I won't leave for. And mainly because I don't what them sticking him a hundred times.

Q Do they know that already or do you just say it?

S I just say it right out. You know, I'll say it right out, no I'm not going to go.

Q And what do they say? Do they say anything?

S No not really. They are not happy about it, because nobody wants you looking over their shoulders.

Q How do you know they're not happy about it?

S Because they make a face. It's body expression more than anything else. So. They get a little stiff. I don't know they'll make a face, they'll try to encourage you to leave, well he's really not going to be happy---well I know he's not going to be happy but I'm going to stay anyway.

Q Does it bother you the fact that they make these gestures?

S Yeah because that's really the relationship between the physician and the medical staff and the parent anyway. That's the attitude, it's them against me, where it really shouldn't be that way. It should be they're working with me to make my child better. And that's not the feeling that you get for the most part particularly at Corner. You don't get it.

Q Have you had Andy at other hospitals?

S Yeah, I've had him at Randal and I've had him at TFC hospital. And um, at Randal which is a private hospital I had a better experience there. I don't really know why, I think it's because they don't usually get such acute patients there. And they don't have an ICU peds per se but when they get a child that has a lot of difficulties they make a particular room that way and um, I think that because they don't get it-------everybody is falling all over themselves to make sure he's okay because they are so worried. It's not so usual for them. It doesn't come like this is second nature, this is just the way it is. They are more concerned, more worried about the child then at Corner. This is just run of the mill for Corner. This is just another kid with all these great big problems. So they are much more concerned. They do ask a lot more and they will go out of their way. And I only was there once with Andy, but they did go out of their way to get you know people that I said can draw his blood or you know get an IV going right away--they did do that.

Q Was that an acute admission?

S Yeah it was. It was an emergency. He wasn't as ill. He wasn't on a respirator at that point. But this was actually the first time since he was born that Andy was on an respirator that he gotten this acutely ill and that he needed a ventilator. But he has been very sick before. It never had come to that. And he was in York Hospital and it wasn't any different. York Hospital was another big hospital with their own difficulties and this was when he was newborn, we were there he was in NICU early on and then he was sent home a little after a month and I had him home for maybe two months and he wasn't doing well so I had seen the ENT and we just decided that the best thing would be a trach. Now he was in the hospital for probably 8 weeks at that point. And I had the same kind of experience and it was much harder because it was so far away. So the only time that I could really get to see him was at night. So we would schlep in after my husband came home from work, settle the kids, have somebody here, schlep in their 2 or 3 o'clock in the morning so you never saw any residents or anything like that you only saw the nursing staff. And the hardest thing at that point was I also don't think social workers listen too well. So the hardest part about that point I knew I had four children, it was six years ago they were much younger and I knew I needed some kind of nursing care at home and they knew I was a nurse and they couldn't understand why I felt I needed help. And so then they thought there was something drastically wrong with me that maybe I didn't want this child, they told me to put him in World Children's hospital and it had nothing to do with that. You know I was already stressed out before he had a trach. And now he had a trach and I need some kind of sleep. I have to be able to at least sleep at night so if I could get some kind of nursing for 8 hours at night is what I thought would have been wonderful. And um the nursing staff and the social worker couldn't understand it. They could not understand it because they only see kids in an acute setting. And at that point sometimes the doctor makes a difference and the ENT is wonderful and I don't know if it's because he's had so many experiences, with his personality it's a mixture of things. He was very supportive and they actually called a conference to find out why I thought I needed nursing care. The nursing staff was there, the residents were there, the social worker was there and I was in the middle and they were like attacking me, you know why do you think you need this and how come you're not taking your child home, because I had gotten to the point where I am not taking him home until we decide on a better discharge plan. And when I finally explained to them that I have four children already, this is a child with a trach, you told me that he is probably having seizure difficulties so we don't even know what's wrong with him we didn't have a good diagnosis, I'm asking you to see if I can get some kind of sleep and finally after all of this, then the nursing staff finally came back to me the head of---I think it was the clinician for the floor, she finally came back and she said I understand now why you are so aggravated. It had to do a lot with insurance, medicaid trying to get all of the forms filled out and I'm in J. county and TFC hospital didn't want to be bothered so they are ready to send you home. I already knew that once you're home you get no help. You have to get it when you are in the hospital. So they couldn't understand it so with me explaining all this then they understood why I was the way I was and things progressed. But it comes to that. It comes to them against me.

Q Do you work with social workers at Corner also? What are your interactions with them?

S At Corner I don't know if, I haven't dealt with them too much. I don't really remember their names. There was one on the peds floor that I felt was absolutely useless. I don't think that she does peds anymore. I wind up working with discharge planners. One was very good and one I could do without and um, it's like I probably have the card. The one that I think is very good is not in that position anymore. She used to work in ICU and then they gave her, I think her name was Paula, she's very abrupt at times, but some times I think you need to be that way. The other one, Karen, um Paula is the first nurse and I think as a discharge planner she's very good and maybe she doesn't do, she's unfavorable with all the physicians there, but she understands on a family basis what you need. And that's what you need. You need an advocate for the patient. You don't need somebody that's going to bow to the physicians just because it's easier. The other one I just don't think that she's organized at all so she's very very difficult. I would rather just do it myself. You wind up being your own case manager, your own discharge planner. But there were two of them at the time but we of course got the other one that I didn't want. So I wound up really having to do for myself.

Q Do you find that there is someone there that advocates for you?

S Paula did, she's not in that position any more so I don't know how I would find it at this point.

Q Did you have to seek her out or---

S No

Q Did she seek you out?

S She would seek me out yeah, because I guess after so much time, you know you begin to know somebody. You know even when she wasn't on Andy's case, now this particular time, she didn't have him this time I don't know why, she sought me out anyway and asked if things were okay. And she would advocate for Andy there. So um that's the kind of person you need and I don't think that makes her have friends there------but for my needs it's better. And I think that's what she's there for.

Q Oh absolutely.

S You know, I don't think she's there to meet the physicians needs, she's a discharge planner, she's there to meet the needs of the patient. And whether that interferes with what the physicians want or whether it makes their life harder well that's just too bad.

Q How was the discharge planning for this last hospitalization?

S It was okay. It was okay, um we didn't have, um pretty much Andy is pretty well set and the only difficulty was them trying to contact the nursing agency to have nursing care at home for Andy. I have no plans on taking him---if he's in such an acute way I'm not going to take him home unless there is nursing care and if they are not able to schedule them then I'm not going to take him home until it's set because even though I'm a nurse (pause) it's very difficult, it's very different for me to treat Andy than for me to go out and treat another child and I have to deal with everybody else in my family and also worry about him, and he was on oxygen when he came home, they almost thought they were going to have to send him home on a respirator but you know wonders of wonders this little guy keeps on fighting back and I just knew that he was very acute and I was just not going to take him home so that wasn't as organized as it could have been. Another difficulty was the second admission was that I was hoping not to have to admit him, and nobody anywhere could get IVs started at home which was what we were trying to do. The agencies can't help you quick enough, what good is it if nobody can do it when you need it. So if we could have gotten IVs started at home he might not have gotten so bad, but it couldn't happen, nobody could get the IVs going so he had to be admitted anyway. So I find that hard. Corner can't deal with that you know.

Q Was there a delay in trying to start the IV therapy in his admission?

S Yeah there was, it was about two days. Yeah.

Q Now was that at your request or was that a medical---

S With the pediatrician, you know he had just been discharged you try to keep him out as much as you can so he thought if we could start IVs at home we knew he was starting to get something, some kind of respiratory thing all over. I don't think that he had pneumonia at the time. I think I had gone and gotten a chest x-ray and I think maybe he had like a little bit of a shadow or whatever and so they were going to try to start something. I forget even what it was. But it couldn't be organized between the nursing agency that we have and even Corner couldn't help us out so after two days he just kept getting worse and I just finally said it isn't going to happen I know we are going to wind up admitting him and then he was admitted. Now when he was admitted he still wasn't as bad as I had said before he still was up and smiling and happy and um so then that was a need that couldn't be met and because, I guess because the delay was longer than it could have been, then by the next day he was really sick even though he had started antibiotics on the day he was admitted on a Thursday by Friday night he was really bad, so I think that's unfortunate I think, they say all of these services are available but they're not, they're not there when you need them. So I think that that's difficult and I also think that if they did something with him when they discharged him the first time, in November---

Q Such as what?

S If they had continued with antibiotics which is what I really wanted he might not have been admitted the second time. But they said that he had just had---I knew he wasn't right, I mean I don't know if that would have been the right course of treatment, but I don't think that he should have been finished with something so they finished the IVs and they thought that he was fine, but he wasn't as I said, because they don't listen, they don't understand that he doesn't look like this all the time and this is not how he is. If they had continued with something, I don't know what they could have done, if they discharged him at home with maybe further therapy of some kind he might not have been, but those of the what ifs and the could ifs, and you'll never know.

Q When you need these outside services, do you have to negotiate with them on your own or does the physician call or does the nursing staff that you have at home call?

S It's a combination of things, because not everybody knows what's available. For the most part a physician will---like if he needs IV---the physician had to call the nursing agency and then the nursing agency at that point is supposed to come with um--who they are going to use. He just puts the order in the physician and then it has to go from there. But I don't think the services are readily available. Obviously they weren't at that point. So they don't have, even the home care agencies, I don't really think that they really had an IV team at the time, or if they did it wasn't available, you need it acutely, I need it now, I don't need it like next week, you know you can't plan for it that way and they weren't willing to let the nurses here do it even though they have IV experience and they have also been ICU nurses and stuff like that, they weren't willing to do that.

Q Whose they?

S The nursing agency.

Q The nursing agency wouldn't allow the nurses in the house to treat---

S I think so, yeah, they wanted to go through an IV company. I think it always boils down to either money or liability and in the meantime the kid in the middle, the patient in the middle is stuck, so I think the agency is worried about liability maybe because they don't have the right IV team and if these are all concerns then they should have this all set up to begin with you know it shouldn't all come to light when a patient needs something. So I don't know---

Q What changes would you like to see made in the hospital arena?

S I think that something that would really help the physicians a lot is if the physicians doing their training really had to go out and spend time, they have rotations on different floors in a hospital, different areas, I think they need to do it at home. I think they need to spend a long time with families whether it's with the elderly or child or I mean I think that in their training it has to change, they have to actually live with the family as that may be and spend a long time with the family and actually take on the care of the child or an elderly person. Not just go in as an observer, but actually be there and care for somebody at home so they can know what it's like if they are going to be treating children or even elderly people that are going to be home with disabilities. The health care system is now all switching to home care. So they get you in there, you take care of whatever the acute illness is and then they boot you out the door but nobody's worrying about what happens to them afterwards and I think that if the physician is more aware of what happens in a true home as they are trained, their decisions would be---would involve understanding. I think that would be a big help and I think that that is like high pie in the sky, the ideal thing, but it would help. I think um--in the hospital if they would take a little bit more time trying to understand-----especially for peds---like if they would talk about and try to understand what he's really like. They don't see him on a healthy basis but if they would try to understand a little bit better what he's likes normally then they would understand when I was telling him no he's not right, no he's not really well enough to go home, no if you send him home I think you have to do something else with him because he's completely not right I think they would understand that a little bit better and I also think that they need more staff. You know I know that the health care system is in a crunch for money but I think you need more staff and-----it affects the patient in the long run.

Q Do you think nursing needs to change it's ways or react differently to parents?

S I think that nurses in general are very stressed out in a hospital setting and I think that even if they wanted to spend more time with the family they absolutely can't. And so I think that those kinds of things have to change. I think that if nurses had inservices at the hospital relating to these kind of issues like working more closely with the family and understanding a baby, a child, is not just a child that's not the only patient, you really have the family to deal with. If they understood that a little bit better they could deal more effectively with parent's anxieties and parents could work better with the staff. I think that would be kinda a big help. I don't think nurses are kind of aware that sometimes they just fly in and fly out but that's very stressful. But I think for my own opinion for the most part is the staffing. They are not staffed very well. The ICU is fine, but because they are so acute they are not thinking of even the personal stuff either and so a little bit more of that would be a big help. You know inservicing or talking about yeah you have to deal with the IVs and the bags and the respirator and the treatments and the doctors orders, but you have to remember that there is a family there too and you need to spend some time and not only the first nurse that sees you but it has to be all the nurses that take care of him. So that's another thing. The first nurse will talk to you and get a wonderful history even if it doesn't include everything that you need but it never follows through to the people behind her it never does and so they don't even know.

Q Does your realization that nursing is so short on help and so stressed out does that change the way you deal with them also, do you hold back?

S I definitely hold back. I think it's because I'm a nurse and I see both sides of it. I've been a nurse for families and I've also been a family so I understand and so I hold back a lot , because I understand what's going on. I understand that they are stressed out, but in the end it's really not fair to my family and to my child. It's not really fair. I shouldn't have to worry about that. That's an administrative problem and there should be staff there and I shouldn't have to worry about leaving my child you know and I shouldn't have to ask somebody to you know introduce themselves or to wash their hands or all these little things. I shouldn't have to do that.

Q Does anyone ever ask you about your other concerns, about the other members of the family?

S They will do it by a fly by kind of way. How's everybody doing at home kind of thing. And actually they are not doing well especially when you're involved in an admission it affects everybody else in the family which then affects me. You know you're not there for the concerts. My daughter remembers it to this year. Like today she said to me, next week is the high school concert and um I didn't go last year and I didn't go because Andy was in the hospital and she still remembers you weren't there. She understands it logically. She understands why, but emotionally she can't.

Q And how old is she?

S She's 15, that's the golden age where everything is narcissistic anyway. And um she's not being selfish anything she just remembers that somebody else had to take her. And I'm always there, I've been always there but I couldn't be then and so those are the things that affect everybody else at home. You know they come home from school and nobody's there or they have to go to the neighbor or whatever and okay it works for the time but it still affects them. And they also worry, because they knew he was very sick last year. Anytime I take him to the doctors now they ask me is he going to the hospital. Anytime I can go to Corner just for a GI follow-up and they're worried he's going to be sick. So I don't only have to deal with this child that's sick and the people that are in my home 24 hours a day I also have the other kids.

Q How does that make you feel? How do you deal with it?

S It's very stressful, it's extremely stressful and um-----I don't know how I deal with it. Sometimes I think that I don't deal with it very well at all. And I, I think that at this point with the 15 year old beginning to affect her much much more. She's resenting people in my home. She loves all the nurses but she wants them out of here. And Andy takes an awful lot of my time and even though I have nursing at home he still takes a lot of my time which is above and beyond any other child who would be normal. So of course I think that she's angry with him and feeling guilty about that. You know it's the whole thing and I think it affects all the other kids. My nine year old is not as mature as I think a nine year old should be. And I think that he got cheated.

That's the only term that I can use. He got cheated out of being a little guy because he was only two when Andy was born and Mom wasn't there and so then of course I know that I can't change that------------but does it make me feel guilty. Yeah it does. Does it make me angry if Andy wasn't the way he was? Sure it does. It's the way it is and I can deal with that but those feelings come up every now and then you know what are you going to do you know that's the way it is.

Q When you're in the hospital with Andy does anyone ever come to you and ask you you know to talk about anything?
S No. No. No.
Q Do you ever ask---do you ever feel that you want to talk to someone while you're in the hospital?
S There are times yeah. The chaplin comes. Once in awhile there's a nun I don't even know her name but she'll come around and I probably could speak to her if I wanted to but I don't if that's the appropriate person, sometimes like I need a psychologist you know. I don't know, I mean she will be there and very supportive in that way, emotionally that way but I don't know if she can understand all of the other things that go wrong or all these feelings that you know.
Q Does nursing ever come in and say do you need to talk to them and can they help you with anything---?
S You know it's more how is everybody at home kind of thing but the way you are approached you really know that it's just like you know somebody saying Hi,how are you kind of thing. It's not really I'm here so that I can help you take care of it if you really do have a need. Do you know what I mean?
Q Yeah it's true
S You know its---
Q Something that has to be done and they really want you to say everything is fine.
S Right exactly that's it. You already know the answer they want so you give it to them and that is something that should or could be changed. Families do need some kind of support and I'm fortunate because I have a very supportive family my husband's and my family and I also have a lot of support through friends and through people that I know here. So I am not, I usually have a lot of

help I do. So I can't complain in that respect but it still gets to you know sometimes. It still gets to you.

Q Do you ever interact with other parents?

S Yes and no. There are parents that I will interact with. Not on a steady basis. I used to a number of years ago we used to get together with a few parents and try to have like more of a support group. There was no professional person but a lot of times they get to be pity parties and I don't, I can't deal with that you know. I would rather speak with somebody that has same kind of um difficulties and they express them and sometimes that in itself is a help and maybe I'll have an idea or she'll have an idea for me but I can't wallow in that I can't I don't have time for it and it doesn't help me. What helps if somebody is positive or trying to be positive even though everyone has their moments when they are down. If you get somebody who is relatively positive even though you have all these problems and you're just trying to get ahead, that's the kind of person that I can deal with and I've gone to a number of even support groups that have psychologists and stuff and your very guarded in what you say anyway so you know you always feel like it's them against you and so we tried to do it like with families just mothers and sometimes that doesn't work either. What'll happen is---one family will resent, like they think they have it harder than another. Do you know what I'm saying. (Yeah) and that's no good. Everybody has their own problems no matter how I perceive them, mine are mine and theirs are theirs and they feel them just as much as I do even if I think that my are worse, but you can't really think that way so then they get to be not supportive then, that kind of stuff.

Q When you're in the hospital itself do you ever form a relationship, did you form any type of relationship with any parent that--

S Yeah there was a family in there in last year, their child had some kind of brain cancer and the child actually died a few days after Christmas. And just the fact that they were there, it was just more of that kind of being supportive of each other. That is really what you wind up doing. You are not in a hospital long enough to form any kind of long term things and especially in the ICU when you have normally healthy kids that come in with asthma or whatever they are in and out very quickly um so there isn't a lot of time for that. What you wind up doing is finding families that have children with disabilities whether you meet them at the doctor's office or you meet them through schools or things like that and you wind up having the same physicians that's who you form relationships with.

Q Now for this last admission and actually the one that was two weeks before because they were really the same is there anything that stands out in your mind that occurred that really had an effect on you?

S That they didn't listen. The thing that was the most distressing is the resident that did not come when I asked her to and then Andy was so bad the next day and this was the November admission like two weeks, that really stands out and it makes me very uneasy and I know when he was admitted again I wouldn't feel that someone would come when I thought and I don't that they give credence to what I say. You know especially residents that don't know. I have to say now that there are physicians that actually know my family and know how I react, they're more apt to listen. I don't have as much of a hard time, it's the new ones that come along and they're the ones that are on at night and the attendings are no where around and the people that know you are nowhere around. You're stuck with somebody who really already has a preconceived idea of families and they are not going to listen to you and I find that very distressful. And then the positive aspect of it is, is that Dr. A. she did allow me to stay, I didn't get in her way and it got to be a little bit more personal now and I don't think she is going to be such a wall if Andy is admitted again.

Q Do you feel you finally broken through?

S Right.

Q But it has taken you almost six years.

S Almost six years. Even with the, like Dr. P. is Infection Control and um right from the start though she was very very in tuned. But she's a mother, she has three kids and maybe it is just her personality anyway. And I think that she did get involved with Andy at this point because he has such bad pneumonia and um she listens. Dr. B.

listens to a point. I think that she wanted to discharge him too early. You know they still have their set ideas and I think that even if---I don't know how this would work I always thought that if parents could get together and just speak with physicians in a very informal setting it would be a very ideal thing but I almost think that it wouldn't work because it would still be them against us. They already have their ideas about how things should be and they already have their preconceived ideas and they would feel like we were attacking them and I think a lot has to do with personalities and I don't think that I have a negative---I don't really don't think that I'm negative when I first go in you know I try very hard to be compliant and to do what they want and to listen. I don't think it comes from the other way. And even though you know I'm talking about how I'm very guarded it has gotten to be this way after so long you know. It wasn't originally that way and I've learned to be aggressive and assertive and it wasn't that way when Andy first started. I used to listen to everything everybody said and I would drag him to every kind of doctor and everything that they said I would do and after turning around it's really not in the best interest of your child, so I don't know I think that I don't know how it would work. I just think that training has to start from the very beginning. It's probably too late now for some but I think it should be incorporated into training, even in nursing school and stuff like that.

Q The D.O.C.C. group that never got a chance to speak are you familiar with them? (Prior to the interview the subject realized we attended a conference where this group was supposed to present, however their presentation was cancelled.

S No.

Q That's what they are trying to do. I'll talk to you about it after. Is there anything else that you want to say or anything. I really appreciate----the interview

S I don't think so at this point. No.

Q Okay, thank you.

Appendix G

Interview #2

S She (daughter, Lisa) plays the Oboe, she goes for swimming lessons. She just finished up to where she can go now for a lifeguard course. So she does a lot of things, you know, she takes care of horses, she takes riding lessons, she works and does this on her own, like she earns her own money and takes these lessons so she's the kind of kid that does a lot and still gets decent grades. She should be OK.

Q What type of work does she do?

S Right now she is working in Carvel but she also works with horses, cleaning up yucky stuff. She'll do anything, baby sitting, anything to just have a little extra money.

Q That's good.

S Yeah.

Q If she's good in sciences she might want to think about veterinarian school

S Yeah, she's thought about that too. She's thought about that. I think people are too young when they are in 11th and 12th grade, and even the first two years of college to know what they're gonna do for the rest of their lives, so I don't know---I think it is just too early to even go in a direction of a particular major but everyone needs to take English, everyone needs to take certain math courses and language courses so within the first two years you can get rid of all that stuff and pretty much that's what you need anyway.

Q It helps then to go in a certain direction.

S Yeah, yeah, to get a little taste of everything maybe.

Q Your daughter is in the 11th grade?

S She is going into 11th yeah.

Q She's 17?

S She'll be 16 in August.

Q And your other son is?

S Bobby is going to be 15 in September and Mark is 12, Tom will be 10 the beginning of August and then we have Andy who is 6 1/2.

Q What do the kids do during the summer?

S Right now the two boys are at basketball camp and then there is wrestling camp in the afternoon. We just did a whole series of swimming lessons. So that's basically what they are doing. Bobby is trying to get some kind of job at the beaches, you know, they are trying to hustle to have a little extra spending money. And the other guys you know I'll drive them to the beach or they have a lot of friends that get on their bikes and they do things like that, a lot of visiting too, so cousins come out from wherever they are and basically that's what we do for the summer.

Q The camps that they go to, do you have to pay?

S Umm, they actually pay themselves but it's only at the schools. They cannot possibly, we cannot do anything like the camps they have at Greens but they have like a basketball camp up at our high school that is run by um--by the district and so, you know, they begin to know what is expected from the coaches and things like that and then the one that they are going to do for wrestling I think is sponsored by Jay Jay so there is no charge for that one. So things like that, that's what we do. Even the swimming lessons, no charge, I schlep out to the Shore, (laughs) found a place where we can get them for free, so that's what we do.

Q Oh, that's great. Who is Jay Jay?

S He's the legislator in this district and he sponsors certain programs, which is good.

Q How much do they have to pay for the camps at school?

S Fifty dollars for two weeks. So that's not bad.

Q That's a good deal.

S Yeah.

Q And they pay it out of their own money?

S Yeah----That's the way it is around this place. If they want to do it, they have to cause we can't. No, there's no way.

Q How do you handle the financial matters when it deals with Andy?

S It's very stressful. You know, it's really, actually right now we are in a very stressful situation because we have no money at this point. We have less than no money. We are like trying to scramble around to pay the bills and all we did was shuffle them last night and um---it's really difficult because if I worked full-time, that would be a wonderful thing but I can't because of Andy, there's lots of time that there isn't coverage and I probably couldn't handle the stress of it and the other part is um if you made too much money then you wouldn't have Medicaid anymore and so we are actually between you know a rock and a hard place is really what we are between. He doesn't have private insurance anymore and he could get private insurance but what they tell me, I had called Arkin and other companies, and they said that he would be covered but still not for pre-existing and um. So he could have insurance but it wouldn't really do us any good. So he has to stay on Medicaid and the only way for him to stay on Medicaid is to have it through SSI. And then SSI bases his eligibility on what our income is and assets so its never an easy thing. It is really quite stressful, quite hard.

Q At what level do you have to be to meet the requirements for SSI?

S Probably barely above the poverty level. Really. That's probably what it is. Our family probably can't make more than I would say $30,000. And we have a family of seven and so um---you know like actually within the very very low income area and I think even $30,000 might be a little high. So you struggle, you struggle, you struggle. It's not how we started.

Q Hi.

S This is my husband Hal. (Husband was just passing by the kitchen).

Q You struggle with that. Everything is affected when you have a child with disabilities-----And it didn't even start out this way. I mean we both were working, uh we had insurance. Um the company that we had the insurance through, I guess because of *the area's* (substition made to maintain anonymity) economics, they went bankrupt and that's when Andy lost his insurance and so you can get insurance. The laws have changed so that if you are going from company to company, he would get insurance, he would be covered by a company that my husband worked for, but because he has no insurance, they don't have to pick him up.
so---so that's the hard thing.

Q So if you had applied for another insurance company immediately after you lost the insurance that you had originally, Andy would be covered for all the pre-existing conditions?

S No, because they didn't have that law set at the time. No, that would be only very recently within

I don't know within the last year or year and a half maybe. So---, that's the way it is.

Q How did you get that insurance for him?

S Which?

Q The original insurance that you had.

S You just sign up as you have children if you have an insurance plan, just sign them up at the time of birth.

Q OK. Now was that insurance plan through your husband's employment?

S Yeah,Yes. So everyone was covered------at that point.

Q Do you have insurance for yourself?

S No, no, and my children I am applying for, Umm, what is that called Umm---

Q Childrens Health Insurance?

S Childrens Health Insurance. So the other kids will have it. I think that they are even covered until 19 so Lisa can still have it but we don't.

Q With Childrens Health Insurance, do you have to pay a fee?

S We haven't---you know so um---so far. I think that we are under their requirements. I was actually going to look into that today. I think that we are under the requirements. But if you do, it would be a minimal fee you know. For us it would just be I think $25.00 for each child.

Q Who sponsors the program?

S The state sponsors it and certain health companies pick it up. I think that the one we are looking into is sponsored by Gold Blue, but it's run by the state and I think that um um the Governor's wife, not this Governor, but I forgot, she did the Year of the Child---I forgot---

Q Latch?

S Latch yeah, I think she sponsored it or in part pushing for it so that's a good thing. But we access the Health Center and that's how we deal with it.

Q So you and your husband are covered by what type of insurance?

S None.

Q When you go to the Health Center, who pays for your visits?

S We do, it's on a sliding scale so the fee is not much at all-----, so that's not bad. They do it on a sliding scale so everything that you would go for, like if I went and um-----If I fell and needed x-rays, whatever, the whole thing for that visit is $15.00 no matter what it is. Lab work, everything is all included. So that's not bad---at all.

Q Do you make sure that you go once a year?

S Actually no---no I don't. I've been forced to go because of work. You have to have a yearly exam so that kinda pushed me, but I wouldn't probably go----if I didn't have to go for work. Just put it off until uh---there was a problem I think.

Q Is your husband working full-time?

S He is, he is, he is doing a few things, he is doing consulting work for a company that still does office partitions and modular furniture and that's actually the same company that went bankrupt but it was bought out by somebody else, another faction of the family. They are not a company that is doing real well but they're struggling and beginning to uh---have a little bit of success. So he is not employed full-time by them but they still need him because he does all their design work and layout work and things like that. So he does consulting work for them and he also does construction, and has been doing architectural drawings. So basically he works full-time----but because of construction he doesn't make anywhere near what we used to make. You know the way he works now is very very changed so our income has drastically been reduced.

Q If he was offered a full-time job where the salary was much better, would it be worthwhile for him to take that job?

S No, no, it wouldn't be worthwhile because that would bring our income above the level that Medicaid would allow---with SSI. Andy would be covered by an insurance company but not for the things that he needs. So we would be in a worse situation for Andy that way. He wouldn't be eligible for Medicaid plus the insurance company wouldn't cover his needs.

Q What are his needs?

S Um--he's very handicapped. He is 6 years old but he is probably at a level of a 9 month old so he is developmentally delayed. He's CP. He's microcephalic. He has a seizure disorder. He has um vocal cord paralysis so he's a trach. He has a G-tube because he would never get enough---any other way. He's total care, total needs. He has apnea. Um he needs a lot of respiratory treatments and CPT and a lot of that kind of stuff. and so that's what his needs are and so there is a lot of medical equipment, there's a lot of doctor visits, a lot of medications. I wouldn't say a lot of medications, but they're there. You know he is on certain nebulizer treatments and medication to keep the seizures in check and they have been for a long time so we are lucky that way, but those are he's needs. You know he's constant care all the entire time somebody is here. He needs 24 hour nursing care. They're working basically the whole time they're here, unless he is sleeping.

Q And all of his needs are covered under Medicare right now.

S Right.

Q If he wasn't under the Medicare, what would not be covered?

S What would not be covered----if he didn't have insurance?

Q Yes.

S Basically nothing would be covered, nothing at all I don't think. We would have to pay everything out of pocket. That would mean that I would not be able to go to work at all because I would be you know the total caregiver. Um and that would even make financial situations around here a whole lot worse. I can't deal with my other children, you know with their needs at all if I am taking care of Andy. His needs come first and he has a lot of needs. And so um, I can't just put him in the car to take kids to soccer games, I just can't do that. I can't bring them anywhere. He's basically home and he goes to school. He is not able to really go out visiting or doing any of that and even if we do go to Grandmas, we lug oxygen and suction machines and all that kind of stuff with you. So um--everyone else's life would be completely restricted because I would not be available.

Q You had mentioned before when we were talking that they were thinking of changing the insurance?

S They were thinking of changing not the insurance, the um---they were trying to change his level of nursing care and the amount of nursing care that he received. That is the Health Department here but so far they haven't done that. They've tried.

Q What do they want to change?

S They want to change him to LPN care and um--I really don't feel that is suitable for him because he has a lot of needs for assessments and for the most part LPNs are not skilled really to do that and um-----they also wanted to decrease his hours which would create total havoc here. So----so far we have been able to ward those changes off through a lot of support from physicians and that kind of thing.

Q What is their reasoning for decreasing the hours?

S It's money. They come in and they say that they are here to make sure that your child gets everything they need, but that's not why they are here. They are here to come in to make sure that they can give you the least amount, bare minimum so they can save money. That's why they are here.

Q Who is they?

S The Health Department sends two nurses to make some kind of an assessment. It is very stressful when they come because they act as if they are your best friend but in the meantime, they're not, you learn that the hard way and um-----anything you say they are writing down. Well the last time they were here was probably a year ago, they talked for hours about Andy's needs and then they left and told me they were switching everything to LPN, now Andy had RN's and they were trying to decrease his hours and it was just amazing because of all the things that we said. I was just totally stunned. And they also said things like it doesn't matter what the needs of the rest of your family are, it doesn't matter at all. All they hear are what Andy's needs are. And in reality Andy has all of those needs for all of this care---because if nobody was there to take care of him he wouldn't survive. So yes, he has to have care 24 hours a day whether it's me or somebody else but the care is needed. And I also think that they take the fact that I am a registered nurse and it's like on one hand they use it to their advantage. They will say things like everything that we assess Andy for is only based on Andy but in the meantime they also know that I am a nurse so they use that, they assess his needs based on what I can do which really isn't fair. It's all used to their advantage. Do you understand what I am trying to say?

Q Yes.

S So I am very guarded when they come. They try to show up at your door just unannounced. They just come and knock on the door and expect to be let in which I don't allow. They even said to me things like--Well we're Medicaid, we're the people that supply the nursing care for your son and I in return said---Well I didn't realize that Medicaid took away my right to privacy---so you will have to make an appointment to come. And I don't allow them to see him at school and I don't allow them to see him when I'm not around. I want to know when they are here and I want to know everything that they ask and exactly what they do. So um---I never was an untrusting person but I am now I guess I have become cynical. I don't trust anything or anybody when it comes to Medicaid or the Health Department. So that's a shame too. It's really not supposed to be that way.

Q Have they obliged you, do they call you?

S Now they do, they do. Cause they have no choice, this is my home. So, I have even gone as far as to notify the school that they are not to let anybody in to---to observe him unless I am notified well in advance so uh ---because they don't warrant trust. They really don't. So, so, it's always scary. I will go as far as going to a fair hearing and I have done that too for a lot of things and when I started applying for a fair hearing because they were changing the level of his care, that's when they decided to leave it alone.

Q What did you apply for?

S A fair hearing where you can go to Medicaid and you can dispute any changes that they're trying to make.

Q Did you get one?

S I had applied for one and it was scheduled but they started talking some more and then they left his care the way it was so um------

Q How long ago was this?

S It was probably a year ago. They're due back. They actually were due back around Easter and they tried to make an appointment but Andy doesn't get home until after 3 p.m. so I guess they don't want to come after 3 p.m. He's on vacation so they could come, I even informed them when his vacation was but they didn't make it, I guess it wasn't convenient for them. He had like a spring break.

Q From school?

S Right. So I'm waiting for them for the summer but so far they haven't been here and they haven't called so----

Q Now does your husband have to be here when they come?

S No, he's not usually here, he usually works------I don't know if he would be all that helpful. He'd be kind of-----I do most of the care for Andy. Everything is pretty much up to me, you know. Uh---If there is any discussion, he would probably defer to me anyway and what I wanted. So basically all of Andy's needs and uh his care really falls on me. I have the whole load, I carry the whole load by myself.

Q How do you feel about that?

S It's stressful, it's extremely stressful. I don't know if he can deal with it. You know I really don't know if he can deal with it. I have never left Andy for a real length of time with him and I don't think that he would be able to deal with it if Andy had a problem. Andy is a very sweet little guy, he really is and he's happy all the time unless he is uncomfortable and then you have to figure out what it is. But when he's uncomfortable and he's crying it could be pretty severe and he becomes cyanotic and things like that. So dad has a hard time I think dealing with that. So um basically all the responsibility is mine. And he is supportive of me but I don't think that he can really deal with Andy.

Q How do you feel about that?

S It's um----How do I feel about that? ----Sometimes I am frustrated and sometimes I'm sad about it. You know it makes things for me, another responsibility that I have. Knowing even financially when I work, that's what keeps us going. My husband's salary is not what keeps us going and although he works full-time what he makes is no where near what he used to make or what I could make if I worked full-time. And so I think that is frustrating for him---- because that's not where he thought we would be at this point---you know. And---and the fact that he has to rely on me actually even to work makes it hard for him. And not that it is a conscious thing but sometimes I think, this sounds like a very strong word, but sometimes there is resentment over the whole situation. Not actually for Andy but for the whole situation.

Q Resentment on whose part?

S Dad.

Q Dad.

S Dad, dad yeah----And I think there is resentment with the kids too. The kids you know will feel it at times because things are limited because of the situation.

Q Do you ever discuss Andy's condition, things that surround it as a family?

S Probably not in a group. I don't think that we ever sat down like that but there has been times that I have needed to talk to at least the the older kids um about things about Andy because my daughter and my son who are almost 15 and 16, um-----they're at that adolescent age and especially with my daughter, things revolve around them at this age. That's like a normal thing as it is and she is restricted or they are both restricted in a lot of things. And they do have to---if they are going to do anything extra they have to earn it themselves and that's the way it is. They don't have the things that other people have. They don't go out and buy new clothes every season, things that are important to a kid, they just don't do that. They don't go to camp and they don't go away. I mean they go to basketball camp. My daughter is earning money so she just started giving herself riding lessons again, but they don't get that, they don't get that from us and I guess they see other kids that you know are able to do things. We don't go away, we don't do things like that so I um--think resentment comes--with that. And then they also feel guilty about that. So um--- that's what I think they find difficult. They also resent people in the house. And as much as the nurses that are here are of great help and they know that if they weren't here, I'd be really restricted, it is also there's someone here all the time. And so, there isn't the privacy that other people have and we are fortunate because the people who do care for Andy have been here a long time and they kind of go well with the flow of the family and they kinda do know when to disappear, when to be around. Um and we never exclude anybody. And Andy is part of our family. We do not want him in----his bedroom is in our living room and there is no way he is stuck in there at all. I want him to be out among the rest of us-- but there is always someone extra here. So---I think they resent that.

Q Do you and your husband ever have time to spend alone, go out?

S Very very rarely. Very rarely so that's difficult too. We have a friend who is going to give us a week in New Hampshire in the beginning of August. They have a cabin up there so we are going to take the four older children, Andy is not going to be able to come. So that will give us time alone. It's almost like we have two sets of family. We have us and the four children and then we have Andy. It's like two separate things, and so they need a week of normal, you know being a family without all the stress from Andy. The thing that is stressful about that is, that so far all the shifts are not covered, and so if the shifts are not covered, I can't go. So that's the next thing. So Andy cannot be left alone. We don't have family that can handle Andy either. We have supportive families. Hal's parents and sisters and brothers are wonderful and so are mine but----nobody is able to care for him-----other than me so there really isn't anybody I could leave him with unless I have a nurse.

Q Do you think the agency will be able to supply you with the nurses so you will be able to get away?

S I think what will happen is the nurses that are here---will do extra---because I just think that is how wonderful they are. I think that they'll fill it in someway if they have to beg, borrow, steal and stay up three days in a row, I think that that is what they would do.

Q The agency sends the same nurses for each shift?

S Umm, basically the nurses that we have, have a steady schedule, but we have now a couple of nursing agencies and we have Agency One who has been the primary agency but they have not been able to be very supportive lately. They have not been able to send anybody new and there has been a number of shifts that have been open because um---life changes for other nurses. One of the nurses that had taken 4 and 5 shifts, and she was here for years, and I still hear from her, she moved to Florida with her family. Those shifts since she has moved have not been steadily covered. So it's been difficult. We have had some nurses that just have not worked out---for various reasons. So we are still trying to find somebody that is steady and for the most part there are very few that I would say couldn't come back. You know, I get along very well with a lot of people and the ones that don't or I choose not to have been really problems. So, so we are just trying to work it out and the staffing isn't there. Agency One for some reason has not been able to recruit new nurses and I don't know why that is. Actually I probably could guess why it is, their salary is not as high as many agencies and I think that has a big part to do with it. The fact that he's Medicaid and the agency reimbursement is not as high as private is also why they pay a lower fee. And uh-----there are other agencies involved now and so there's been some nurses coming. But it seems that money is the issue over everything you know---except for the nurses that have been here. Once people are here and are here for a long time, they aren't being paid the higher rate, but they stay, which is really nice, it's just trying to get somebody else that has that same, I don't know, they are not out really for the money. People work because they have to work----but to people who are just concerned about the dollar, they are not going to work here and actually that's probably who I don't want here anyway so---

Q How did you get access to the other agencies, are you allowed to use more than one agency?

S Right, you can, actually Agency One has called some and I have called others. I have also tried Medicaid providers and so far I have not had a lot of luck with Medicaid providers and I actually am a Medicaid provider, but what I have found with people that come here, if they don't have direction or somebody looking over their shoulder, that's not good, so I kind of geared back towards the agencies.

Q When you say Medicaid providers, are you talking about individual nurses?

S Nurses who have applied to Medicaid to get a Medicaid provider number and they can bill directly so they really are self-employed. But they don't have a supervisor, they don't have anybody checking up on their work or checking nursing notes or making sure they are doing all the treatments Andy needs and so um I can't do that all the time. Why would I have somebody here if I have to be in there the whole time making sure they are doing what they are supposed to do. So um---so that so far has not worked out.

Q When someone new comes in, who tells them about Andy's needs, do you have to do that, or does the agency train?

S Yeah nobody trains anybody. They come in probably the first time when they are on and the nurse that's going off will give them a little background and then it is up to me. I do all the training. People come in here sometimes they don't know much about Andy at all---So as long as their skills are okay, as long as they have decent enough skills, it's not so hard and if they have a little bit of common sense, otherwise it doesn't work as well. So-------sometimes it is just hard, people come into your home, they don't know where anything is, they don't know anything about your child----so it's not only the medical part, it's also the regular, just taking care of somebody kind of stuff. What are his habits, what does one crank mean compared to like a cry and he can't communicate, so it's really a guessing game. So they have no clue----you know. If he's happy that's fine but if he is not happy, what they do, they don't even know what to do with him.

Q Tell me something about Andy's medical condition, has it changed since birth?

S No, I don't think so. He has become a lot more stable within the last year and he's a lot more healthy then he was I would say about a year ago. He has just gotten stronger that way. But his diagnosis has not changed. He is not going to get any better. He is just the way he is. So um---it is just a matter of keeping him infection free. I mean I think his biggest problem would actually be respiratory because first of all he has a trach and uh the fact that he is immobile, he is very prone to respiratory infections and picking up things like that. So, you know that is our biggest concern really. He's been lucky this year. He's been pretty healthy and he has not really gotten too many infections and we started him on Intal four times a day and so his respiratory problems have not been as severe as say they were a year ago and um when he does get some kind of a cold, if Albuterol nebulizer treatments don't cut it then we start with Prelone so that's been a big help. That has kept him out of the hospital actually this year which is a great thing. He had an infection I guess around Christmas. That seems to be when he gets his things and he was very very sick but he was able to stay home and I think it had to do with the Prelone that he was started on. So he got so bad and then we started the Prelone and he didn't get any worse and so that was a good thing. We have oxygen and everything else here and I think that if he was in an ICU he gets excellent care but if he is on the general floor at Corner Hospital, you have to stay 24 hours a day anyway and he gets better care here because there is somebody with him and that kind of thing. Staffing is not available at Corner Hospital.

Q Were you the only one that stayed with him when he was on the regular unit?

S I was basically the only one but I would get breaks from people, from the nurses that were here, they would come and visit him because they actually genuinely like him and love him, and so the ones that are local would go up and visit with him so I would get a little time. I also have a friend who is a nurse and she sometimes will go up with him---if I am not there depending on her own work schedule and things like that.

Q Does your husband ever stay with him?

S Um------no, I don't think so. I don't think at all. He'll come up with me--but he won't stay by himself.

Q When Andy was born, did you know before his birth that there were problems or was it once he was born that you found out there were problems?

S We didn't know beforehand at all and then at birth um he had difficulty breathing and that's really all they thought at the time. They didn't know anything else, they just thought that for some reason he had vocal cord paralysis and whatever that was caused from, they couldn't figure it out. And then as time went on, I would say by the time he was four months old----actually I realized that there was something wrong with him, he is my fifth child and so he wasn't responding the same way the others did and he was in the NICU for a month after he was born and the professionals at the time were saying maybe it's because he was so long you know in the institution, but um, that wasn't really what it was. I couldn't put my finger on it but I knew he wasn't the same as the other kids. So uh---he was born in December, he came home the beginning of February and that um was really stressful because the doctors and professionals really didn't think there was much else wrong with him but they sent him home on monitors and an oximeter and they thought he would do just fine and when he got home it was terrible because he couldn't do anything without being in any kind of distress. If he slept he was fine but as babies get older they don't sleep that much anymore. He couldn't eat, he couldn't cry, you couldn't do anything with him but he would be crying and getting very cyanotic so it was a viscous cycle. I held him all the time and uh---he wasn't thriving at all, he wasn't really able to gain weight, he wasn't able to suck on a bottle, all of those kind of things and I even suspected at the time that he was having some kind of seizure problem because he just wasn't behaving the right way and there would be times that he made these very distinctive kind of cries and throw out his arms and things like that. If you went to the doctor you were only there maybe five or ten minutes and it's never always evident when you go and uh---he had EEGs but nothing was ever picked up---that early on. So they would just continue to watch him but it was very very hard at home and then by March, the idea that he probably needed to be trached, kind of had to be dealt with because he just couldn't breathe. He couldn't breathe and eat. He couldn't cry. And babies cry but he was always in distress. He was trached in March which made things better, it made things better, but then even at that point I knew that I wouldn't be able to sleep---you know----so I then at that point looked into trying to get nurses for night. And when all was said and done, they wound up approving 24 hours for him and I think that it was a good thing at the time for us. I didn't expect that but that is what they approved. Then by the time um, by that time he was four months old and he was in the hospital they told me that they thought his brain was immature and they had to wait a little bit longer. They also thought at the time that he had craniosynostosis when the sutures closed too soon and um----they were really looking into that because now the circumference of his head wasn't really growing at the rate it should have. And um----it took quite a number of months, maybe by June of that year I think when we saw the neurologist, because of things I was telling her she put him on a small dose of phenobarb and then in October um----he was being recommended for surgery by plastic surgeons that work with the ENT's and things like that. And I took him over to *another state*, I think *Airy*, I forget which hospital, but I didn't want to see anybody here because I figured there's a network, you know, and I just wanted a completely different opinion. And so I took him to a neurologist over there and he was very kind and he just said that this is what you have to deal with. He doesn't have craniosynotosis. This is all it is. Which I really knew anyway. But I needed him to say that to me. When people are pulling at you, well maybe it's this and maybe it's that and surgery will help. So uh---the very next day after we came back he had a severe seizure where he was apneic for ten minutes and we were bagging him at home so that's when we really knew then, and that's when it was clinically evident.

Q What actually did the physician in *Airy* tell you the diagnosis was?

S He just said that he was microcephalic and that was really what the whole thing was and---so then we just had to deal with that. Also they say that he has pachygyria which the involutions on the cortex are not as many as there should be and I think that they are a little bit deeper than they are supposed to be so----it looks like the folds of elephant skin, that kind of thing. So then from there we started to deal with the fact that he was going to be handicapped and I think that the good thing for me was that it was a slow thing, I didn't find all of these things out all at once although, you know there is something wrong but it didn't have to smack me--- you know right up front. This is it, this is how it's going to be. And as he has gotten older you just kind of accept that this is the way it is. As a baby you don't know how handicapped he is gonna be------but as he is older now and he is not meeting any of the milestones and he is probably really at the level of a nine month old at best, um it's been hard. If I have to really think about it, there are times that you really have to think about it and face the fact that he is so handicapped, that's when it's difficult but you don't think like that every day. You know if he is sick and you have to deal with sickness and illness, that makes it hard. When he is in school and they have to do their reports and you have to listen to where he's at you know very clinically, that makes it very difficult but on a day to day basis, Andy is just Andy, so that's how you deal with it.

Q How did the rest of the family deal with the diagnosis initially?

S The children don't have an understanding or they didn't at the time and they just grew or Andy grew with them that this is how Andy is. So they don't really have an understanding of it. As the older ones are getting older they start asking questions about the future and what's going to be with Andy and things like that. So they have those concerns too and I think it's very stressful for them when Andy is sick. And it's been a long time since he's been admitted so I am really happy about that. But even if I take him to the doctors at all, like there was a week after school, I try to save all the appointments for after school so that we don't have to take him out of school and he misses all of that---and so at the end of the school year in June, I made three appointments in the same week and then they begin to get a little nervous----what's wrong, where are you going---so I just to explain that it's just regular visits like you go for regular check-ups----it's just that I save them all for this week. So they get worried, they are concerned about his future and how we are going to deal with that.

Q Do you ever discuss it with them?

S Yeah, with the older ones basically. Tom is still too young to really understand. He'll listen but he doesn't ask any of those questions yet. But the 16, 15 and the 12 year old really have begun to ask questions and so um---because at this age they're all saying of course we'll take him. We'll take care of him, which is nice but I clarify that because I don't want any one of them to think that they have to. They are gonna have their own lives and he is not gonna be, not that he's not gonna be their responsibility, but they don't have to feel like they have to take him to their home. We have to figure something out in the future but um all I ask is, I said to them, the only thing that I ask of you is to watch over him and love him and if you do that then he's going to be just fine. So wherever we wind up with him-----you know----

Q Do you have any plans, have you sat down and thought about any plans for the future?

S We've not really done that. We think about it but there isn't any local place at this point. I mean we have looked that far. People will ask me----what will happen with Andy. I can't even say what's going to happen with him for next year but at this point in our lives he's home and that's the only plan that I have right now. I mean right now if he wasn't home he wouldn't be alive any more. He needs the stimulation of home and family and I think that as he gets older I don't know what's going to happen with him. But for now we are able to deal with it at home. I don't want him in a facility right now, there aren't any that I would choose to put him in and know that he would be cared for the way in the way I want him to be cared for so that makes it hard too.

Q Have you looked at different facilities?

S Well, there aren't any, there aren't any here. Sim's maybe, all the way, I don't even know where it is, somewhere in *Ashton* maybe. And I haven't been there recently----but say 10 years ago I think I had been there and it wasn't a place that I wanted him to be. It's like a mini hospital and he wouldn't get any of the stimulation or family or love kind of stuff that he needs to grow and um I think that there are places upstate or in other areas and it's too far.

Q Ten years ago you visited Sim's?

S Yeah, with school.

Q As part of the curriculum?

S With school, when I was in school. I think we did a rotation through there a little bit. It's probably changed a little bit by this point I'm sure but it's very clinical, you know, and it's not family oriented, it's like a nursing home for children with disabilities.

Q Have you thought about what you might have to do if they take away some of your medical needs that SSI and Medicare is supplying for Andy?

S I think that the biggest thing right now, the thing that would affect us the most is the nursing care if they took that away. And um-----I have thought about it, it's probably not realistic but I have thought about it and I would just have to be the one to care for him. You know, it would--the consequences of that would be very stressful on our family, financially and emotionally I think so it is something that we keep trying to push off and hope doesn't happen. I know it is like sticking your head in the sand but right now it is not upon us so we don't have to really deal with it. I would not at this point put him any place. I could not deal with that, I would have too much guilt. He is a part of our family and we do love him and I don't think that anybody right now would very happy placing him somewhere and not being with him so it's a double thing. How do you take care of him because he is so much care but at the same time you don't want him to be any place else. So that's what is hard.

Q Do the children play with him on their own when you are not around? Do they need somebody always present like you or the nurse in order to play with him or do they feel comfortable enough to play with him without you?

S There is always somebody there but they would go up to him anyway. If he's in the bed inside they will just jump into bed with him and do whatever. I mean they can't really play like other children could play. He doesn't even play like a nine month old, he's so limited physically but they will be in there and he responds to visual, toys that have lights and sounds and noise and they will bring music in there and they will talk to him and I know that he is aware of who each one is. He distinctly knows that each one is who they are, not that he knows them by name, but I think maybe sometimes he recognizes his name, I'm not really sure---, but I think he does. If he is sitting in here, they will take toys and they will play with him. He knows which one is which. As far as the older ones, like Bobby is very good with him, he is the oldest boy and he's more of a gentle type with Andy and he will come over and he will talk softly and he will play with small little toys or the music boxes and things like that. And then the younger ones, they will come over and they are a lot more rough, and Andy really knows the difference because when Bobby comes he's very calm and when the other two come he laughs but he kind of like ducks. So he knows that they are not going to be quite as gentle and um----he's ready for that. If they have friends, friends come in the house and Andy is among the friends, you know he just sits there and he just likes to be among the action. Not that he can say that, but you know by the way he is. You know when you know somebody and the way they respond to things. We know that he enjoys being among the crowd and if we are not here, he misses us and I know he does. Last year this same friend gave us this house in New Hampshire so we were able to go and when we came back, he was really mad at us. That's the only way that I can describe it because the house had been so quiet I guess. So when we came back he really just kind of cranked and yelled at us the whole time, the whole evening and even the next day he just kind of cranked and crabbed and I think that it was his way of really telling us that where were you---you know. So---I think that he is more aware than they are able to give him credit for because physically he can't perform but uh---he is aware of a lot of things. He is even aware of the way that Hal and I are. I'll take him and I'll squeeze him and I will hug him and I will sit him on my lap and sing songs to him and that kind of thing where Hal, dad will just pick him up and he is more rough and he juggles him around and that kind of thing and so he does know that, he anticipates things. Hal will tickle him on his neck, Hal has a beard, and he like waits for it, he scrunches up his shoulders and he knows it's going to happen but he's happy about it. He's aware of the differences of who we are and I think that he is even aware, I mean he is definitely aware of the differences of the nurses and people who take care of him and he knows when somebody new is here. And so when you know Andy you know how he reacts like he becomes very quiet and very still when there is somebody new as if he is just kind of like taking it in, that kind of thing.

Q Physically, does he have physical motion in his feet, his legs and in his arms?

S He has range of motion, he has full range of motion but you know he's not able to--he is not really able to---uh----he has no self-care skills and no mobility skills or anything like that. He's very very limited. My basic goal for him, what I would love to see is that he could sit up without falling over and I don't even mean to sit, I mean just to put him in a sitting position not even that he get there himself. So his trunk and head control are not as good as I wish they were and things like that. He can manipulate toys that are close to him but he doesn't have the strength to reach out for too long and things like that. He doesn't walk or crawl or do any of those kinds of things at all.

Q Does he have a special chair that he is able to sit up in?

S He has a wheelchair, and um so that's good and there is a tray on it and he has a prone stander. But is able to be a supine stander or a prone stander and he has something called an advancement chair which has a lot of supports and as he gets stronger and is able to do things and hold himself more, we take more of the supports--away----so he is doing very well with those kinds of things. For short periods of times we can take away a shoulder harness and he is able to hold himself up a little bit so that's good. Even with the prone stander he can tolerate lengths of time in it, which is a nice thing.

Q Since the last time that we spoke have you thought about anything else you wanted to add to that conversation about his hospitalization?

S I think that I really said a lot of what I wanted to say, you know.

Q Is there anything else that you want to add to the whole conversation that we've had?

S I guess that just having a child like Andy affects the entire family and it is very, very stressful emotionally on everybody and it's financially difficult so it just affects the whole family structure in a lot of ways. You need a lot of support---and um sometimes you don't know how to get it. And uh I think that you find out things uh accidentally, like support things that you really could have used a while ago, you find things out accidentally through other people. It would be nice if professionals knew a little bit more and not that it is their fault. I am not saying that at all but if people were more aware of things that are available or even how much there is such a need that these families have. You know If they could understand that, and I don't think that people really do. Not that you want them to walk in your shoes but if they could understand that it is really a difficult thing, especially these Medicaid nurses that come in from the Health Department, they really don't understand. They really don't understand what your life is like. And if they could understand, they would have a very different outlook on families. If we don't have the help that we have now, our whole family although it is difficult as it is, it would be much, much more difficult. I really don't think that we would survive as a family. I really don't. If we never had the help that we had-----, I don't know---------if my kids would be doing as well in school, I don't know if Hal and I would have even stayed together you know. That's something that you don't even like to think about but---and I would think that we have a good marriage. That's how I feel at this point. But the stress is on---is on the family and on your relationship when it comes to dealing with Andy. If I am always constantly taking care of him. I don't have it to give to a relationship so I think that it would be very hard.

Q How do you deal with the stress, do you have someone that you can talk to?

S A lot of what I have as far as Andy goes, I don't talk too much to Hal about. I kind of keep my own feelings to myself on that score. But I have friends that I can say things to and actually even some of the nurses here who have been here for years and years and years, they're here. They wind up being part of the family when they are here for their eight hours so a lot of times I can express how I feel to them. And it just helps to be able to say things and for them to get somebody who is really not part of your family but can see into it, they can give you an outlook which is very helpful sometimes. In the community I have a lot of friends too and so they can be very supportive and that's good. My family is far, an hour and that's far, I don't have them right next door to be able to talk to but they are very supportive too. I used to try to go to support groups, but I find that they are not what I need at this point. Um--------I need the positive stuff and sometimes people start talking too negatively and I just couldn't deal with that. And I tried a few different kinds of support groups. If they are always negative, that is not what I need so I basically talk to people that I know who aren't in the situation and it kind of gives you a boost that way. There is a neighbor actually, very close to us and she has a child with disabilities and we did not connect because of that, we knew each other before, but it just happens to be that way and she's supportive too. So you have, we get it, we get the support that we need when we need it so----

Q You said that you don't discuss how you feel with your husband. Can you explain that a little?

S Um-----I don't think that Hal can really deal that well with Andy. He kind of doesn't ever really think about how we are going to think about things in the future or what is going to become of Andy or anything like that and if I have those worries, he is not the one that I would talk to about it because I don't think that he can even deal with it yet. I mean the child is 6 years old, he's 6 1/2, I don't know when we are going to deal with it. But um-------and I know he loves him but he could never take care of him if I was not here, I don't know what would happen to Andy.

Q How do you feel about that?

S I worry about Andy you know--------------------I think I just take it for granted that that's the way it is-----When I am dealing with a lot of stress I get angry. On a day to day basis, it's OK but when I have a lot of stress and a lot of appointments or if I am fighting over a piece of equipment and I have to deal with Medicaid or today I have to sit and fill out SSI forms, like I am so sick of it and I wish that I had a little bit more help. And um--------I guess if I asked for it, he would be able to give help but I don't know if he can give the emotional support for what I need towards Andy. If I said you need to help me fill these forms, he could do that but um, but um you know I find that extremely stressful especially----when I'm overwhelmed that I just can't go somewhere, I don't have the luxury. So that----I find it very hard that way------------- (long pause as husband passed by)

Q Is there anything else that you want to add?

S I don't think so. You know I can't think of anything. I don't know if haven't answered anything enough.

Q I would think you did very well. I really appreciate the time that you've devoted.

S Here is my husband Hal.

Q Hi, it is nice to meet you.

(Husband says to wife "see you later" and leaves).

S "Have a nice day, see you later". See he tries to be supportive but he doesn't really know how and um it was hard to answer those things like when he is standing right here and he doesn't really know how. And I don't think that he really realizes how much he is not supportive and I don't think that I could even get it through to him. I worry about Andy because if I am not here or if something happens to me, what is really going to happen to him? So um----I think that I would ask, um---and I don't know legally how things happen, but if something happened to the both of us, I would probably wind up asking my sister to take care of him um---with a network of people. There would have to be somebody, one person legally responsible. And I know that she would be as---we both have very different personalities, but I am a fighter in a quiet way, she is a fighter probably in a more aggressive way but she would get what he needs. And she would make sure that he was taken care of. She feels as strongly about him as if he were her own so I know that somebody would care for him if both of us weren't around but if only one of us wasn't around, like if it was me not around, I don't know how Hal would deal with it. I think he would just tune out---When he is stressed out or things are overwhelming, he just doesn't deal with it. He doesn't deal with it. Even things that could happen in a marriage or you know you have your ups and downs and we have had some stressful things about other things----building this house and all that kind of stuff. He just tunes it out. And uh that's how he deals with stress, so I don't know how he would deal with Andy and I would worry that he wouldn't get what he needs. And I don't even think that Hal realizes how much time and effort I put into getting Andy what he needs and making sure that he is taken care of because he takes things for granted. Even at school, you have to make sure-----that they have an educational plan and you have to make sure that people are doing that because as good as some people are, some people are not and we have had those kinds of incidents where if I wasn't as aware as I am, he wouldn't be having needs met that he should have met or goals worked on that should be worked on. I don't think that Hal would know a good nurse from a bad nurse. And that wouldn't help Andy. I don't want somebody just sitting and leaving him like a lump, not giving him medical attention that he needs and you also need somebody who also likes him. You can't have somebody here that is just clinical.

Q You said that you think your sister would take care of Andy? Have you discussed it with her?

S Yeah, yeah we have discussed it. Actually there are a lot more people that would help with him. She might legally be the one on the paper but she would know that she would not have to be the only one worried about him. And this particular nurse that I told you about who is my friend, she would be very helpful, not that she could take Andy into her own home, but she would be very supportive of my sister. So those kinds of things I don't have to worry about if both of us aren't here but if only one of wasn't here and it was me, then I think that I would worry. I would worry because he is clueless, he really is clueless. He doesn't know or understand the amount of time and effort that has to do with Andy.

Q How does that make you feel?

S Uh---sometimes I just push it off and I don't even want to think about it but when I have to, I get kind of annoyed and mad. Because it's not like Andy-- he is not just my child. And I know Hal loves him, it is not that he doesn't love him, it's just that he doesn't deal with it and so I kind of get a little bit mad at that. Even with our financial situation, I need to go back to work, I need to work, but who does all of this when I am not here? That's when I start to get angry. I need to sit here and block a time and fill out forms again which I am sick of and if I don't fill them out, they'll be after me, they're already after me because I have already put them off. I really have to fill them out, but it's that kind of thing. I have gone to fair hearings for equipment that he needs, I am fighting with the agencies all the time because they're not supportive in a way that I think that they should be. If a shift isn't covered, well, oh well, it's like what are you doing to recruit nurses, you are not doing a whole lot. And I know they are not. So it is always these things. And if I don't have a nurse, life stops and that has happened quite a lot in the last couple of months. You know I have had to cancel things that I would have liked to do or the kids would have liked to do because I haven't had someone to be able to be with Andy. So it is very stressful.

Q Have you ever said anything to your husband about how you feel?

S Yeah---, but that is just really where it stands. It is just said and I don't think he would even know how to, he doesn't know how to be supportive in that way. He doesn't know how to help out. And a lot of it has to do with the fact that he's mostly not here. You know most of the time he is not here at this point in the day, and he's gone all day and he doesn't deal with the doctor appointments or the school situations or going up to the CSE committees where you go up to the school and that's when they plan Andy's care and he doesn't have to deal with the agencies and trying up make sure there is coverage. He only worries that there is. If there isn't, he doesn't have to deal with it. So I think that part of it, is time that he not here, but I seem to be the one who juggles everything around and if I work, I work night shifts. So I am really miserable the next day. So um, so I kinda think that's hard to. I think that it is not fair but I don't know how to change it.

Q Do you get any sleep when you do the night shift?

S When the kids are in school I do, but um---the summertime is hard---the summertime is harder. because even if I'm sleeping it's not really a good sleep because they are always here and it's noisy and it's daytime and kids are kids, so-----

that's what is hard.

Q Well again, I thank you very much. You have really been a tremendous help and I think you are doing a marvelous job.

S I don't know, something gives, the house gives, the house is a disaster so that bothers me too but there is nothing I can do about it. I can only do just so much.

Q Did you build this house from scratch?

S Yeah, we did. Yeah, yeah Hal, of course made the designs and the layout work and everything and the only thing that we had somebody do is the foundation and the framework. We hired somebody to do the framework and then everything else we've done pretty much ourselves, all the plumbing, electric, sheetrock. Hal even made the beams for the roof. We have this um----it's a bow house and so the roof looks like the bottom of a ship so he was out on the front lawn making the rafters for the roof. You know, we basically done the whole thing ourselves. We started it when we only had two children---you know, so it has been a long, long time and then everything was going smoothly until Andy came along and that kind of put a squash on a lot of things. We did it ourselves to save money and to have what we wanted, the way we wanted and once you have kids, you don't have as much time. I mean we didn't build it over night the way some builders are able to build a house, but things came to a standstill when Andy was born. So even now, I mean I think that um that's a stress and I think that is a stress to my husband because um I guess men look at things a lot differently than women and well that's not supposed to be this way. This is not where I wanted to be. I wanted the house finished or I wanted to be in a financial situation that is different so-------, it's hard.

Q How long ago did you move in here?

S We moved in here probably eight years ago. And we moved in when it wasn't ready you know. It really wasn't ready. We had a functioning toilet bowl and that was it. But just to be in, we had been living with my mother-in-law, we were schlepping from Grayton every weekend. We were still working both of us were working regular jobs and then schlepping on the weekends and every time we had off to work on the house----so um when we were able to just barely move in, that's when we did and my mother-in-law is just wonderful. Very supportive. But you need to be a family in your own house. She needs her space, we needed ours. And so it was time to move.

Q How long were you living here before Andy was born?

S Three years, two years? (Pause). Probably three. A lot of things happened in those three years which was good. Tom was born, we hadn't had him when we moved in here I don't think-----and I was still working. You know I was doing fine. I was probably working part-time, three sometimes four days a week, but when Andy was born the entire place came to a standstill and uh eventually, slowly we are still doing it, slowly, but financially you need to be able to buy supplies----so that is a difficult thing too. My bathroom is finally getting done. That probably wasn't done when you were here last------It's getting there.

Q You have something to look forward to.

S Yeah, yeah we do. It will be a nice house when it's done. Structurally it's nice, now it needs cosmetic stuff. A lot of paint (laughs). The kitchen is no where near what it's gonna be. This is supposed to be a room full of cabinets and we were even thinking of an island which I think I am not going to do at this point. We have too many kids and we need a big table so I think we are not going to do the island, but uh, these cabinets are just cabinets that we had just gotten at Sears to be able to have a sink and experimented with crazy colors which I hate but---eventually everything is supposed to be cabinet work--Eventually---someday---

Q Good, well again, thank you very much. It was really a great help.

S I hope it gets you where you need to be. One thing that I wanted to add is that Hal would not go to a support group, that's something that he would never do and I don't know if I have met a lot of men that would do that. It's not something that they would do. They kind of keep their feelings inside. And so I think women are more apt to find support. I would go out and find somebody but my husband would never do that. He keeps it to himself and if he says anything at all he says it to me. And you know I think that

that's hard, I don't know to deal with that or even what to do about that. Sometimes I think that he would benefit----from talking to people who maybe have similar things going on, but men don't talk about feelings. And I don't think that it is just my husband. So that's the only thing I wanted to add, I guess.

Q Have you ever spoken to other mothers and asked them how their husband's----deal with it?

S Yes, actually I have and that's pretty much why I think that men just don't do that. With this neighbor that I have, you know their child has severe disabilities and the prognosis is very poor. The child will probably not live a very long life at all and um he doesn't really talk to anybody about it he'll talk to his wife only when she really kind of initiates it. And if we say, oh, how are things going? He will just always tell you that everything is fine when I know from Mom that things are not fine. So um, I think that men, you hate to categorize but that's uh you know a quality or trait or whatever word you want to use. I think that they just don't seek someone to talk to about their feelings. Maybe just in their relationship, that's all.

Appendix H

Interview # 3

Q How's Andy? Did he have any other hospitalizations since I last saw you?

S He's doing fine. He hasn't been hospitalized since I last saw you. The few problems that he did have we treated him at home with oxygen. He still has the nurses 24 hours.

Q Did you ever get to go away?

S Yes, we went away to the country and we had a wonderful time.

Q Is Andy still going to the same school?

S Yes. Yes he is in the Sources educational program.

Q What types of early intervention services is he getting?

S Vision, speech, physical and occupational therapy. He was without vision therapy for a while because the therapist had to leave for a family illness.

Q Have you seen any improvement?

S Yes. He is able to make choices.

Q What do you mean? What choices does he make?

S If he doesn't want to participate in an activity, he'll cry and squirm, but if he likes the activity he smiles and won't give them a hard time. They keep working with him because they (therapists) think he still has potential to improve. Not a lot, but there is still room to improve.

Q What level is he functioning at now?

S Still 9 months.

Q He is still at the 9 month level?

S Yes, I don't think he will get much further. Maybe he'll get to the 10 month level.

Q On Saturday and Sunday, is he at home?

S Yes.

Q So he goes 5 days a week?

S Yes, and he goes for 6 weeks during the summer. When he is at home we do stretching exercises with him and some therapies. If we don't, Andy regresses very rapidly.

Q So, the therapists have set up a program for you to follow?

S Yes.

Q Do you do the therapy with him as well as the nurses?

S Yes.

Q Do you still have the nurses 24 hours?

S Yes. But Medicaid will be coming back to reevaluate the situation within the next few months.

Q The one thing I would like to see the speech therapist do, is work with him to help him swallow better.

Q Does he take anything by mouth?

S Yes. We give him thick puree food which he spits back as he swallows some of it. He thinks it's a game, but he does get some of it down. He can't swallow liquids, so he gets that through the gastrostomy tube, but we do give him food by mouth.

Q So he is able to swallow the puree foods?

S Yes.

Q I need to verify a few more things. Did you know anything was wrong while you were pregnant?

S No.

Q Did you have a normal pregnancy?

S Yes. I had sonograms and everything showed up normal. So there was no indication that anything was wrong until delivery.

Q What happened then?

S He was very blue and not breathing. He had to be resuscitated.

Q So, they resuscitated him right after delivery. Did he start breathing right away?

S No. The nurses were having a hard time intubating him, but there was an anesthesiologist around, so he was able to intubate him. So it took longer than normal to get him to breath. That could be part of his problem too.

Q Did they ever ask you at any point if you wanted them to continue to resuscitate?

S No.

Q They never gave you that choice?

S No.

Q Do you know how you think you know would have reacted if they asked you?

S I probably would have told them to continue, because at the time I had no idea how sick he was. He spent a month in NICU.

Q Were you told there was a problem?

S They thought he was slightly delayed because he spent one month in NICU but he would catch up. He had vocal cord paralysis, but I didn't know anything else for at least 3 months.

Q How do you feel now? Say you were given the choice now, knowing the circumstances now, do you know how you would react to a DNR?

S If they told me he would not have any quality of life and that he would always be in pain, I would probably do a DNR. I would never want to see him in pain.

Q What about you and the impact he has on the rest of the family? Would you take them into consideration when deciding about a DNR?

S I probably would only think about Andy's quality of life and if he would be in pain.

Q Not only about his quality of life but your quality of life and the rest of the family's. If they asked you about a DNR and you started thinking, would that come into consideration? How it would impact you?

S My husband and I talked about it once, during one of his hospitalizations, after they spoke to me about a DNR.

Q What did you say?

S I told them we would decide at a time when an incident occurred.

Q If it came to a time when he was very bad, do you think you would have okayed a DNR?

S Probably, especially if his quality of life decreased and he was in pain.

Q So, if he got sick again and they asked you about a DNR, it would be only if it would affect Andy's quality of life and he would remain in pain?

S Yes.

Q Again, thank you so much for all your time.