FAMILY EXPERIENCES WITH LONG-TERM CHILDHOOD TECHNOLOGY DEPENDENCE: AN INTERPRETIVE INTERACTIONIST APPROACH

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FAMILY EXPERIENCES WITH LONG-TERM CHILDHOOD TECHNOLOGY DEPENDENCE: AN INTERPRETIVE INTERACTIONIST APPROACH

by

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DEDICATION

In memory of Kevin and his family, who first taught me about life with long-term childhood technology dependence and the importance of home care.

And to Samantha and her family, who continue to teach and inspire me through their courage, devotion, adaptability, and joyful appreciation of life with technology.

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FAMILY EXPERIENCES WITH LONG-TERM CHILDHOOD TECHNOLOGY DEPENDENCE: AN INTERPRETIVE INTERACTIONIST APPROACH

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Increased numbers of children who are technology-dependent are now being cared for at home by parents and other caregivers. However, there is inadequate understanding of the daily lives of families who care for technology-dependent children at home and how these families manage over time.

The purpose of this descriptive, naturalistic study was to explore the meaning of and factors involved in the long-term home care of a child who is technology-dependent from the family's point of view using an interpretive interactionist approach (Denzin, 1989). The sensitizing theoretical framework for the study was Kazak's (1986, 1989, 1992) systems and social-ecological model.

The purposive sample consisted of 15 families which included at least one child aged 3-12 years who: (a) had been technology-dependent and living at home for at least one year, and (b) was medically stable at the time of the study. Family experiences with childhood technology dependence were explored using unstructured parental interviews and home observations of family members engaged in usual routines and activities of daily living. Demographic data were also obtained.

Four themes emerged from the interpretive interactionist data analysis: (a) managing daily life with technology, (b) negotiating with outside entities, (c) maintaining a functioning family, and (d) making sense of life. The potential for frequent and unexpected change, unpredictability, and limited parental control inherent in each of these major thematic areas contributed to families' perceptions of the fragility and instability of family life with technology. The contextualization of the phenomenon of family experience with long-term childhood technology dependence revealed that families felt as if they were "living in a house of cards." Major strategies used to increase stability were vigilance, advocacy, and reframing. Based on the results of the study, recommendations for nursing are made.

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CHAPTER ONE

INTRODUCTION TO STUDY

Reliance on and faith in technology have long been viewed as characteristic features of American society (Allan & Hall, 1988; Sandelowski, 1993). Advances in biomedical science have enabled us to save and extend the lives of many individuals, including children, who formerly would have died. Some of these individuals continue to live, however, with an ongoing need for a high level of care and are reliant on technological devices for their survival. Consequently, a growing number of children in the United States are dependent for their well-being and survival on sophisticated technologies and on expert care in the home that has traditionally been performed only by registered nurses and physicians in institutional settings (Hutchins & McPherson, 1989; Stein, 1985).

It is estimated that in 1987 there were between 10,000 and 68,000 children in the United States receiving ventilator assistance, parenteral nutrition, prolonged use of intravenous drugs, or other device-based respiratory or nutritional support in their homes (Hochstadt & Yost, 1989; Office of Technology Assessment [OTA], 1987). Since that time, even more of these children are probably being cared for at home by parents and other caregivers. However, the experiences of families who are dependent on technology for the maintenance of a child member's life have not been fully examined.

Purpose

The purpose of this naturalistic study was to explore the meaning of and factors involved in caring for a technology-dependent child at home. Investigation of childhood technology dependence from the family's point of view is lacking, and little is known about the long-term impact of caring for a technology-dependent child on family life. This study focused on the subjective and personal experiences of families with technology-dependent children through the use of an interpretive interactionist approach and as such will contribute to the body of knowledge concerning the phenomenon of long-term childhood technology dependence.

Background and Significance

Chronic health problems, whether present at birth or diagnosed later in childhood, present many challenges for children and their families. The terms chronic health problem, chronic condition, or chronic illness refer to any long-term impairment that interferes with an individual's ability to function fully in the environment (Thomas, 1987a; Woods, Yates, & Primomo, 1989). The course and prognosis of chronic conditions vary greatly and are unpredictable in many instances. Chronic conditions are rarely cured; instead, they are managed through individual and family effort.

An estimated 20 million children under the age of 18 in the United States, or about 10-15% of the childhood population, are affected by some type of chronic health problem, with approximately one million of these children having severe chronic conditions (Newacheck & Taylor, 1992; Patterson, 1988; Walker, Epstein, Taylor, Crocker, & Tuttle, 1989). Because of improved health care technology and treatment, more children with severe chronic conditions are surviving for longer periods of time. A subpopulation of children with chronic conditions are those who are technology-dependent.

According to Sandelowski (1993), technology dependency refers to the short- or long-term reliance on devices and techniques to evaluate, satisfy, or resolve health-related needs or problems. The technology-dependent child is defined by the U.S. Congress Office of Technology Assessment (1987) as one who needs both a medical device to compensate for the loss of a vital body function as well as substantial and ongoing nursing care to avert death or further disability.

Most children with chronic health problems, even those who are technology-dependent, are now being cared for at home. Several reasons for the increased use of technology in the home have been identified: (a) technologies have improved in recent years, making it technically feasible to care for children with complex medical care needs in the home setting; (b) it has been demonstrated that families can learn to provide safe, effective care to children with special health care needs; (c) the search for alternative approaches to care in light of rising hospital costs and reduced payments for inpatient care led to the discovery that home care was more cost-effective than hospital care; and (d) the potential for adverse developmental consequences appears to be greater for children in prolonged institutional care than for children who are cared for at home (Aday & Wegener, 1988; Handy, 1989; Hazlett, 1989; Kaufman & Hardy-Ribakow, 1987; Patterson, Leonard, & Titus, 1992).

Despite the increasing incidence and special needs of children who are technology-dependent and their families, there is little published research specific to this population. Most of the research to date has focused on the safety and cost-effectiveness of home care, and the initial transition phase from hospital to home (Aday, Aitken, & Wegener, 1988; Frates, Splaingard, Smith, & Harrison, 1985; Hazlett, 1989; Hochstadt & Yost, 1989; Leonard, Brust, & Sielaff, 1991; Quint, Chesterman, Crain, Winkleby, & Boyce, 1990; Youngblut, Brennan, & Swegart, 1994). Very little is known about the daily lives of families with children who are technology-dependent and how these families manage over time.

Research Questions

The goal of this research study was to address the following research questions in order to elicit information about the ongoing experiences of families who are caring for a child who is technology-dependent at home.

1. What does it mean to families to have a child member who is technology-dependent?

2. How do families that include a child who is technology-dependent adapt to and manage daily life with technology?

3. What do parents perceive as factors which hinder their family's abilities to adapt to life with a child who is technology-dependent?

4. What do parents perceive as factors which enhance their strengths as a family?

5. How do parents with children who are technology-dependent perceive their family's relationships and interactions with members of the health care system?

Knowledge of these phenomena will enable families with children who are technology-dependent and the health care professionals who work with them to better understand the effects of technology dependence on family life, and will aid nurses in planning and implementing more effective and holistic care for these families.

Conceptual Orientation

Interpretive interactionism (Denzin, 1989), a qualitative method which endeavors "to make the world of lived experience directly accessible to the reader" (p. 10), was employed in this study to provide insight regarding family experiences related to caring for a technology-dependent child at home. The interpretive approach advocated by Denzin (1989) is used in research attempting to examine the relationship between personal problems and the public policies and services created to address those problems. A major goal of this study was to provide a deeper understanding of long-term childhood technology dependence as it relates to family life and the interface between family life and the larger society.

The interpretive interactionist approach, according to Denzin (1989), is deliberately nonpositivistic. While the positivistic paradigm presupposes human behavior can be examined within the structure of a theoretical model, interpretive interactionism strives for a "concept-free mode of discourse and expression" (Denzin, 1989, p. 25). When conducting an interpretive interactionist study, the researcher's personal biases and conceptual orientation, which influence the approach to the study, must be acknowledged so their influences on the phenomenon may be recognized (Denzin, 1989; Spradley, 1979).

The purpose of a naturalistic study is to discover, not verify (Sandelowski, 1986). In other words, theory does not determine the research design; rather, theory emerges from the implications of the research data (Reinharz, 1983). Therefore, a conceptual orientation or sensitizing framework would be an appropriate representation of the role of theory when the researcher adopts an interpretive perspective.

The conceptual orientation that provided a sensitizing foundation for this study is Kazak's (1986, 1989, 1992) systems and social-ecological model, which is a synthesis of family systems theory and Bronfenbrenner's (1979) model of the ecology of human development. This model is consistent with the stated purpose and methodology of the proposed study.

Originally adapted from biology and physics theories, systems theory emphasizes the principles of organization and interrelatedness (Bertalanffy, 1968). Major assumptions of systems theory as they apply to the family system include the following: (a) families are composed of interrelated and interdependent members; (b) changes or problems in any one of the family members affects all other family members as well as the system as a whole; (c) the family system is greater than and different from the sum of its parts; (d) family systems change constantly in response to both internal and external stresses and strains; and (e) the family maintains a state of homeostasis via multiple mechanisms, including intra-family hierarchies, family rules and paradigms, and maintenance of family boundaries (Mercer, 1989). From a family systems perspective, then, a chronic health problem such as childhood technology dependence does not affect only the child; instead, it has ramifications for all members of the family system.

One criticism of family systems theory is that the emphasis on the system aspects of the family may obscure the individual's experiences, contributions, personality, and development (Kazak, 1989). An integration of systems theory with a social ecological model may be useful in providing a conceptual base for studying families as well as the individuals, including children, who comprise these families.

Social ecology is the study of the interactive process of progressive accommodation between the developing human being and the settings and contexts in which the person is actively involved (Bronfenbrenner, 1979). The model of the ecology of human development delineates four nested systems in society: the microsystem, mesosystem, exosystem, and macrosystem (Bronfenbrenner, 1979). The microsystem consists of resources, activities, roles, and interpersonal interactions experienced by an individual or a family in a particular setting, usually the home. Elements of the microsystem in the context of childhood technology dependence would include the home environment, patterns of communication, and adaptations in coping with stressful life events related to technology dependence.

The next system, the mesosystem, encompasses the interactive relationships of smaller settings outside of the home in which the child or family actively participates. Schools, hospitals and clinics, neighborhoods, church activities, and parent support groups are examples of parts of the mesosystem.

A system more peripheral to the child and family is the exosystem. The exosystem is defined as including settings that do not involve the child or family directly as active participants but in which events occur that affect the family. For the technology-dependent child and his/her family, the exosystem may include such elements as parental work environments, home health care agency policies, school board meetings, and the media.

The most distant system from the family is the overarching entity referred to as the macrosystem. The macrosystem consists of large environments that have an impact on the family such as culture and social policy. Some macrosystemic issues, including health care financing and the provision of access to educational services, have affected technology-dependent children and their families in a direct, tangible way. Other parts of the macrosystem such as societal norms, stigma, religious ideologies, and cultural diversity have a more subtle impact on families and are thus more difficult to assess.

The systems and social-ecological framework for viewing the family considers the child as nested within the family and the family as an open system which is actively influencing and being influenced by the larger systems (Kazak, 1992). Families with children who are technology-dependent interact frequently and often intensively with other systems in society. In addition, societal issues and mandates influence family adaptation and adjustment. This research study examined family experiences with long-term childhood technology dependence from a microsystem perspective as well as from the "larger systems" perspective, and in particular the families' experiences with the health care system.

Definitions

For purposes of this study, four essential concepts were defined as follows:

1. Childhood technology dependence: A condition which requires both: (a) a medical device to compensate for the loss of a vital body function, and (b) substantial and ongoing nursing care to avert death or further disability (OTA, 1987). In this study, technology-assisted category 1 (children on mechanical

ventilators), category 2 (children requiring prolonged intravenous administration of nutritional substances or drugs such as total parenteral nutrition), and category 3 (children with daily dependence on other respiratory or nutritional devices such as tracheostomies, suctioning, oxygen support, or gastrostomy feedings) were used as prototypes of childhood technology dependence (OTA, 1987).

2. Technology-dependent child: A child 3-12 years of age who has been technology-dependent and living in the home for one year or more.

3. Family: A group of interdependent individuals, containing at least one parent and one child who is technology-dependent, who have been living together for a minimum of one year.

4. Parent: A natural, adoptive or foster mother or father, legal guardian, or other significant adult living in the household who acts in a caregiving relationship with a child who is technology-dependent.

Assumptions and Limitations

This study was based on the assumption that home care is generally preferable to institutional care for the stable child who is technology-dependent. Individuals are viewed as being in a state of continuous development and are considered to be capable of creating and discovering meanings for themselves (Reinharz, 1983). Therefore, parents and other family members were aware of experiences related to living with technology that affect family life and were able to articulate these accurately to the researcher.

Naturalistic research is based upon the assumption that humans are complex beings that are best studied in their naturalistic environments using a holistic approach (Denzin, 1989; Lincoln & Guba, 1985). In addition, this researcher also accepted three assumptions addressed by Denzin (1989) as organizing the process of interpretive interactionism. These assumptions are: (a) in the world of human experience, causal explanations cannot capture reality; thus, only interpretation of subjective human experience is possible; (b) understanding can be created by attempting to make interpretations available to others; and (c) all interpretations are provisional, incomplete, and can never be finished.

Generalizability is not a characteristic of research done in the naturalistic paradigm. Instead, the results of this study have provided a thick description of the lived experience of family life with a technology-dependent child. Thick description, as defined by Denzin

(1989), refers to capturing the meaning of the experiences in a rich, detailed manner in contrast to thin description which is simply a factual description. Such basic research is essential in areas that have not been thoroughly explored in order to establish the foundation for further research and theoretical development.

Replication of naturalistic studies is generally not possible due to the complexity and uniqueness of each study's participants. Therefore, although the methodology may be replicated, it is doubtful that the results would be duplicated. However, common patterns exist, are reproducible, and are relevant to health care professionals.

Summary

In conclusion, the purpose of this naturalistic study was to identify factors that impact on family adaptation to long-term childhood technology dependence. The sample consisted of parents who had children who were technology-dependent, aged 3-12 years, and had been living at home for at least one year. Bronfenbrenner's (1979) model of the ecology of human development as adapted by Kazak (1986, 1989, 1992) provided the sensitizing framework for this study.

CHAPTER TWO

REVIEW OF LITERATURE

This chapter presents a review of the literature pertinent to the phenomenon under study. In the context of interpretive interactionism, a literature review is an essential early step in the interpretive process and is referred to as deconstruction.

According to Denzin (1989), a deconstructive reading of a phenomenon is constituted by a critical analysis of how the phenomenon has been "presented, studied, and analyzed in the existing research and theoretical literature" (p. 50). The process of deconstruction is characterized by the following steps: (a) prior conceptions of the phenomenon in question are identified and then critically analyzed; (b) an examination of the underlying theoretical model of human action used in previous studies is undertaken; and (c) the preconceptions and biases that surround current understanding of the phenomenon being explored are discussed.

The literature on chronic illness in childhood is extensive, complex, and ranges in scope from the individual to the societal level of analysis. This deconstruction will focus on selected representative literature where the family is the primary area of interest and will include three major components: (a) impact of childhood chronic illness on the family; (b) environmental influences on families with chronically ill children; and (c) families with technology-dependent children. All three of these components are interrelated and interactive. As a whole, they provide an inclusive overview of the research related to families of children who are technology-dependent.

Impact of Childhood Chronic Illness on the Family

The presence of a chronic condition in one family member affects the family as a whole (Hobbs, Perrin, & Ireys, 1985). For both child and family, chronic illness is a "perpetual, demanding companion; a lifelong associate; a constant shadow" (Hobbs et al., 1985, p. 62). This section of the review of literature, impact of childhood chronic illness on the family, will focus on four major areas: (a) family perception of and beliefs about the illness experience; (b) uncertainty in chronic illness; (c) stresses and strengths in families who have a child with a chronic condition; and (d) family management of childhood chronic illness.

Family Perception of and Beliefs about the Illness Experience

One of the factors that influences the impact that a childhood chronic condition will have on a family is the family's definition of the situation. This term refers to the meaning ascribed to the illness by the family of a chronically ill child and includes how the family members identify and interpret significant events in their lives (Knafl & Deatrick, 1990).

According to Strauss et al. (1984), the meaning of the chronic illness experience to the individual and the family affects the entire course, or trajectory, of the illness. The shape of each person's trajectory of chronic illness is different because it is comprised of not only the physiological characteristics of the disease, but also of individual and family definitions of what is expected in the course of the illness process. Uncertain trajectories, such as those found with many chronic conditions, tend to maximize personal and familial hardships. Since chronic conditions are often unpredictable in progression and are not curable, the child and/or family expend a great deal of energy and resources in areas related to the disease condition. In order to adapt successfully to long-term chronic health problems, it is essential that the individual and his/her family come to terms with the illness trajectory, however they define it.

Although the importance of the individual family's perceptions of their experiences has been acknowledged in both the literature and in clinical practice, there is little research related specifically to beliefs about illness in families who have a child with a chronic health problem. One reason for this may be the fact that the meaning and the demands of childhood chronic illness change with the child's age and developmental status, as well as with developmental changes in the family (Kazak, 1989). Longitudinal studies that would support or dispute this contention are lacking.

Marteau and Johnston (1986) hypothesized that parents' beliefs about their child's chronic health problem were based upon their experiences with people who had that particular illness. Parents of children aged 1-15 with diabetes (n=197), asthma (n=37), epilepsy (n=30), and no chronic illness (n=69) participated in the study. Measures of two specific beliefs, perceived seriousness of an illness and perceived vulnerability of an individual to illness, were obtained, as well as information related to the course of the child's illness, family history, and experience with illness. Overall, parents of children with a particular health problem perceived that health problem to be less serious than did parents of children without that particular illness. For example, ratings of the seriousness of epilepsy by mothers and fathers of children with epilepsy were significantly lower than ratings by all other parents ($F = 9.70$, $p < .01$). Experiences with relatives and other persons who have a particular chronic illness may influence parents' beliefs as well. The majority of parents did not feel that their child was more vulnerable to any of eleven other childhood illnesses because of the child's health status. The researchers felt the results were congruent with the tendency of individuals to minimize the severity of a stressful situation or event.

Parental attitude towards epilepsy was studied by Austin, McBride, & Davis (1984). Subjects were 50 parents whose school-aged children were being treated for epilepsy but had no other health problems and were not mentally retarded. Attitude scores were found to be neutral or slightly positive as a whole, and the majority of parents expressed both positive and negative beliefs about epilepsy. Parental attitudes were not significantly influenced by seizure control, perception of seizure control, or the length of time that the child had had epilepsy. However, parental attitudes were more negative when the child was a female (F(1,28)= 7.56, p <.01). There were no significant differences in the attitudes of fathers as compared to mothers.

Parents' perceptions of the family experience of learning to care for a child who is blind and the meanings associated with that experience was the focus of an interpretive study by Kodadek & Haylor (1990). Intensive interviews of 20 parents (8 fathers and 12 mothers) representing 12 families provided data for the study. Analysis and interpretation of the data revealed four paradigms or models that captured the various family response patterns to the experience of having a child who is blind. These paradigms were labeled by the researchers as "the realistically accepting family", "the perfect blind child family", "the devoted parent family", and "the overwhelmed family". The four paradigms differed in several areas, including the meaning of their child's blindness to the parents, their acceptance of the diagnosis, and the values parents placed on independence for their child. The researchers suggested that families in these different paradigms probably require different nursing interventions and that movement from one paradigm to another is possible.

Overall, the studies cited indicate that parental perceptions of their child's chronic health problem can have a substantial impact on family life and family interactions with society. Perceptions of parents who have children with other types of chronic conditions, including technology dependence, remain largely unexplored.

Uncertainty in Chronic Illness

One of the most difficult aspects of chronic illness may be the uncertainty that accompanies it. Many factors related to the experience of parenting a child with a chronic condition can engender uncertainty: the type of health problem, the prognosis for survival, the unknown elements of the future, and concerns about one's ability to love and parent a child with a disability (Anderson, 1981; Koocher, 1984; Mishel, 1983; Van Riper & Selder, 1989). Uncertainty occurs when one is unable to determine the meaning of illness-related events; it generally results from an inability to assign definite values to objects and events and/or an inability to accurately predict outcomes because of lack of sufficient cues (Mishel, 1988).

A qualitative, descriptive study of 16 parents of young children with Down syndrome found that initial sources of uncertainty for these parents included the unexpected diagnosis of Down syndrome, concerns about the future, apprehensions regarding parenting abilities, and the initial responses by health professionals (Van Riper & Selder, 1989). Parental concern about the future continued to be a source of uncertainty as their children grew older. Other ongoing sources of uncertainty were the child's health status and the child's involvement in an educational program. Parents attempted to decrease uncertainty through information-seeking, comparison with other parents in similar circumstances, and normalization.

Parental uncertainty generally increases whenever the child with a chronic health problem is hospitalized, whether this is the prolonged initial hospitalization that may occur after the child is born or the additional hospitalizations that may occur throughout the child's life. To measure the uncertainty parents experience concerning their child's illness, Mishel (1983) developed the Parental Perception of Uncertainty Scale (PPUS). The PPUS was administered to 272 parents of children ages infancy to 19 who were hospitalized for medical, surgical, or diagnostic reasons. Parents in the medical and diagnostic groups felt they had less information, experienced greater ambiguity, and had a greater sense of unpredictability about events than did parents in the surgical group (medical vs. surgical $t = 3.03$, $p <.01$; diagnostic vs. surgical $t = 3.60$, $p <.01$). When comparing the medical and diagnostic groups, no significant differences were found on the total PPUS scale; thus, the author concluded that both the medical and the diagnostic groups of parents appeared to be dealing with multiple uncertainty-producing events.

A qualitative study of the families of 60 children with acute myeloblastic or lymphoblastic leukemia revealed that the experience of uncertainty and the search for meaning were the characteristic features of the impact of childhood cancer on the patients and their families (Comaroff & Maguire, 1981). These features affected all aspects of the illness experience, including the initial impact of diagnosis, the treatment phase, remission, and the threat of uncertain outcome. Parents also felt that their relationships with others, and even with their child, were influenced by the pervasive uncertainty they felt.

In a review of the literature related to the psychological stresses of treatment of serious childhood illness, Koocher (1984) used cystic fibrosis and acute lymphoblastic leukemia as paradigmatic examples of chronic life-threatening diseases. Along with the prolongation of life due to more aggressive treatment regimes in these diseases comes an extension of the duration of the illness and an increased amount of ambiguity regarding the ultimate outcome. In some instances, the course of treatment for the illness has become noxious or even life-threatening in itself. Parents and older children may choose to deal with uncertainty through the use of adaptive denial, which serves to enable the individual to escape distress about matters over which he or she has basically no control. Persons who are unable to cope with high levels of uncertainty may experience chronic anxiety, depression, or loss of future orientation.

Parental response to the uncertainty caused by childhood cancer was also the focus of a longitudinal study of 10 families, five of whose children died within two years of diagnosis and five of whose children were long-term survivors (Cohen & Martinson, 1988). As a result of the unexpected diagnosis and unpredictability of the disease, parents' ability to adequately interpret their children's physiologic and behavioral cues was found to be impaired. In families with a surviving child, parents were unable to distinguish normal variations in the child's behavior from behaviors that were indicative of illness, and there was a heightened sensitivity to any sign of threat to the child's health. Families whose child did not survive transferred their uncertainty about determining normalcy to younger siblings. Impaired ability to appraise normal childhood illness and behaviors continued, and parents frequently worried when a younger sibling approached the age at which the child with cancer had been diagnosed or showed any type of resemblance to the dead child. Uncertainty was thus perceived to be a chronic facet of the lives of these families, regardless of the survival or death of the affected child.

Jessop and Stein (1985) used a noncategorical approach to chronic illness in their study of 209 mothers of children aged birth to 11 years with a variety of chronic health problems. The sample was urban, predominantly poor, and primarily composed of members of minority ethnic groups. Data were obtained from a home interview and from a provider's assessment conducted at the time of enrollment in the study. The researchers' hypothesis that the specific type of chronic illness was not as important to the child and family as were variables such as prognosis, visibility, severity, disability, and types of physical cares and treatments needed was supported. Several significant dimensions of illness emerged: (a) interference with the child's ability to engage in activities of daily living, (b) normal or abnormal appearance, (c) the presence of major surgical procedures, and (d) whether the family needs to expect changes in the child's condition. Interestingly, mothers of children with normal appearance reported that the condition had a greater impact on the family, and these children were reported to have poorer functional status than children whose handicap was visible ($F= 7.43$, $p <.01$). The lack of visible difference between a child with a chronic condition and a child without such a condition may have made it more difficult to recognize, diagnose, and deal with the chronic condition, thereby increasing parental uncertainty. Uncertainty was also associated with the need to be vigilant for changes in the child's condition (Jessop & Stein, 1985).

According to Mishel (1990), the high levels of continual uncertainty which are associated with chronic conditions can lead to disorganization and confusion in one's life. However, this uncertainty may also be a stimulus for families to reformulate their view of life from a mechanistic paradigm to a probabilistic one. This probabilistic world view enables uncertainty to be evaluated as opportunity rather than danger. Maintenance of the new paradigm is accomplished in part through the use of two environmental forces: support resources and health care providers. Although the assumption that chronic uncertainty can lead to a new perspective on life has not yet been examined empirically, a changed world view could have a profound effect on the overall impact of childhood chronic illness on the family. Moreover, this may explain how families achieve success in managing the long-term care of a child with a chronic condition.

Family Stresses and Strengths

Families who manage the lifetime care of a child with a chronic health problem encounter multiple stresses and demands over prolonged periods of time. These stresses, which can have a profound impact on family life, include altered family relationships, changes in family activities and routines, need for compliance with time-consuming treatment regimens, financial strains, worries about the future, social isolation, and stigma.

Family Stresses

Strauss and associates (1984) presented a holistic framework that delineates seven key problems of daily living associated with chronic illness: (a) prevention and management of medical crises; (b) control of symptoms; (c) management of treatment regimens; (d) prevention of, or living with, changes in social supports and networks; (e) management of the illness trajectory; (f) normalization of lifestyle and interactions with others; and (g) financial management. Long-term adaptation to chronic illness involves continuous attention to all of these problems. Parents who have a child with a chronic health problem certainly encounter all of these problems in addition to the unique challenges to parenting that arise on a daily basis.

Parents of children with three different chronic conditions, neuromuscular disease (n=16), cystic fibrosis (n=16), and renal disease (n=11), were compared with parents of healthy children who were matched by age with the affected children to determine differences in family functioning (Holroyd & Guthrie, 1986). Parents of children with chronic health problems had higher stress scores than the control groups, and each of the three groups exhibited different patterns of stressful response, with parents of children with neuromuscular disease demonstrating higher levels of stress than the other two clinical groups. Parents of children with cystic fibrosis experienced less stress than had been predicted, and parents of children with renal disease were similar to parents of healthy children in their view of family problems and strengths. The researchers felt that family stress may increase as the chronic condition progresses to stages of more severe functional impairment, and that differences found in family functioning in this study were reflective of differences in the children's chronic illnesses.

McKinney and Peterson (1987) examined child diagnosis, social support network, type of early intervention program, and perceived control as moderators of stress responses in 67 mothers of developmentally disabled children aged 7 to 41 months. Diagnosis itself did not relate to stress response outcomes, but specific characteristics of children with developmental disabilities, such as child demandingness and mood, acted as greater stressors than characteristics of nonhandicapped children. A pattern of increased stress scores across levels of severity of physical disability was also found, implying that children with moderate and severe physical impairment placed more demands on the mother. Mothers with a high degree of perceived control and less perceived spouse support showed significantly higher stress scores than other mothers ($F(1, 62) = 5.45$, $p < .05$). Type of early intervention program had no significant effects on level of stress.

Using a telephone survey (N=201), McCormick, Charney, and Stemmler (1986) assessed the influence of a variety of sociodemographic and child health factors on maternal perception of the impact on the family of having a child with spina bifida (myelomeningocele). Parents perceived higher levels of stress on the family due to the child's health problem in single-parent families, in families with lower maternal educational attainment, and in families with lower incomes. Step-wise multiple regression analysis revealed that child characteristics such as number of limitations in activities of daily living, parental assessment of fair or poor health, frequency of visits to a physician, and expenses of medical care; and family resources such as family income, educational level, and number of adults in the home were the major predictors of high family impact, accounting for 27.6 % of the variance. Other factors, including age and gender of child, number of other children in the household, and employment status of the mother, were not related to the impact on the family.

Family stress, resources, parental coping, and family types were measured in 58 two-parent families of children with myelomeningocele (McCubbin, 1988). The sample was divided into three groups based on whether the child had a mild (n=19), moderate (n=23), or severe (n=16) impairment, and each set of parents was requested to jointly complete a series of mailed questionnaires. Specific risk factors were identified for each level of impairment. Families with mildly impaired children were at greater risk for family dysfunction if they were experiencing financial difficulty. In families with moderately impaired children, families at risk included those who were experiencing higher levels of overall family stress. In families with severely impaired children, vulnerable families included those with low levels of social support, high levels of overall family stress, or inadequate family system resources. Results of the study indicated that the more severe the child's disability, the greater the demands and the greater the need for involvement of the entire family system in the management of the illness experience. However, the small sample size precludes generalizability of the results.

Family adaptation factors have also been used as predictors of emotional or psychological problems in children with chronic health problems (Austin, 1990; McAnarney, 1985). Austin (1990) studied the families of 90 children with epilepsy and the families of 88 children with asthma. The children, who ranged in age from 8 to 12 years old, were placed into good (43% of epilepsy, 56% of asthma children) and/or poor (28% of epilepsy, 11% of asthma children) adaptation groups on the basis of parent and teacher ratings of general behavior. Next, the family characteristics and the coping mechanisms of the children who were well-adapted and of those who were poorly-adapted were compared using measures developed from the Double ABCX Model of Family Adaptation (McCubbin et al., 1983). Overall, the families of poorly-adapted children had increased demands or more stressful events during the previous year, low family esteem and poor communication, more financial difficulties, little perceived control over the child's medical condition, and negative attitudes towards the affected child. It is impossible to determine, however, whether these family characteristics were the cause of poor adaptation in the child or were instead the effects of having a poorly-adapted child in the family.

Stresses on Siblings. Several research studies and literature reviews have suggested that the siblings of a child with a chronic condition are at risk for emotional and behavioral difficulties (Drotar & Crawford, 1985; Hobbs et al., 1985; Seligman & Darling, 1989). Parental attention and family resources are often less available, and siblings may experience feelings of anger, jealousy, resentment, guilt, or embarrassment. Older sisters of a child with a chronic health problem appeared to be more vulnerable than younger sisters or boys in general (Vadasy, Fewell, Meyer, & Schell, 1984; Kazak, 1986).

Psychosocial risk and resistance factors were examined in one study of children with juvenile rheumatic disease (n=93, mean age 10.84 years), their healthy siblings (n=72, mean age 11.26 years), and a demographically matched comparison group of healthy children (n=93, mean age 10.56 years) (Daniels, Moos, Billings, & Miller, 1987). For the siblings, factors associated with greater risk in the areas of psychological adjustment and physical problems included: increased parental dysfunction, increased dysfunction of the affected sibling, more family stresses, and less family cohesiveness and expressiveness. Higher family functioning tended to be associated with improved outcomes for both children with chronic health problems and their siblings, and, to a lesser extent, for the control group.

A comparison of self-concept in 30 siblings of school-aged children with diabetes mellitus and 30 siblings (mean age 9.3 years) who did not have a brother or sister with a chronic illness revealed that siblings of children with diabetes had significantly lower self-concept scores than did siblings of healthy children ($F(1,49) = 7.62$, $p < .01$) (Ferrari, 1987). Siblings younger than the target child had significantly lower total self-concept scores than older siblings ($p < .01$). In addition, siblings of male diabetic children, especially siblings who were male themselves, had significantly lower self-concept scores than siblings of healthy children and siblings of female children with diabetes.

Research done by Lobato, Barbour, Hall, and Miller (1987) examined the psychosocial characteristics of 24 three- to seven- year-old siblings of children with disabilities in relation to a control group of 22 siblings of children without disabilities. The chronic health problems of the children varied in type and severity. Results of the study demonstrated some significant differences between maternal perceptions of their healthy children and the children's own self-perceptions. Brothers of children with disabilities were rated by their mothers as being significantly more depressed ($F(1,45) = 10.12$, $p < .01$) and aggressive ($F(1,25) = 5.02$, $p < .05$) than brothers of children without disabilities. Sisters of children with disabilities were rated by their mothers as being significantly more aggressive ($F(1,16) = 5.81$, $p < .05$) than sisters of children without disabilities. However, no statistically significant differences were found between the groups of children themselves on measures of perceived self-competence and acceptance, understanding of developmental disabilities, empathy, or child care responsibility.

Family Strengths

One of the underlying themes of the literature related to children with chronic health problems and their families is that, while these families definitely experience stress, they also have many strengths (Doherty & McCubbin, 1985; Kazak, 1986; McCubbin, 1989; Singer & Farkas, 1989; Van Riper, Ryff, & Pridham, 1992)). Maternal perceptions of the impact of infant disability on family life were reported in a cross-sectional survey of 27 mothers of young children (mean age 4.0 years) with long-term tracheostomies (Singer & Farkas, 1989). Respondents stated that their child's disability affected all facets of family life, particularly in the areas of finance, emotional stress, and family and social interaction. However, the majority of mothers reported that parenting their child was a positive experience. Every mother in the sample agreed that learning to manage the child's chronic condition had made her feel better about herself. Other positive outcomes included increased family closeness (85%), extra support and understanding from relatives (89%), and increased communication with their partners (96%).

Research by McCubbin and Huang (1989) investigated resources and strengths in families of children with cerebral palsy (N=130, mean age of children 12.8 years). Categories of family strengths were measured through the use of standardized instruments and included: (a) family esteem, communication, mutual assistance, optimism, and problem-solving ability; (b) sense of mastery, mutuality, and physical and emotional health; (c) extended family social support; and (d) financial well-being. Adaptive parental coping could also be considered a strength. In families who had a child who was severely impaired, the family resource of esteem/communication was a significant factor in predicting the overall health improvement of the child. Mothers' coping behaviors related to maintaining social support, self-esteem, and psychological stability was also a significant predictor of overall health improvement in the child with severe cerebral palsy. Mothers' coping behaviors were also significant explanatory variables for the health improvement of children mildly affected by cerebral palsy.

Family stressors, family types, parental coping patterns, and child health indices were compared in 27 single-parent families of children with cerebral palsy (child mean age 13.1 years) and 27 two-parent families of children with cerebral palsy (child mean age 14.4 years) (McCubbin, 1989). The two groups of families were matched on the severity of the child's disability and the age and gender of the parent. Contrary to expectation, there were no significant differences in family stress, family cohesion, extended family social support, family resources of esteem/communication, or child health status between the two groups. In fact, single-parent families exhibited more flexibility and adaptability than two-parent families. Areas of significant vulnerability in single parents were: (a) lower financial well-being (t=2.82, df=23, p <.01); and (b) lower maternal coping behaviors in the areas of maintaining family integration, cooperation, and an optimistic definition of the situation (t=2.69, df=23, p <.01). McCubbin (1989) concluded that with adequate support and resources, single parents of children with handicaps may be at less risk than was previously thought.

A comparative study of families of children with Down syndrome (n=34) and families of children without disabilities (n=41) (Van Riper et al., 1992) revealed no significant differences between the two groups of families on measures of individual, marital, and family functioning. The results of the study suggest that parents of children with a chronic condition such as Down syndrome may respond to their situation with resilience and adaptive functioning, and that they are more comparable to than different from families who have children without disabilities.

Strengths of Siblings. A few reports have concluded that siblings can adjust successfully to the presence of a child with a chronic illness in the family (Austin, 1991; Brett, 1988; Menke, 1987; Taylor, 1980; Seligman & Darling, 1989). For example, Taylor (1980) found that one-third of the siblings in her study could identify positive outcomes, including increased self-esteem, empathy, and cognitive mastery, from having a brother or sister with a chronic illness.

Seventy-two school-aged siblings of children who had serious chronic conditions and their parents were interviewed by Menke (1987) to determine the impact of a child with chronic illness on his or her siblings. Children in the study had an older (n=52) or younger (n=20) sibling who had cancer, cystic fibrosis, congenital heart disease, severe burns, and/or myelomeningocele. Structured interview schedules were used to compare the responses of the healthy siblings with the responses of their parents. The majority (68%) of the healthy siblings worried about their ill siblings, and overall concerns appeared to be related to the nature of the sibling's illness and the healthy child's age, with older siblings expressing significantly more protective concerns about their ill sibling than younger children (chi square = 7.27, df=1, p=.01). Children also identified a greater number of changes in their parents than in themselves. Parents and their children did not usually agree regarding the nature of the children's concerns about their ill siblings. Parents reported few behavioral or academic problems in their healthy children, implying that they felt their children had adapted appropriately to the situation (Menke, 1987).

In a review of the literature related to sibling responses to chronic conditions, Brett (1988) maintained that the theoretical perspective employed by the researcher has an impact on the conclusions of the research. Those researchers who utilize the coping paradigm acknowledge that chronic illness can represent a major stressor to the family, but emphasize the ability of families to adjust to and be strengthened by such stress. Active involvement of siblings in information sharing about the chronic condition, open expression of feelings, and individualized attention from parents may enhance sibling adaptation.

In summary, high levels of stress are often experienced by families who have children with chronic health problems. Major stresses identified by families included the severity of their child's condition, perceived lack of control over the situation, perceived lack of social support, financial problems, and disruption of prior family relationships, roles, and routines. However, studies that identified positive family outcomes were also reviewed. Strengths that families experiencing chronic childhood illness developed or built upon related to family cohesiveness, communication skills, and feelings of mastery and accomplishment.

Family Management of Childhood Chronic Illness

The concept of family management of childhood chronic illness encompasses the coping strategies and specific actions that family members use to manage their situation on a daily basis. In this section, coping strategies used by families of children with chronic conditions will be reviewed. In addition, the specific management strategy of normalization will be examined because of its pervasive use by parents of chronically ill children in Western society.

Coping Strategies

Much of the literature related to families of children with chronic health problems addresses the ways that parents attempt to cope with, or adjust to, the experience of chronic illness in the family. According to Shapiro (1983), the adaptive tasks of chronic illness to which coping must address itself include tolerating or adjusting to negative events and changed reality, maintaining emotional equilibrium, maintaining hope, and continuing satisfying relationships with others. As various aspects of chronic illness are delineated, different family coping strategies may be employed.

Knafl and Deatrick (1987) proposed that the literature contains two major approaches to understanding how families respond to a member's chronic illness or disability. The Objective Passive Outcome Approach is based on the assumption that illness is an inherently negative situation which adversely impacts on family life. Family response is generally seen as passive, and the focus of research is on measuring, predicting, and/or controlling the outcomes of chronic illness and disability. The other approach, labeled the Subjective Active Process Approach, emphasizes the meaning of chronic illness to the individual family and attempts to discover how families actively manage and adapt positively to their situations. Examples of each of these approaches will be included in this section of the literature review. Because each approach is based on a different paradigm, it is important for the reader to critically examine the assumptions that underlie specific research studies on family responses to childhood chronic conditions.

Coping strategies utilized by 38 families (N=63 parents) of children who had osteogenesis imperfecta, juvenile diabetes mellitus, or cystic fibrosis were elicited via interviews as part of the development of the Chronicity Impact and Coping Instrument: Parent Questionnaire (Hymovich, 1984). Seven subcategories of coping strategies used by parents across diagnoses were identified: (a) seeking, which included strategies used by parents to obtain information and resources; (b) utilizing available resources for information, health care, educational, financial, and community support; (c) managing stresses, which involved specific actions taken by parents to manage their child's physical needs and the parents' emotional responses to having a child with a chronic illness; (d) modifying strategies, which were actions taken to alter conditions or situations affecting family functioning; (e) anticipatory planning, including family, financial, and educational planning; (f) educating others about their child's condition and its management; and (g) helping/supporting other individuals, groups or organizations that were related to their child's condition. These categories may represent common ways of coping for parents that transcend the specific chronic health problem of their child.

Parental coping in families who have a child with cystic fibrosis has been the focus of several studies

(Gibson, 1988; McCubbin et al., 1983; McCubbin, 1984). Gibson (1988) found that social support, problem-solving skills, and a system of beliefs were the major types of resources used by parents of children with cystic fibrosis. Parents relied on both action-oriented and intrapsychic coping behaviors. Examples of action-oriented coping strategies included adherence to the treatment regimen, establishing routines, and maintaining family stability. Intrapsychic efforts were reflected in an underlying way of thinking that was characteristic of the families in the study. Parents maintained a positive self-image, and most felt capable of successfully managing the illness and maintaining a normal lifestyle. As a result of effective coping mechanisms, parents were able to alter their perception of the situation from one of threat to one of challenge.

McCubbin et al. (1983) identified three parental coping patterns in a study of 100 families who had a child with cystic fibrosis: (a) maintaining family integration, cooperation, and an optimistic definition of the situation; (b) maintaining social support, self-esteem, and psychological stability; and (c) understanding the medical aspects through communication with other parents and consultation with health care professionals. McCubbin (1984) further analyzed these coping patterns and found that coping strategies between mothers and fathers in the study were not significantly different. Both mothers and fathers used all three coping patterns, and both emphasized family integration, although mothers appeared to place a stronger emphasis on consultation with the health care team and fathers emphasized social support.

Other researchers have found differences in coping between mothers and fathers who have children with chronic health problems (Powers, Gaudet, & Powers, 1986; Schilling, Schinke, & Kirkham, 1985; Tavormina, Boll, Dunn, Luscomb, & Taylor, 1981; Van Cleve, 1989). The type and quality of coping strategies used by 133 mothers and 93 fathers of 144 children with diabetes, asthma, cystic fibrosis, or hearing impairment were studied by Tavormina et al. (1981). Overall, mothers reported more deleterious effects from the stress of daily management of chronic illness than did fathers; in addition, mothers consistently reported more problems in their children and more involvement in their child's care than fathers. However, mothers had better attitudes towards their abilities as parents than fathers did, especially in the areas of understanding, trust, and acceptance of the child.

In a review of research related to parental coping, Schilling et al. (1985) found that mothers and fathers differed in how they appraised and coped with the stress of raising a child with a disability. Parental and marital roles tended to be more traditional in the family with a chronically ill child, with the mother bearing the primary responsibility for the care of the child and the home, and the father being the primary wage-earner of the family. Thus, each parent may have had different sources of stress and therefore may have used different coping strategies. In general, mothers were reported to have a wider range of coping responses, and in particular relied more on social support.

Powers et al. (1986) reported differences in coping patterns between mothers and fathers of children with chronic illnesses as well as between Hispanic-American parents and Anglo-American parents. Differences between maternal and paternal coping strategies were also noted in parents of children with spina bifida (Van Cleve, 1989). In contrast, a study of parents of children with cystic fibrosis found no significant differences between coping strategies used by mothers and fathers (Hymovich & Baker, 1985).

Trute (1990) proposed that marital satisfaction would be a strong predictor of positive family coping with the stresses associated with family care of a child with a chronic condition. A cross-sectional, random sample of 88 families containing young children with developmental disabilities were surveyed using in-home interviews of mothers and fathers. The conclusion of the study was that families who had children with disabilities were not significantly different from families with children without disabilities in their levels of organization and functioning. The attributes of the child with the disability had little influence in explaining variance in family adjustment. However, a key factor in positive family adjustment was the level of dyadic cohesion in parents. As marital cohesion among couples with a disabled child increased, coping abilities and family strength also increased.

Van Cleve (1989), in a study of 100 parents of children with spina bifida, also found positive relationships between marital satisfaction and coping as well as between coping and attending a parent support group. A striking finding was that parents who had high scores on the Chronicity Impact & Coping Instrument: Parent Questionnaire (CICI:PQ) did not employ significantly different coping strategies than parents who had low scores; instead, parents with high coping scores used their coping strategies on a more frequent basis.

A unique perspective on parental management of the child with a neuromuscular disease was obtained by Bregman (1980). The researcher lived with each of six families for four days and nights to gain an in-depth knowledge of the concerns of parents with children with neuromuscular disease, and the ways in which parents managed those concerns. Five general patterns of management were observed: (a) parents change their focus from the future to the present, (b) parents strive to maximize normalization of their family lives, (c) parents attempt to minimize their families' vulnerability, (d) parents develop and capitalize on their personal strengths, and (e) parents cultivate support networks.

Studies related to family coping with childhood chronic illness have resulted in varied, sometimes conflicting findings. It is clear that families may manage childhood chronic illness in different ways; however, a recurring theme is that of normalization.

Normalization. A management strategy used by most families who have a child who is ill or disabled is that of normalization; that is, they attempt to treat the child as much like a healthy child as possible (Bregman, 1980; Gibson, 1988; Scharer & Dixon, 1989; Seligman & Darling, 1989; Strauss et al., 1984). An analysis of the concept of normalization by Knafl and Deatrick (1986) suggested the following criteria for defining and recognizing normalization as a family management strategy: (a) acknowledging the existence of the child's impairment, (b) defining their family life as essentially normal, (c) assigning minimal social consequences to their situation, and (d) engaging in behaviors designed to demonstrate the normalcy of their family to others.

Normalization entails a constant process of actively accommodating the changing physical and emotional needs of the child. It is a conscious effort on the part of family members to treat the child normally while not neglecting his or her special needs. A qualitative study of the parents of 15 children with osteogenesis imperfecta found that in order to achieve normalization, families developed strategies related to: (a) the child's activities of daily living, (b) disciplining and monitoring the child, and (c) engaging in family activities that parents considered important to maintaining a "normal" family life (Deatrick, Knafl, & Walsh, 1988). Sources of concern for these parents focused primarily on the effects of the disease process and included the unpredictability of fracture occurrence, the inability of parents to prevent them, and the fear of causing injury through physical expressions of affection. The need to avoid fractures while promoting normalcy in the child necessitated balancing parental vigilance and monitoring with encouragement of the child's independence and self-monitoring capabilities. This task seemed the most difficult to accomplish for parents of children with mild osteogenesis imperfecta because the reasons for their concerns were less obvious to the children themselves and to others observing their precautions.

Krulik (1980) interviewed 20 mothers of children with cystic fibrosis or childhood cancer and elicited examples of successful normalizing tactics they utilized to reduce their child's feeling of being different from his or her siblings and peers. Mothers' strategies could be grouped into three major categories: (a) management of the medical regimen, (b) changes in the child's physical appearance, and (c) threats to performance of the child's roles. The two overall goals of these normalizing strategies were to strengthen the resources and coping abilities of the child and to alter the environment to compensate and accept the child. As a result of successful normalizing techniques, the illness regimen management was a shared experience by the whole family. Parental and child feelings of control over the situation were increased, as was the child's participation in decision making and management of the chronic health problem.

Another perspective on the process of normalization is Anderson's (1981) ethnographic study on the social meaning of sickness in four families with a child with a chronic illness. A major finding in this study addressed the inconsistencies between parents' accounts of their children as "normal" and the parents' actual everyday practices. Parents adjusted family lifestyles in many ways so that there would be minimal discrepancy between the child's lifestyle and the rest of the family's. However, results of the study also suggest that although parents had their own definition of the concept of normality, they were also aware of the lifestyles and developmental achievements of healthy children (Anderson, 1981). Parental expectations of the child with a chronic illness were different than those of healthy children, and it is possible that parents are communicating two conflicting sets of messages to the child with a chronic condition --- one that "you are like everyone else", and the other that "you are not well, you are different". This double bind pattern of communication may lead to increased stress and uncertainty in the child and family, especially during times of exacerbation of illness or hospitalization when normalization is threatened.

Robinson (1993) expanded on the concept of normalization in an analysis of 62 accounts, or stories, related to managing life with a chronic condition. Robinson found that a shift in perspective occurred in the process of normalization which involved a reframing of perspectives and experiences. Two ways which supported the evolution of the story of life with a chronic condition as "normal" were identified: (a) minimizing the significance of problems associated with the chronic condition through selective focusing of attention, and (b) reconstructing the reference points by which the experience is judged. Normalization was found to be beneficial because it supported hope and focused on abilities rather than deficits. Significant costs related to normalization included energy expenditures; strains on relationships; and the masking of important concerns or health problems, which made obtaining needed resources or support difficult.

Summary of Impact of Childhood Chronic Illness on the Family

This portion of the review of literature presented studies which have considered the impact of childhood chronic illness on the family. The results of these studies have provided insight into the ways that families perceive, respond to, and manage chronic health problems, yet there does not seem to be one overall pattern of adaptation. Clearly, the impact of childhood chronic illness on the family is influenced by a variety of factors: (a) the meaning of the illness to the family, (b) the uncertainty that is engendered by medical conditions that are rarely cured, (c) the family stressors that arise, (d) the strengths that families bring to or develop as a result of the situation, and (e) the strategies families employ to manage daily life with childhood chronic illness. Additional research which explores these factors in greater depth is needed to further clarify the effects of childhood chronic illness on the family.

Environmental Influences on Families with Chronically Ill Children

The impact of a chronic condition on a given child and family depends not only on characteristics of the chronic illness such as type and severity, but also on external factors such as psychosocial support, access to services, and acceptance by the community (Newacheck & Taylor, 1992). The second major area of this review of literature, environmental influences on families with chronically ill children, will examine studies related to the social, cultural, and economic processes that shape how family members define and manage the chronic illness experience.

The Influence of Western Culture

The beliefs and cultural norms of Western society have a great impact on U.S. children with chronic health problems and their families. For example, children with disabilities are likely to be shunned, ridiculed, avoided, and/or ostracized because they deviate from the societal norm of physical and mental perfection (Seligman & Darling, 1989). Goffman (1963) referred to this social intolerance of deviation from the norm as "stigma", and distinguished between two different kinds of stigma: discredited and discreditable. A discredited chronic condition is one that has visible cues, such as physical deformity, obvious medical equipment, or special medical or dietary requirements. These visible signs of illness are not considered "normal"; thus, they may create anxiety in persons who do not have these characteristics. In contrast, a discreditable condition is not readily apparent to others because there are no visible cues of the chronic illness. The child with a discreditable condition and his or her family may be able to keep the chronic illness hidden and avoid stigmatization.

The social stigma attached to the child with a disability is often, by association, extended to others in the child's family as well. This potential "courtesy stigma" (Goffman, 1963) was the focus of a study of well siblings of children with a variety of chronic illnesses (Gallo, Breitmayer, Knafl, & Zoeller, 1991). Analysis of interviews with 27 siblings revealed that younger siblings tended to be more secretive about the ill child's condition and chose to reveal information about the chronic illness to others less frequently than older siblings. Overall, however, there was little evidence that childhood chronic illness had a stigmatizing effect on the well sibling's everyday life or relationships with friends.

Anderson and Elfert (1989) explored another dominant ideology of Western culture in an ethnographic study of the role of women as caretakers. Interviews with 22 Euro-Canadian families caring for a child with a chronic health problem found that women assumed the primary role of caretaking for their chronically ill children, but that their work often went unnoticed and unrecognized by society. It is assumed in Western society that women are and will be competent caretakers. In fact, <u>not</u> performing competently caused serious consequences for the women in the study in their interactions with family members, health care professionals, and others in society. The researchers concluded that the present structure of illness management in the home is not in the best interests of women as a whole, and that the impact of caregiving on women's lives needs to be more fully explored and appreciated (Anderson & Elfert, 1989).

The cultural and subcultural diversity in today's society can also affect family responses to childhood chronic illness. Seligman and Darling (1989), in a review of literature related to cultural reactions to childhood disability, emphasized the importance of the family's ethnic background, social class, and religion as factors that influence parental response and adaptation to caring for a child with a chronic condition. An illustration of this concept is provided by a qualitative study of six immigrant Chinese families caring for a chronically ill child in the home (Anderson, 1986). For the Chinese families in the study, "looking after" the child with a chronic health problem and fostering his or her happiness and contentment took precedence over the process of normalization emphasized by the Western health care system. In addition, the families often considered treatment regimens as the responsibility of the health care providers rather than the responsibility of parents or other family members. These differences in beliefs, added to the relative inexperience of immigrant families in caring for persons with long-term health problems, frequently led to misunderstandings as well as concern on the part of health professionals that families were noncompliant with prescribed cares.

The studies cited demonstrate that differences in cultural beliefs and potential conflicts with the values of the dominant society must be considered when analyzing family experiences with childhood chronic illness. In the Western ideology of health care, families are often seen as passive recipients of care. An alternative approach to caregiving was proposed by Anderson (1986) which calls for valuing and respecting the contributions of the family and viewing the family and child as the primary managers of the chronic illness experience. However, in order for families to manage the chronic illness experience effectively, they must have access to needed resources.

Family Resources

Families that include a child with a chronic health problem are in need of and tend to utilize resources outside of the family more intensively than families with healthy children. Perceived needs of families with children who have chronic conditions has been the focus of several studies (Horner, Rawlins, & Giles, 1987; Hymovich & Baker, 1985; Walker et al., 1989).

Horner et al. (1987) sent a mail questionnaire (N=164) to families of children who had a variety of chronic health problems. Needs related to information, programs and services, and health care were surveyed. The major informational needs identified by parents were related to planning for the child's future (55%), identifying appropriate community resources (49%), understanding how the disability affects their child's emotional and physical development (45%), and improving communication among the child's health care providers

(44%). Program and service needs included help with medical bills, recreational activities for the child, and respite and other child care services.

A larger survey (N=910) of parents of children with a variety of chronic conditions and of various ages and sociodemographic backgrounds found similar results, with the most common needs expressed by parents related to communication and information issues, health care, and insurance coverage and expenses (Walker et al., 1989). Services considered "very important" to parents included parent education on rights and entitlement (74%), help in getting needed services (72%), physical therapy (64%), and information on community resources (61%), early intervention programs (59%), and social/recreational opportunities (59%). The differences that existed for particular illness categories were due to specific characteristics of the illness; for example, parents of children with cerebral palsy considered adaptive equipment important, while parents of children with autism expressed more importance for help with behavior problems. However, the authors concluded that the perceived needs and rankings of important services by parents of children with a number of chronic health problems were more alike than different (Walker et al., 1989).

Hymovich and Baker (1985) studied 116 families of children with cystic fibrosis with an emphasis on parental needs, concerns, and coping. The investigators found that most families were concerned about their children's future, and wanted more information about their child's emotional, physical, and intellectual development. The majority of parents coped with the demands of caring for a child with cystic fibrosis by talking with health professionals, friends, relatives, and other parents with children with cystic fibrosis.

As part of a large (N=1726) survey of parents of special education students in five metropolitan school districts (Palfrey, Walker, Butler, & Singer, 1989), parents were asked a series of questions related to the effects that their child's handicap had on their job situation, family friends, vacation plans, child care, house/community, or marriage. Of the six domains, parents were least likely to state that the child's handicap affected their marriage. Families of children who had physical/multiple problems felt the greatest effect; many of these families reported difficulty obtaining child care (38%), compromise of their job situation (31%), and constraints on vacation plans (25%). In addition, the choice of the house and/or community in which the family lived was influenced by the presence of a child with a sensory impairment (19%) or physical/multiple problems (18%). The authors suggested that greater attention to the external resources that families with special needs children require, such as competent respite care and community supports, may enable these families to better manage daily life with a child who is chronically disabled. In other words, in order to manage successfully, families need both intrafamily and extrafamily support mechanisms.

Social Support

As noted in several of the studies previously cited (Bregman, 1980; Hymovich & Baker, 1985; Strauss et al., 1984; Van Cleve, 1989), another factor that influences a family's capacity to adjust to the experience of living with a child with chronic illness is social support. A family's social support system may serve as a variable that can buffer the effects of this stressful situation; conversely, lack of social support may contribute to family dysfunction.

In a longitudinal study, Capuzzi (1989) compared the attachment of mothers with and without an infant who was disabled and examined the relationship of social support to maternal-infant attachment. The two groups of mothers were found to be equivalent before birth in terms of such variables as demographics, reproductive history, self-concept, prenatal stress, and maternal-fetal attachment. Types of infant disability varied, as did their chronicity and severity. Maternal attachment was found to differ significantly at one month postpartum, with mothers of infants with disabilities displaying fewer attachment behaviors than mothers of infants without disabilities ($t= 1.87$, $p <.05$). However, no significant differences were noted between the two groups at six and 12 months postpartum. The presence of social support appeared to reduce the stress of having a child with a chronic condition, thus facilitating maternal attachment.

Studies done by Kazak and associates (Kazak, 1987; Kazak & Marvin, 1984; Kazak, Reber, & Carter, 1988; Kazak & Wilcox, 1984) have demonstrated differences in the stress levels and social support networks of parents of children with chronic illness as opposed to parents of children without chronic illness. For example, two of these studies (Kazak & Marvin, 1984; Kazak & Wilcox, 1984) found that mothers of children with spina bifida experienced more personal stress than fathers of these children or parents of children without chronic conditions. Levels of parenting stress were higher in families with children with spina bifida, but there were no significant differences in marital relationships between the two groups of parents. Families of children with spina bifida had similar family network sizes when compared to those with healthy children, yet had significantly smaller friendship networks. A corollary to this finding was that the families of children with spina bifida had significantly more dense networks than families of children without disabilities; that is, members of their social networks were more likely to know and interact with each other (Kazak & Marvin, 1984; Kazak & Wilcox, 1984).

Kazak (1987) compared mothers and fathers of children with institutionalized mentally retarded members who visited their families on weekends (n=36), parents of children with phenylketonuria (n=43), and parents of children with spina bifida (n=46) with matched samples of mothers and fathers of children without any known physical or psychological disorders. Overall, families of children with chronic conditions were not more isolated than other families. The only significant difference in social networks was that higher density networks were found for mothers of children with chronic conditions (T^2=3.03, df=2232, p <.05). However, significant differences among the three groups of families with chronically ill children were found in several of the social network variables, including both parents' total network size, network density, and fathers' friendship network size.

In a related comparison study of parents of children with phenylketonuria and parents without an ill child (Kazak et al., 1988), larger social networks of lower density were significantly related to lower levels of psychological distress for both groups of parents. This suggests that the mere presence of a child with a chronic health problem does not make high levels of family stress an inevitable conclusion.

Ferrari (1986), in a study of 148 married adults, found that parents of children between the ages of 9 and 11 years with chronic illness (juvenile diabetes and autism) perceived a lesser amount of social support than did parents of children without health impairments. Overall, fathers of children with chronic illness had the lowest perceptions of social support. In addition, parents of children with diabetes perceived significantly lower amounts of social support than parents in the other two groups. This finding may support the contention that parents who have children with less visible disabilities or chronic conditions may be more apt to receive lower levels of support.

In a sample of 57 mothers of children with developmental disabilities, higher satisfaction with family functioning was correlated with factors such as social support ($r=.37$, $p <.01$), family hardiness ($r=.45$, $p <.0001$) and maintaining an optimistic definition of the situation ($r=.22$, $p <.05$) (Failla & Jones, 1991). Lower levels of satisfaction with family functioning were associated with loss of social support ($r= -.32$, $p <.01$), increased parental age ($r= -.25$, $p <.05$), and higher family stress scores ($r= -.27$, $p <.05$).

The availability of social support can be a mitigating factor in the maintenance of physical and psychological health in families who have a child with a chronic condition. The type and intensity of support required by families coping with childhood chronic illness, however, is influenced by the specific context in which the support is experienced (Quittner, 1992). The type of chronic illness, the developmental stage of the child and family, and the disruption of normative social roles must be considered when studying the impact of support systems, including formal support systems such as health care providers, on the family.

The Health Care System

A significant change in the social environment of the family with a chronically ill child is the addition of health care professionals as network members and socially supportive individuals (Kazak & Marvin, 1984; Seligman & Darling, 1989; Thomas, 1987a). Health professionals expect parents to become experts in the care of their child with a chronic health problem, yet the acquisition of this expertise may cause conflict between the family and the health care system.

A multiphase, qualitative study of ongoing health care relationships from the perspective of the family of a child with a chronic condition demonstrated that these relationships evolved over time in three predictable stages (Robinson, 1987; Thorne & Robinson, 1988, 1989). The first stage, naive trust, occurred early in the chronic illness experience and was based on the family's assumption that its perspective was a perspective held in common with the health professionals who cared for their child. As discrepancies arose between family members' views and professionals' views as to the best interests of the child and as unmet parental expectations increased, this trust was shattered. The second stage, disenchantment, was characterized by dissatisfaction with care, frustration, anxiety, fear, and mistrust. Parents felt torn between actively advocating for their child and being afraid that doing so would have a negative effect on their child's care. Eventually, some type of resolution occurs and an alternative form of trust is reconstructed so that the child and family can continue to receive health care. This third stage is one of guarded alliance, and families differ in the type of relationship that they reconstruct with health care providers. Families may continue to trust and receive support from health care professionals, but the trust is highly selective and contingent on revised role expectations for both parents and providers.

Summary of External Influences on Families

Families who have children with chronic health problems do not live in isolation. In fact, the family affects and is affected by numerous settings and contexts (Bronfenbrenner, 1979; Kazak, 1986, 1989). Factors most frequently cited by families as having an impact on their abilities to adapt successfully to caring for their chronically ill child include informational resources, financial assistance, social support networks, the availability of respite care, and the health care system. In addition, the attitudes of the community and of society as a whole play a major role in successful family adaptation to childhood chronic illness.

Families with Technology-Dependent Children

A small but growing number of children with severe chronic health problems are technology-dependent. The third and final area of review will examine literature that specifically addresses technology dependence, with an emphasis on research related to families with technology-dependent children.

The Impact of Technology on the Family

The realization that an individual is totally dependent on a technological device for continued survival has a profound impact on both the individual and his or her family. Relationships with friends, extended family, and community entities are often changed as a result of technology dependence. Multiple modifications must be made in the home environment and in personal and family lifestyles. In addition, the psychological effects of technology dependence on the individual and family may be overwhelming at times.

Having a technology-dependent family member in the home frequently requires the addition of multiple pieces of equipment to the environment. Living space must be reorganized to accommodate all of the equipment and extra supplies without making the individual's room or the home itself seem like an extension of the hospital (Donar, 1988). Sleeping arrangements may need to be changed so that the technology-dependent individual is in closer proximity to the primary caregiver or to an exit, and rooms that were formerly utilized for one purpose may be converted for other uses (Geary, 1989; Johnson, 1987; Odom & Chandler, 1990). The physical displacement of siblings or other family members and their possessions because of the technology-dependent individual's needs must also be taken into consideration (Handy, 1989).

Another perspective on technology can be gained by considering the technology's effect on daily living and the individual and family's functional capacity to engage in that daily living (Carnevali, 1985). In addition to making changes in their physical environment, individuals and families must also modify their habits, routines, lifestyles, and roles in response to technology. Patterson (1988) referred to this phenomenon as changing the internal structure of the family in response to the needs of the chronically ill family member.

Caring for a technology-dependent individual requires a great deal of time, energy, and creativity. Family routines and daily schedules are often rearranged because of clinic appointments, home health care visits, and vendor deliveries. An even greater disruption, however, is the amount of time and effort spent in treatments and cares related to the technology. In addition to routine daily care, treatments such as dressing changes, chest physiotherapy, suctioning, or dialysis, and tasks such as assessing the individual for iatrogenic effects of the technology, changing tubing, or cleaning equipment may require substantial amounts of time among family members, especially the primary caregiver (Andrews & Nielson, 1988; Handy, 1989; Johnson, 1987; Patterson, 1988).

Restrictions on the activities of the primary caregiver, usually the mother or other female relative, are very prevalent among families with a technology-dependent member (Anderson & Elfert, 1989; Sims, Boland, & O'Neill, 1992). Mothers of technology-dependent children, for example, reported having less time for themselves, less time for their spouses and their other children, less time for sleep, and less time to engage in growth and development promoting activities with the affected child (Andrews & Nielson, 1988; Nuttall, 1988). Family social activities may also be curtailed; decreased interaction with friends and decreased activity outside the home are frequent occurrences (Aday, Aitken, & Wegener, 1988; Geary, 1989; Perl, 1987; Stevens, 1990).

Family roles may be modified or new roles may be created as a response to technology. Parents, spouses, siblings, or adult children may take on roles as specialized caregivers or act as liaisons between the family and multiple health care professionals (Diehl, Moffitt, & Wade, 1991; Odom & Chandler, 1990; Sims et al., 1992). Career changes or modifications may be necessary for parents or other caregivers. Even young siblings may be expected to take on increased responsibility for household tasks or in assisting with the care of their technology-dependent brother or sister (Johnson, 1987; Seligman & Darling, 1989).

The adaptations families must make in their environments, lifestyles, roles, and interactions with entities outside the family all contribute to the psychological impact of technology on the individual and the family. In a study of 19 families who were providing care for individuals with various types of high-technology care, Stiller (1988) suggested that factors other than the specific type of technology mitigated family success with home care. Lower family coping scores, poor medical prognosis, and increased role disruption were present in families who were not able to manage home care. Fatigue of caregivers and emotional distress in caregivers and technology-dependent individuals were also experienced. These findings have been corroborated in studies of persons receiving home parenteral nutrition and their families (Perl, 1987; Smith, Giefer, & Bieker, 1991) and persons receiving ventilatory support at home and their caregivers (Thomas, Ellison, Howell, & Winters, 1992).

Technology-Dependent Children and Their Families

Research studies that focus specifically on technology-dependent children and their families remain limited. Many of the stresses encountered by families which include technology-dependent children are similar to those described earlier in this review of literature. However, certain phenomena are particularly or uniquely stressful in families with technology-dependent children (Aday et al., 1988; Andrews & Nielson, 1988; Hazlett, 1989; Nuttall, 1988; Patterson, Leonard, & Titus, 1992; Scharer & Dixon, 1989).

Determinants of the number of home care nursing hours that 31 families with technology-assisted children received was the focus of a study by Leonard, Brust, & Sielaff (1991). Almost all (98.6%) of these families received some hours of professional nursing care per day, with 16.1% having 24-hour nursing care for their child. The number of nursing care hours allotted to families caring for technology-dependent children at home is normally based on the severity of the child's medical condition, the family's willingness and ability to provide care, the availability of nurses in the community to care for the child, and the funding policies of the reimburser. Results of the study indicated that family factors, rather than the child's medical condition, had the greatest influence on the number of home care nursing hours received, with married, lower-income families with a younger child receiving the fewest hours (Leonard et al., 1991).

Focus group interviews conducted with a total of 80 caregivers of medically complex/technology-dependent children revealed that their most pervasive concerns related to family issues, the need for illness specific information, difficulties with equipment, interactions with health professionals, finances, and educational needs (Diehl et al., 1991). Family issues expressed by parents included lack of acceptance of the child by other members of the family, lack of ability to function spontaneously as a family unit, concern about the availability and quality of respite care, and fear of deterioration in family relationships. In general, professionals were viewed very negatively. Parents did not feel that professionals, especially physicians, listened to them, treated them with respect, or displayed a high level of professional competence. Parents expressed the need to be constantly vigilant and assertive in order to get the information and services they needed for their children.

Patterson et al. (1992) examined the long-term impact of caring for a medically fragile child on the health of other family members. Information obtained from 48 families via standardized questionnaires and parental interviews revealed that families had greater physical illness symptoms when the financial burden of providing care was greater and when relationships with care providers were more strained. Care provided by home health aides was associated with a greater negative psychosocial impact on the family, while care provided by professional nurses reduced the negative impact. Sources of stress related to home care providers included invasion of family privacy, inadequate training, lack of skill and competence, and unreliability. In addition, the degree of severity of the child's condition exacerbated the negative impact of the condition on the family.

Family adaptation to specific childhood technologies

Research related to family adaptation to specific types of childhood technological devices has also been noted in the literature. These categories include: (a) families of infants on apnea monitors (Dean, 1986; Geary, 1989; Nuttall, 1988; Stevens, 1990; Wasserman, 1984); (b) families of children receiving continuous ambulatory peritoneal dialysis, or CAPD (LePontois, Moel, & Cohn, 1987); and (c) families with ventilator-dependent children (Aday & Wegener, 1988; Hazlett, 1989; Quint et al., 1990; Scharer & Dixon, 1989; Wegener & Aday, 1989). Studies dealing with parents of infants on home apnea monitors will not be included in this section of the literature review, however, because monitored infants are not technology-dependent in the strictest sense of the OTA definition. That is, substantial and ongoing nursing care is generally not required for infants on apnea monitors, and the use of technology is not imperative to avert death or further disability (OTA, 1987).

Families of children receiving CAPD. Family adjustment to pediatric continuous ambulatory peritoneal dialysis (CAPD) was the focus of a clinical study of 39 children and their families who were enrolled in one hospital's CAPD program (LePontois et al., 1987). The authors found that the social and emotional benefits, as well as the difficulties, of caring for pediatric CAPD patients at home varied according to the child's developmental stage, the individual family dynamics, and the support systems available to families. Parents frequently mentioned the sense of responsibility they felt for the medical welfare of their child, yet they often acknowledged that this responsibility conflicted with other family and parenting goals. For example, parents are asked to monitor the child's physical status intensely, yet they are also told not to allow the child's medical problems to become the main family focus. Encouraging self-care and independence and providing for opportunities for normal growth and development without endangering the child's health also requires considerable skill and judgment. LePontois et al. recommended that parents be given increased assistance from health care professionals in decision-making related to these issues.

Families with ventilator-dependent children. The impact of providing home care for ventilator-dependent children was studied by Quint et al. (1990) in a cross-sectional survey of 18 families. Major concerns identified by families included finances, difficulties with equipment or vendors, and in-home nursing care. Analysis of scores from the Impact on Family Scale revealed no differences in the perceived family impact between primary caregivers and their spouses. However, primary caregivers in the sample showed significantly reduced coping ability when the duration of in-home ventilation was longer than 2 years ($t = 4.2$, $p < .001$). This suggests the possibility that the stability of family impact over time may be gained at the expense of the primary caregiver's coping abilities.

In a qualitative study of the management styles of 10 families, five of whom had a ventilator-dependent child living at home and five whose child was hospitalized (Scharer & Dixon, 1989), three major management themes emerged: resources, barriers, and parenting. Resources for these families included significant others; health care personnel; sources of financial assistance; and systems such as schools, hospitals, and home care agencies. Strategies for parental management of resources involved maintaining support systems and acting as advocates for the best interests of the child. Barriers to successful management of the family's situation included the health care system and/or health professionals, other bureaucratic systems, and financial difficulties. Negotiating skills and assertiveness were the main strategies used to try to overcome these barriers, but many families felt that they had little or no control in these areas. Finally, management strategies utilized in parenting the child with a chronic health problem included sharing the responsibility for the child's care, comparing themselves with others, taking things one day at a time, trying to define the child's future realistically, and trying to treat their child as normally as possible (Scharer & Dixon, 1989).

Hazlett (1989) also examined families of ventilator-dependent children in a case study of one program of home ventilator management. The sample consisted of 15 families, and data were collected by chart review, telephone interviews with mothers, and review of financial records. Results indicated that home care of ventilator-assisted children was significantly less expensive than prolonged hospitalization, was medically safe, and was associated with psychosocial benefits for the child. However, the majority of mothers reported that home care of their child was very stressful. All mothers indicated that family activities were restricted by the child's use of the ventilator. Eight of the 15 mothers reported physical and/or mental exhaustion associated with their child's home care. Problems with home nursing care were mentioned by over half of the mothers, and home care costs were often a tremendous burden on families. Hazlett (1989) concluded that home care may not be the best option for all families, and suggested that families need increased support and assistance if they are to manage successfully at home.

Different aspects of a national evaluation of programs for ventilator-assisted children were studied by Aday and Wegener (Aday & Wegener, 1988; Wegener & Aday, 1989). Conclusions drawn from demographic information and semi-structured telephone interviews with 138 families of ventilator-assisted children were presented by Aday and Wegener (1988). These conclusions were: (a) ventilator-assisted children and their families are heterogeneous groups with complex and diverse needs; (b) while children benefit from being at home, most families have experienced many difficulties in the process of caring for their children at home; (c) full-time nursing care at home provides important support for families but is also seen by families as an invasion of privacy; (d) both children and families need continued psychological and social support; (e) the needs of the child and family may change over time; and (f) the financial burden of having a ventilator-assisted child can be a substantial family stressor.

The second study (Wegener & Aday, 1989) utilized data from parents of 121 ventilator-assisted children who were being cared for at home to develop a model for predicting stress in families of technology-dependent children. The profile of an at-risk family contained three categories of significant predictors: (a) family finances, (b) family structure and home environment, and (c) comprehensiveness of the medical plan of care. Of these indicators, the most powerful predictors of caregiver stress and family impact were the factors related to family finances; specifically, family assessment of finances as problematic and family identification of large numbers of out-of-pocket expenses. Unlike some of the studies previously cited in this review of literature (McCormick et al., 1986; McCubbin, 1988; McKinney & Peterson, 1987), none of the child-specific characteristics included in this model (severity of the child's condition, long-term prognosis, and number of hours per day that the child is on the ventilator) were predictive of higher caregiver stress. Families with nurse case managers exhibited significantly lower stress scores on the Impact on Family Scale than those families whose cases were managed by other health professionals or those families who had no designated professional case manager ($r = -.2081$, $p < .05$).

Summary of Families with Technology-Dependent Children

There is no question that technology can prolong the life of an individual with a chronic or life-threatening health problem; however, the financial, psychological, and emotional burden of caring for a technology-dependent family member at home may be overwhelming (Kaufman & Hardy-Ribakow, 1987; Lynch, 1990). The daily, unrelenting care demands of a technology-dependent child, the constant vigilance that must be maintained, the continual uncertainty related to the future, the financial burden, and the lack of support systems such as counseling or respite care can be devastating to a family (Aday & Wegener, 1988; Burkett, 1989; Gale, 1989;

Johnson, 1987; Urden, 1987; Wegener & Aday, 1989). Some families may cope well at first. Evidence of overwhelming stress may not appear until months or even years later when the strains of caregiving become too difficult to bear (Frates et al., 1985). Other families develop effective strategies that enable them to cope with the experience of having a technology-dependent child as a family member. Professional nurses can play an important role in helping families accommodate to long-term childhood technology dependence by empowering families (Dunst, Trivette, & Deal, 1988), providing quality nursing care in the home, and coordinating case management services in which families and health care professionals work in partnership.

Summary

In summary, this review of literature has demonstrated that there are a multitude of factors that affect families of children with chronic health problems. Research in this area has only begun to explore the complexities of living with and parenting a child with a chronic illness (Austin, 1991; Burke & Roberts, 1990). Most of the research that has been done has relied on maternal self-report, although there is an increasing amount of data being obtained from fathers. Siblings have been studied, often from the parent's perspective of how the sibling is coping, but the impact of a child with a chronic illness on siblings is still largely unknown. Also unknown is the effect of childhood chronic illness on the family as a whole, since the majority of research does not include more than one member of the family units being studied.

The literature shows that studies have been almost exclusively cross-sectional in design. Methodologies other than structured self-report have rarely been used, although qualitative research is being reported with greater frequency in the literature. Theoretical perspectives on family functioning now emphasize the transactional nature of interaction among children, parents, and their environment; however, empirical studies on the impact of chronic illness on the family continue to focus primarily on unidirectional effects of family characteristics on the child or child effects on the family (Garrison & McQuiston, 1989). Longitudinal studies are needed in order to understand the nature of family adaptation to the child with a chronic health problem over time. The effects of normative family events on the adaptation process have not been studied, nor have the cumulative effects of years of continuous care and responsibility.

Most of the research related to families of children with chronic health problems has focused on two-parent, white, nuclear child-rearing families. Little attention has been directed toward nontraditional families, minority families, or divorced and blended families. Multigenerational studies would also be useful in advancing our knowledge of family processes over generations and in possibly predicting high-risk families more accurately.

A continuing issue in the literature is whether children with different types of chronic health problems display different personality and behavioral characteristics, thus potentially contributing to different types of family adaptation. Some literature, most notably the work of Stein and Jessop (Jessop & Stein, 1985; Stein & Jessop, 1982, 1989), stresses the need to focus on coping with chronic conditions in general, rather than maintaining an illness-specific model. The literature reviewed in this chapter would seem to indicate that there are many factors that families of children with chronic health problems have in common, thus indicating the possible benefit of a noncategorical approach to chronic illness. For example, there is evidence that severity of illness and financial burden are important factors in family adaptation. In any case, understanding intergroup similarities and differences is critical to understanding family network patterns, disability-specific family needs, and overall family coping styles.

Despite the increasing numbers of children who are technology-dependent in the community and the multiple needs of these children and their families, there is a paucity of research specific to this population. Reports of impact on the family from providing intensive, long-term care to technology-dependent children are just beginning to emerge. The deconstruction of the literature presented in this chapter indicates that children who are technology-dependent and their families adapt to and are affected by chronic illness in the some of the same ways as children and families without high-technology needs. However, effects on families that are unique and specific to the use of technology in the home have also been identified. Since knowledge of families with children who are technology-dependent is still in its early stages of development, a qualitative approach can assist the researcher to describe the phenomena of interest more accurately and in greater depth. This investigator employed the qualitative method of interpretive interactionism to provide a starting place for research that can potentially influence both family and health provider understanding of long-term childhood technology dependence.

CHAPTER THREE

METHODS

The focus of this chapter is the research design and methods that were employed in this study. Topics include: (a) a discussion of the interpretive interactionist perspective; (b) sampling procedures; (c) methods of data collection and analysis; (d) criteria for rigor in qualitative research; and (e) protection of human subjects.

Design

A descriptive, naturalistic design was used to answer the research questions of this study. The naturalistic paradigm provides methodological guidelines for conducting research consistent with the humanistic, nonreceived world view (Lincoln & Guba, 1985). Specifically, the study was based on interpretive interactionism, an approach developed by Denzin (1989).

The focus of interpretive interactionism is the study of areas of concern to human beings. The researcher aims to interpret human experience from an ideographic, emic viewpoint (Denzin, 1989). Thus, interpretive interactionism involves collection and interpretation of human interactions and turning point experiences, or epiphanies. The researcher seeks to view things from the informant's perspective, and interpretations emerge from the personal accounts of the research participants. However, interpretive interactionism assumes that every person is a universal singular. The individual is not just an isolated entity; he or she is studied in an attempt to "...uncover this complex interrelationship between the universal and the singular, between private troubles and public issues in a person's life" (Denzin, 1989, p. 19).

An overview of the research design and actual process of the investigation can be gleaned from Denzin's (1989) description of the steps of the interpretive process. The initial phases include: (a) framing the research question, which involves asking "how" a problematic or turning point experience occurs rather than "why"; (b) deconstruction, a critical analysis of how the phenomenon of interest has been conceptualized, studied, and analyzed in the literature; and (c) capturing the phenomenon, or locating and securing multiple instances of the phenomenon in the natural world. Subsequent steps include: (a) bracketing, in which the phenomenon is taken out of its natural context so that its essential recurring features can be uncovered; (b) construction, which classifies, orders, and reassembles the phenomenon; and (c) contextualization, which locates the phenomenon back into the social world and reveals how the phenomenon is experienced by the persons being studied.

The purpose of this study was to explore the meaning of and factors involved in caring for a technology-dependent child at home from the family's perspective. Because of the complex nature of family life, the multiple demands and problems that families with a chronically ill member must face, and the social issues these families must deal with, studying the family from an interpretive interactionist point of view was appropriate.

Population and Sampling

A process of theoretical, or purposive, sampling (Lincoln & Guba, 1985; Woods & Catanzaro, 1988) was used to select families for participation in the study. According to Morse (1989), this form of sampling first involves the selection of participants who are likely to have wide-ranging experiences with the phenomenon under study or experiences that are deemed typical. Data from these informants are analyzed, and further sampling is then done based on the results of the analysis. Such sampling techniques increase "the scope or range of data exposed...as well as the likelihood that the full array of multiple realities will be uncovered" (Lincoln & Guba, 1985, p. 40). Sampling of families continued until the point of redundancy. Lincoln and Guba (1985) define sample redundancy as the point that is reached when no new information is being obtained from participants.

Participants were obtained through a home health care agency that served children who were technology-dependent, school nurses working in a large metropolitan school district, social service agencies, parent support groups that included families with children who are technology-dependent, and parent referrals. With the permission and assistance of these entities, a letter was distributed to families inviting them to participate in the study and asking them to contact the researcher for further information. A notice was also placed in one parent support group newsletter. When contacted by potential participants, the researcher discussed the study with them in greater depth. If the family agreed to participate, the researcher made arrangements for data collection and obtained written consent for participation in the study. A detailed discussion of the procedures for protection of human subjects will be presented later in this chapter.

Sample Criteria

All families who indicated interest in the study were asked to participate. Criteria for participation in the interview included: (a) parent, guardian, or significant adult living in the household with a child aged 3-12 years who had been technology-dependent and living in the home for at least one year; (b) able to speak and understand English; and (c) physically and mentally able to participate in the interview process. Criteria for participation in the observation included: (a) child aged 3-12 years of age who was technology-dependent and had been living in the home for at least one year, and (b) any person in the immediate environment of or interacting with the technology-dependent child at the time of the observation.

The presence of developmental delays, cognitive impairments, or other health problems in the child who is technology-dependent was not used as exclusion criteria in this study. However, only families whose children were medically stable and residing in the community with their families on a permanent basis were included in the study. Children under age three who were technology-dependent were not included in this study, nor were adolescents who were technology-dependent, because the developmental tasks and issues faced by children in these age groups and their parents are often very different than those encountered by preschool and school-aged children and their families.

Sample Characteristics

A total of 11 mothers and 4 parent couples (mother and father) were interviewed. Although sixteen families initially indicated interest in the study, one family decided not to participate because of ongoing issues related to the pending adoption of the child who was technology-dependent. A variety of individuals were present during the observation periods, including parents, grandparents, home health care nurses, personal care workers, physical and occupational therapists, teachers, siblings, friends of siblings, and, of course, the child who was technology-dependent.

The demographic characteristics of the children who were technology-dependent and their families varied considerably in this sample. One exception was race: all families were European-American, and all of the children who were technology-dependent were European-American with the exception of one African-American child who was in the process of being adopted.

Of the 15 families who participated in this study, 11 (73%) consisted of 2 biological parents, the child who was technology-dependent, and one or more siblings. One of these families was in the process of a parental divorce during the time the study was being conducted. In addition, one of the families consisted of a divorced mother and her children, one was a blended family, one family had adopted the child who was technology-dependent in addition to having other children, and one was comprised of a never-married woman who was in the process of adopting a child who was technology-dependent. The number of children in each family ranged from 1 to 5, with a mean of 3.27 children per family.

Diversity in parental age, employment, education, and family residence was also present. The age of parents in the study (N=28) ranged from 26 to 52 years, with an average age of 36.9 years and a median age of 36.5 years. Eleven of the 15 mothers (73.3%) were employed outside of the home, with 4 employed on a full-time basis. Occupations of the mothers in the study included registered nurse, attorney, parent advocate, paper mill worker, day care provider, nurse anesthetist, and hairdresser. Twelve of the 13 fathers in the study were employed full-time, and one was unemployed.

Paternal occupations included construction worker, salesman, college professor, attorney, computer programmer, farmer, and comptroller. Parental education ranged from high school completion (14.3%, n=4) to graduate education (21.4%, n=6), with 57.1% (n=16) of the parents having a college degree or more. Most of the families resided in urban or suburban areas (53.3%, n=8), while 33.3% (n=5) lived in small towns, and 13.3% (n=2) resided in rural areas.

All 15 of the families received health care coverage benefits for their child who was technology-dependent through Medical Assistance (also known as Medicaid or Title XIX), either through Supplemental Security Income (SSI), Aid to Families with Dependent Children (AFDC), or the Katie Beckett Program. Eighty percent of the families received financial assistance from more than one source for caring for their technology-dependent child in the home. These sources included private insurance coverage (73%, n=11) and additional financial assistance from state-funded programs such as the Family Services Program or the Community Options Program (33%, n=5).

The majority of families (80%, n=12) utilized formal home health care services to assist them in providing care for their technology-dependent children at home.

Most (53%, n=8) employed RNs and/or LPNs, although nursing assistants and/or home health aides were also utilized by several families. The number of hours provided by home health care personnel ranged from 3 to 18 hours per day. In addition, two families utilized respite care services and 2 families employed child care providers who had no formal health care training. Extended family members also provided additional help for a significant number of the families.

The characteristics of the children who were technology dependent (N=16) in this study reflected a wide range of diversity and variability, although all shared the basic classification of technology dependence. The children ranged in age from 3 to 12.5 years, with a mean age of 7.5 years. Ten of the children were male (62.5%) and six were female (37.5%). Although only 15 families participated in the study, one family had twin boys who were oxygen-dependent and receiving their total nutrition through gastrostomy feedings. In addition, one of the other children in the sample was a twin and one was a triplet. Six of the children had younger siblings, 4 had older siblings, 5 had both older and younger siblings, and one was an only child.

All 16 of the children were classified under one of the defined levels of technology dependence (OTA, 1987), with 12.5% (n=2) dependent on ventilators, 12.5% (n=2) on prolonged nutritional or intravenous drugs, and 75% (n=12) needing other respiratory or nutritional support such as tracheostomy, suctioning, oxygen support, or gastrostomy feedings. Over half of the children (56%, n=9) were dependent on more than one technology, however, and all had multiple medical problems. A variety of chronic health conditions were noted, including developmental delay (n=16), vision and/or hearing impairments (n=13), seizure disorders (n=11), asthma/respiratory disorders (n=8), cerebral palsy (n=5), and latex allergy (n=2). One young man with a tracheostomy also had insulin-dependent diabetes, celiac disease, and Down syndrome.

The aids that the children needed for health maintenance and routine daily activities also reflected their health conditions. Fifteen children required gastrostomy feedings; 11 children required either a wheel chair or other special chair; 8 needed deep suctioning on a regular basis; and 7 children used braces, splints, or ankle-foot orthotics (AFOs). One child took no medications on a regular basis; the other 15 children took an average of 5.67 different medications every day, with a range of 2 to 15 different daily medications. The most common medication groups were anticonvulsants (n=11), followed by GI medications (n=9), bronchodilators (n=8), and antibiotic or antifungal medications (n=7).

Reasons for children's dependence on technology varied from complications of prematurity and congenital defects such as spina bifida to sequelae from acquired diseases (e.g., meningitis) and accidents. The children had been technology-dependent and cared for at home for a period of two to nine years, with an average of 5.84 years of home care while dependent on technology.

Data Generation

In interpretive interactionism, the researcher attempts to capture the phenomenon of interest. Capture involves obtaining multiple, naturalistic instances of the experiences being studied (Denzin, 1989). Varied sources of data can be utilized in order to describe the phenomenon under investigation in its diversity and complexity. In keeping with the assumptions of naturalistic inquiry, no manipulation of participants occurred in this study, and the inquirer did not impose any a priori units on the outcome (Lincoln & Guba, 1985). Data were generated through intensive interviewing and participant observation. A procedural pilot study was conducted with two families to refine the study procedures and identify any needed changes. Because no significant changes were necessary, the data obtained from pilot participants was included in the main research study.

Interviews

According to McCracken (1988), the long interview is one of the most powerful components of qualitative methodology. The long interview allows the researcher to examine the lifeworld of the individual, to see the content and pattern of daily experiences.

For this study, intensive, open-ended interviews were conducted with parents who had a child who was technology-dependent and living in the home. If there was more than one parent in the home, and both consented to be in the study, parents were interviewed at the same time. Individual interviews were offered as an option, but all 4 parent couples that were interviewed chose to be interviewed together (Thomas, 1987b; Uphold & Strickland, 1989). Questions posed to participants were based on the research questions for the study. Interviews were initiated with a guided grand tour question (Spradley, 1979), which was: "How would you describe what having a child who is technology-dependent means to you and to your family?" Additional questions were used as probes to elicit further descriptions (see Appendix A). As the interviews progressed, questions became more structured and focused as the ongoing processes of data collection and analysis began to form the parameters of the study (Fetterman, 1989; Lofland & Lofland, 1984; Spradley, 1979). Sociodemographic data were also obtained from participants during the beginning portion of the interview (see Appendix B).

Participants were given the option of being interviewed in their home or at another location of their choice. All 15 families chose to have the researcher come to their homes. The interview was conducted in private at a time when parents did not need to be directly responsible for child care (e.g., child was in school, sleeping, or being cared for by a qualified provider). All interviews were audiotaped, and field notes were made so that thick descriptions of the setting and interview process could be obtained. Interviews generally lasted 90 to 120 minutes. In addition to providing an opportunity to explore the experiences of families who had a child member who was technology-dependent, the interviews also enabled the researcher to member check; that is, to clarify and verify her impressions and interpretations with the participants (Lincoln & Guba, 1985).

Participant Observation

Observations focused on daily management and coordination of family life when the family included a child who was technology-dependent. Continuous observations were made during a period of time that was identified by families as typical of a usual day, as stressful, or that constituted an exemplar of their family life as they saw it. The period of time for the observation varied with each family according to family schedules and preferences; therefore, the duration of the home visit, which included both the observation and the parent interview, ranged from 3 to 7 hours with a mean visit time of 4.22 hours and a modal visit time of 4.25 hours.

Observations occurred before, during, and/or after the parent interviews. During the observations the researcher assumed a known, moderately active participant role (Marshall & Rossman, 1989; Spradley, 1980). In other words, the purpose of the researcher's presence was known to everyone in the family. She observed the interactions of the actors within the setting but did not hesitate to participate in the interaction as necessary.

Spradley (1980) considers the following nine dimensions common to all social situations: (a) space; (b) actor(s); (c) object; (d) act(s); (e) activity: a set of related acts; (f) event: a set of related activities; (g) time; (h) goal; and (i) feeling. Based on the research questions of this study, a guide to participant observation was developed and utilized which addressed these domains as they related to the phenomenon of childhood technology dependence (see Appendix C). Observations were recorded as field notes or audiotaped in narrative form. As the study progressed, attention to specific domains and new areas for observation emerged based on analysis of the data.

Data Analysis

The qualitative methods used in this study were based on the theoretical position that individuals are active agents in the construction of family life with a child member who has a chronic condition, and that family perspectives of the phenomenon of childhood technology dependence are best understood through an analysis of their personal experiences. Thus, data from the families in this study were elicited through: (a) a parental interview consisting of open-ended questions, rather than from structured questions with predetermined response categories; and (b) observations of the families' daily lives.

The demographic data obtained in this study were analyzed to identify various characteristics of this sample of families with children who were technology-dependent. Descriptive statistics were used to describe the sample as a whole, and demographic data were incorporated into the qualitative analysis where appropriate. Selected demographic data are summarized in Appendix D.

All audiotaped data were transcribed verbatim by the researcher into typewritten format as soon after data collection as possible. Transcribed interview data and field notes were then analyzed using the interpretive process. Analysis of interview and observation data began immediately; thus, a constant comparative method of concurrent data collection and data analysis was employed (Lincoln & Guba, 1985; Reinharz, 1983).

The first two steps of the overall interpretive interactionist process, framing the research questions and deconstruction of the literature, were accomplished in chapters one and two of this dissertation. The mechanisms for capturing the phenomenon in question, the next phase of the interpretive process, were described earlier in this chapter. The remaining three phases of the interpretive process are: (a) bracketing, (b) construction, and (c) contextualization. In the next sections of this chapter, these three phases are discussed as they relate to data analysis.

Bracketing

In bracketing, the researcher critically examines the phenomenon in question in an attempt to isolate, define, and analyze its key or essential features (Denzin, 1989). The essential meaning of the experience is embedded within the thick descriptions and interpretations of the phenomenon. According to Denzin (1989), thick description provides the context and history of an act, states the intentions and meanings that organize the action, and presents the act as text for thick interpretation.

The analytic strategy began by examining each narrative document (i.e., the interview and observation data for each family) in terms of the research questions for the study. Based on intensive reading and consideration, narrative sections pertaining to each of these questions were identified, separated, and coded for further analysis.

First-level coding was done during this phase of data analysis. Rather than relying on predetermined content codes, codes were developed that related to sets of broadly stated categories such as setting/context, definition of the situation, perspectives, process, activities, events, episodes, roles, and strategies (Lofland & Lofland, 1984; Miles & Huberman, 1984). Initially, approximately 50 separate codes were identified. These codes were then examined in light of the research questions and codes that were conceptually linked were combined in the next phase of analysis, construction.

Construction

After the data had been broken down into elements and coded into descriptive categories, the next level of analysis, that of construction, was undertaken. The process of construction represents the attempt to interpret the event or process fully by classifying, ordering, and putting the phenomenon back together in terms of its essential parts and structures. Each element is examined for its relevance and relationship to every other element in the process (Denzin, 1989).

Searching for patterns is an important component of construction. Miles and Huberman (1984) describe pattern codes as those that identify emergent themes, patterns, or explanations. Clusters of data were connected via a process of higher order coding that captured more abstract, or general, themes. Since this process occurred simultaneously with further data collection, the opportunity existed to verify the significance or existence of a pattern during contacts with subsequent participants. Themes and subthemes related to the original research questions were identified. Additional patterns in the data emerged through a process of analyzing the connections among themes.

During the level of construction, the interpretive interactionist gathers together the lived experiences that relate to and define the phenomenon being studied. In the words of Denzin (1989), "the goal is to find the same recurring forms of conduct, experience, and meaning in all of them" (p. 60).

Contextualization

Contextualization, the final phase of the interpretive process, involves attempting to interpret what has been learned about the phenomenon via bracketing and construction and give it meaning within the context of the naturalistic social environment in which it occurs (Denzin, 1989). Individual stories of the experience were compared and contrasted with the intent of demonstrating how lived experience alterd and shaped the phenomenon being studied. The suggested relationships were confirmed through case-by-case comparisons using all narratives, and a contextualization of the phenomenon was obtained. The main themes of the individual stories were synthesized so that a reformulated statement of the process could be made. Thus, contextualization locates the phenomenon in the "real world" and reveals how the phenomenon is experienced by ordinary people (Denzin, 1989).

Criteria of Rigor in Naturalistic Inquiry

Quantitative research which is grounded in the positivist paradigm maintains scientific rigor by attempting to design and conduct research studies which produce valid and reliable results. Approaches used in quantitative research to address reliability and validity issues are not appropriate in qualitative research. Therefore, other criteria for assessing rigor in naturalistic inquiry must be established.

Naturalistic research relies upon what Denzin (1989, p. 22) refers to as "sophisticated rigor." Sophisticated rigor implies a commitment to make one's interpretive materials and methods as public as possible, and includes employment of multiple methods in diverse situations as well as attempts to develop interpretations grounded in the worlds of lived experience. The criteria of credibility, transferability, dependability, and confirmability can be used to evaluate the trustworthiness, or rigor, of studies based on the naturalistic paradigm (Lincoln and Guba, 1985).

Credibility

Credibility refers to the truth value of a qualitative study. Credible studies enable other people to recognize their own experiences in the written descriptions and interpretations of the study (Sandelowski, 1986). Techniques that were used to increase credibility in this study included: (a) prolonged engagement with and observation of participants; (b) triangulation of sources and methods, including literature deconstruction, capturing multiple instances of the phenomenon under study, and utilization of varied methods of data collection and analysis; (c) validation of data with the informants during the course of the study; (d) accurate transcription of the data; and (e) validation of interpretations with selected informants during the construction and contextualization phases of data analysis.

Transferability

In qualitative research, generalizability is not a goal. Instead, the criteria of transferability is used to determine the degree to which study findings "fit" outside the context of the original study environment (Lincoln & Guba, 1985). According to Sandelowski (1986), "a study meets the criterion of fittingness when its findings can fit into contexts outside the study situation and when its audience views its findings as meaningful and applicable in terms of their own experience" (p. 32). In this study purposive sampling and thick descriptions of the sample, setting, and data will enable readers and future researchers to determine the fit or transferability of the research findings. In addition, the parents of a child who is technology-dependent but who did not participate in the study were asked to comment on the applicability of the findings to their own situation. They felt that the overall themes and contextualization of the phenomenon of family life with long-term childhood technology dependence were very congruent with their experiences.

Dependability

The criterion of dependability is used to judge the consistency of qualitative findings. Dependability is enhanced if other researchers can audit the process of the inquiry by following the investigator's decisions throughout the study and arriving at similar conclusions (Lincoln & Guba, 1985). In this study, field notes were kept which provide a description of the study participants and the context of the interview and observation for all study participants. The interviews were audiotaped and transcribed to provide a written record of all interviews. In addition, the researcher maintained analytic and process memos throughout the study to document concepts and ideas related to the conduct of the study and the ongoing data analysis (Sandelowski, Davis, & Harris, 1989). Two colleagues, both experts in parent-child nursing and qualitative methodology, participated in the initial interpretation of three of the interviews. The aforementioned measures will improve the chances that another researcher could follow the decision trail of the primary investigator. Conduction of a procedural pilot study also helped to enhance the dependability of the overall study. Finally, deconstruction of the phenomenon of interest (see Chapter

2) also can assist the researcher in achieving dependability by providing the reader with the researcher's background related to the main concepts of the study.

Confirmability

Naturalistic inquiry is not value-free; values can and do influence inquiry in a variety of ways (Denzin, 1989; Lincoln & Guba, 1985). However, being grounded in the natural world does not preclude the possibility of the study findings being objective, or confirmable. The focus of this study was data generated from the family's perspective. The findings and analysis of the data were confirmed with a subsample of the study participants and through a comparison with the findings reported in the literature review. Overall confirmability was established through the appropriate utilization of the five phases of the interpretive interactionist method discussed in an earlier section of this chapter.

Human Rights Protection

Approval for the study was obtained from The University of Texas at Austin School of Nursing Departmental Review Committee and The University of Texas at Austin Institutional Review Board as well as from the appropriate personnel in the clinical agencies.

Participation in the study was strictly voluntary. Participants were solicited through a home health care agency that served children who were technology-dependent, social service agencies, school nurses working in a large metropolitan school district, and parent support groups that included families with children who are technology-dependent. Agency personnel and parent support group coordinators were asked to identify families who met the criteria and then distribute to those families a general letter from the researcher which described the study and asked interested persons to contact the researcher (see Appendix E). An addressed, stamped postcard indicating the parent's wish to be contacted by the researcher and a telephone number where the parent could be reached was attached to each introductory letter. In addition, several participants were obtained through a notice placed in a parent support group newsletter or by referral from parents who had already completed the study. At no time did the researcher initiate contact with any potential subjects.

Interested parents were contacted by the researcher via telephone to present an overview of the study, to answer any questions they had, to review the consent process, and to schedule a time for data collection.

Interviews and/or observations with parents and family members who agreed to participate were scheduled at a mutually agreed upon time and place.

On the day of the visit, prior to beginning data collection, the researcher reviewed the consent process and obtained consents for participation from all appropriate parties (see Appendix F). Participants were reminded of their option to withdraw from the study at any time. In addition, participants were reminded that they were free to refuse to answer any of the interview questions and/or could refuse to participate in any aspect of the study.

There were no physical risks associated with participation in this study. Only families with technology-dependent children who were medically stable and residing in the community with their families on a permanent basis were included in the study. Inconvenience to participants was minimized by allowing participants to choose the time and place of data collection, and daily activities of families were not interrupted during the observation portion of the study. All parent interviews took place when their child was sleeping, at school, or being cared for by another qualified provider.

There might have been a minor psychological risk involved in participating in this study in that the parents participated in a face-to-face interview with the researcher, and parents and other family members were observed during a typical part of their daily routine. However, the interview and observation were relatively unstructured, which allowed the participants more personal control as to the responses they provided to the interview questions and the activities they engaged in during the observation.

The investigator is an experienced pediatric nurse who has provided home care to children who are technology-dependent. If any family member became distressed during the data collection process, the investigator provided immediate intervention as necessary. A list of community and health care resources was available for family information and referral. The researcher also followed up on specific requests by 3 families by mailing them the information they requested. Participants in the study may have received an indirect benefit in that they gained new insight into childhood technology dependence from sharing their personal experiences of adapting to and managing long-term childhood technology dependence at home.

The privacy and confidentiality of all participants in the study were ensured at each stage of the data collection process. All data were maintained in a locked file cabinet when not in use, and only the researcher had access to the data. Tapes and observations were transcribed in a manner that removed identifying data such as family names, geographic information, or names of health care providers. Audiotapes will be erased at the completion of the study.

Summary

This chapter provided a description of the interpretive interactionist research process, procedures for sampling, data collection, and data analysis, and guidelines for protection of human subjects. The naturalistic paradigm postulates that people are intentional beings who create and discover meaning and that humans are in continuous development over time and in continuous interaction with environments in space (Reinharz, 1983). The research method, procedures for data collection, and analysis techniques described in this chapter stem from these assumptions and are consistent with the research questions posed by the author.

CHAPTER FOUR

ANALYSIS AND CONSTRUCTION OF THE PHENOMENON

This chapter presents an analysis and discussion of the study findings relative to the experiences of long-term childhood technology dependence in fifteen families who had a technology-dependent child member between three and twelve years of age. Interpretive interactionism was the method used to explore with families their experiences with technology dependence in a child member.

The interpretive interactionist analysis of this phenomenon revealed that the experience of long-term childhood technology dependence for this study's participants encompassed four major thematic areas of concern. These were: (a) Managing Daily Life with Technology; (b) Negotiating with Outside Entities; (c) Maintaining a Functioning Family; and (d) Making Sense of Life. Table 1 is a summary of the major themes and subthemes for the experience. Initially, each of the four themes will be discussed individually. The connectedness of the themes relative to the process of family life with a child member who is technology-dependent will be presented later in this chapter. Throughout Chapters 4 and 5, initials were substituted for any names used in participant quotations, and the initials used are not the actual initials of the child or other family member. In addition, other identifying data such as geographic information, school names, and names of health care providers were removed.

Table 1

Major Themes and Subthemes for Family Experiences with Long-term Childhood Technology Dependence

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Managing Daily Life with Technology
    Child's care needs
    Time management
    Home environment

Negotiating with Outside Entities
    Relationships with health care providers
    School and education-related issues
    Dealing with bureaucracies
    Employment issues
    Interactions with the community

Maintaining a Functioning Family
    Meeting the needs of family members
    Finding time for the family
    Financial considerations
    Involvement of extended family and friends

Making Sense of Life
    Reconciling the past and present
    Changing priorities
    Imagining the future

Managing Daily Life with Technology

There were three major aspects involved in managing daily life with technology: (a) the child who is technology-dependent's care needs, (b) time management issues, and (c) the home environment. Each of these categories will be addressed using data from family interviews as well as observation data.

Child's Care Needs

Over time, the parents in this study became very expert at managing the care needs of their child. They expressed in-depth knowledge about the various devices and treatments needed, and often correlated these treatments with the current and past health status of the child. During observations of the home environment, parents displayed comfort and competence with care as they continued to provide the child with whatever care was necessary during the researcher's visit. As one mother stated:

> I think they (health care providers) are always surprised at how much we have had to learn to take care of him but...you can't come home with him unless you know how to do everything. And having had this for so many years, we probably know as much about this particular type of care -- the diabetes, the trach. You really do kind of pick up that knowledge whether you want to or not. Giving shots and all, it's all kind of just part of the day.

The major areas related to the care needs of the technology-dependent children in this study were: (a) nutrition, (b) respiratory status, (c) medications, (d) mobility, (e) growth and development issues, (f) other health conditions, and (g) changes in health status.

Nutrition

Nutrition, including issues related to feeding, was an area of concern for all parents in the study. All of the technology-dependent children in this study had gastrostomies. Fourteen of the 16 received their entire caloric and nutritional intake via gastrostomy, one child was just beginning to be fed orally, and one child had almost made the transition to exclusively oral intake. Several other children took occasional small tastes of foods either to decrease oral aversions or for social purposes (e.g., to share in family social occasions or to be more like the other children at their school). The major reason for enteral intake via gastrostomy was gastroesophageal reflux and potential aspiration; other reasons included impaired swallowing mechanisms and malabsorption.

In general, the children who were technology-dependent received a range of 3 to 7 intermittent feedings throughout the day either as bolus feedings or over several hours via pump. Some of the children also received continuous drip feedings during the night. All except two of the children who were fed via gastrostomy received commercially prepared formulas. In one home, the family used a homemade preparation for the majority of feedings primarily because the child maintained her weight better and had less diarrhea and GI upset than she did when she was on commercial formula. In the other instance, the father felt strongly that feeding his son "regular" food promoted normalcy and made his child less "different", even though the route of feeding and the consistency of the food was certainly not typical of most other 3-year-olds.

Parents spoke of needing to adjust their child's caloric intake to prevent the child from becoming overweight and the related risk of potentially rapid dehydration when the child became ill. Conversely, some parents also spoke about their child having difficulty gaining weight.

For many of the children, their nutritional status as well as their overall health status improved after they were started on gastrostomy feedings. As one father stated, "And then they put that (tube) in and he's just turned around 100%." Another parent said, "it really hasn't caused us any problems at all. It's just done so much good. It's really made his care more enjoyable and easier and fun, and you know, it's just made things better." Parents reported minimal problems with the gastrostomy site, feeding apparatus, and gastrostomy tube or button itself. The most common difficulties encountered were malfunctioning valves in the gastrostomy button devices, the devices becoming dislodged or falling out, and an occasional inability to obtain replacement gastrostomy button devices from the home medical equipment vendors.

Feeding child through a gastrostomy in some cases made care of the child much easier. One mother who tried to continue oral feedings even after the gastrostomy was placed reported that feeding was very stressful. She described the process as follows:

> It was a big fight to feed her. She'd bite down on the spoon, she'd never swallow, it was more of a stress, another stress, in our lives. It was another stress in our lives, and my husband was not highly participating at all with oral feedings....So my husband and I got really frustrated, and we decided to just stop feeding her orally for a while.

Respiratory Status

Parents and other caregivers monitored the respiratory status of the technology-dependent child very closely. Two of the children in the study were ventilator-dependent with tracheostomies and supplemental oxygen, three had tracheostomies and supplemental oxygen, and three children did not have tracheostomies but needed frequent suctioning to maintain airway patency. In addition, there were twin boys in the study who had been decannulated but were still oxygen-dependent. Causes for dependence on respiratory technologies varied, including complications from prematurity or prolonged intubation and mechanical ventilation, vocal cord paralysis, and sequelae of spina bifida. Half of the 16 children received daily aerosol treatments to improve or maintain their respiratory function, and six also received chest physiotherapy (CPT) on a daily basis. Cardiorespiratory monitors or pulse oximeters were used to alert caregivers to changes in respiratory status, particularly when the children were sleeping.

All parents felt that the respiratory technologies currently being used with their children were appropriate, even though they were often time-consuming and frequently limited the child's mobility. However, one family felt that they were engaged in a constant struggle with their health care providers in this regard because the health care providers thought it would be "easier" for the parents if their daughter had a tracheostomy, and the parents were adamantly against this plan. The mother in this family expressed her opinion of the issue by stating, "I truly believe if B. was trached, she would have been dead a long time ago. A long time ago. And her pulmonary damage would have been horrendous, horrendous."

On the other hand, one parent of an 11-year-old girl felt that her daughter's respiratory status had improved significantly after the child was trached, and improved even more after mechanical ventilation had been instituted. This mother commented:

> And as far as M. and her ventilator-dependency, there are always the issues of dealing with the equipment and the size and the restrictiveness of what you can and cannot do just with the volume of equipment. To us, the ventilator was truly a blessing. From the point M. has been ventilated properly, she has progressed tremendously....And being able to rely on the vent breathing for her just sort of was like someone opened up a door, you

> know, and so she has made tremendous strides forward. M. does not feel encumbered by the ventilator. People who work with her feel encumbered by the ventilator, but it is part of her and she knows that she is much healthier so she can spend time on other things rather than concentrating on breathing, which was a very...I mean, now in retrospect to all of us, including her physicians, the amount of time she spent trying to remember to breathe, it just outweighed everything else that she was doing.

Medications

Most of the children in the study were on multiple medications, including anticonvulsants, GI medications, bronchodilators, antibiotics, and muscle relaxants. The interactive effects of multiple medications and the side effects of various medications were monitored closely by parents and other caregivers. For example, one mother discussed the problems her child had with one of his medications:

> P. has an attention deficit also, and we had started him about 6 weeks ago on a very low dose of Ritalin. And we were having all sorts of problems with it...I have no idea if it interacted with some of his other

> medications. They assumed that it wouldn't, but we took him off of it. We were also having some problems, in conjunction with that, with him turning blue and dropping his sats, and they all say that, well, that can't be a side effect.

Another mother related her child's medications to growth problems the child had been experiencing:

> Well, in October we started switching all of her medicine around, her seizure medicine, because she was still having breakthrough seizures....Anyway, we took her off Phenobarbital and Dilantin and Klonopin that she had all been on, and they put her on valproic acid. And since we took her off Phenobarb completely, that was her main seizure med, she started putting on like a pound a week....And her secretions have changed, she used to be real copious. Everything has changed. And for some reason, I think that it's changed her metabolism....And this was a kid that for 6 years, we couldn't get her to gain weight. And all of a sudden, she's gaining a pound a week.

Mobility

Mobility issues were mentioned by the majority of parents as becoming more difficult and time-consuming as their child grew older and larger. Five of the sixteen children in the study could ambulate independently; of the remaining 11, one girl had a motorized wheelchair that she could manipulate on her own, two children could crawl, and the rest were totally dependent on others for locomotion. Additional assistive or adaptive devices utilized by children in the study to promote mobility included wheelchairs; standing frames; ankle, foot orthoses (AFOs); wrist splints; leg splints; body shells; Hoyer lifts; bath chairs; hospital beds; and custom-made Flexiform chairs. These devices all required maintenance, and many needed to be replaced as the child grew or as the child's health status changed.

As the children grew longer and heavier, transferring and access to facilities became much more difficult for caregivers. For example, one child could have a tub bath only when his father was home because his mother was unable to lift him out of the tub and the family did not have any type of lift device. Other limitations to mobility arose because of the child's need for equipment such as feeding pumps, oxygen tanks, and humidification systems.

Mobility issues were also related to the home environment, in that the child's limited mobility became more problematic as she or he grew because many lived in homes that were not conducive to a child with impaired mobility. Parents identified stairs, doorway widths, bathroom configurations, bathtubs, and the location of bedrooms and play areas as being factors that impacted on their ability to manage their child's care needs related to mobility. As a result, some children spent most of their time in one room of the home. Additional information related to the home environment will be presented later in this section.

Finally, mobility for the children in this study was affected by the means of transportation families had available to them. Fourteen families owned a car or van, and one family relied on public transportation and taxicabs. Many families expressed a desire to purchase a van with a wheelchair lift, but because of the expense of this type of vehicle, only two families had done so. Therefore, children were lifted into the family vehicle by caregivers. Special vans or buses were used to transport the children to school. In the case of the family that did not own a car, factors such as weather, transportation schedules, distance, and amount of equipment that needed to be brought along influenced the child and parent's mobility.

Growth and Development Issues

Child development issues mentioned by parents as components of the management of daily life with technology included: (a) communication skills, (b) activities of daily living such as dressing and toileting, (c) behavioral issues, and (d) promoting the achievement of developmental milestones. Many parents found that they did not have the time they needed to concentrate on these areas with their technology-dependent children as much as they wished to because of the physical care demands of the child or because of the needs of other family members.

Communication. The children in the study used a variety of communication modalities, and all of them had difficulties with receptive and/or expressive communication skills. The majority of the children in the study were receiving speech therapy, and several of them were nonverbal. Communication strategies included sign language, communication boards that used words or pictures, computers, and an electronic speech synthesizer, which is a computer-generated voice that responds after the child has pushed a specific sequence of icons on a keyboard. Two of the children were able to speak through their tracheostomies, although their speech was difficult to understand at times. Others communicated primarily through sounds or other nonverbal means. Parents and other family members spent a great deal of time trying to understand and be understood by the child who was technology-dependent.

Complicating the issue of communication was the fact that several of the children had hearing loss or visual problems such as cortical blindness, nearsightedness, nystagmus, or strabismus; in addition, some were thought to have difficulty processing information. As one mother put it, "Her processing time is like, 30 seconds to 45 seconds, so it takes a while for her to process information. So if you expect her to kiss right away as soon as you say "kiss" it's not going to happen."

Activities of daily living. Independence in toileting had only been achieved by two of the children who were technology-dependent. Several mothers reported that they were beginning to toilet-train their children; however, most did not feel bowel and bladder control was feasible at this point, and some did not feel that complete control would ever be a realistic goal for their child, whether for physiologic or psychologic reasons. One child required intermittent urinary catheterization, and another occasionally wore a condom catheter. The majority of the children needed bowel management programs in the form of stool softeners and laxatives to alleviate constipation. However, two of the children, who had undergone multiple bowel resections, suffered from loose stools that were very irritating to the skin.

One mother provided an interesting perspective on the issue of independent toileting. Her 12 year old, 100 pound son was incontinent of both urine and stool and wore a diaper most of the time. This mother explained:

> I think we could probably get him (onto the toilet) right when he's gonna go, but who's going to lift him? And then you're talking about adaptive toilets, and at the time when it was time for potty-training him we didn't think he was going to live that long, and so we thought why put ourselves through the stress of it for no reason?

Behavioral issues. Another developmental issue that concerned the parents of the technology-dependent children in this study was child behavior. For example, one child demonstrated what her mother described as typical behavior during the time the researcher was in the home by putting her finger over her ventilator and making it alarm, shaking the pole that held her formula and feeding pump, kicking the walls, and hitting herself to get attention. Another child's headbanging was frequent and severe enough that her parents sometimes resorted to putting a helmet on her to prevent injury.

Short attention spans, low tolerance for frustration, and difficulty controlling or expressing emotions were additional child behavior issues mentioned by parents. These factors sometimes made it difficult for parents to meet their child's care needs. As the parent of a 7-year-old commented, "Her chest clapping is supposed to be 4 times a day, but she's so active that if we're lucky we do it like twice a day, which is fine. And she won't even let us do it, that's the thing. She hates it."

Developmental milestones. In general, the children who were technology-dependent in this study achieved developmental milestones at a later age than their siblings or other healthy children did, or did not attain some specific developmental skills at all. One mother commented that it was like "pulling teeth" with one of her technology-dependent twin sons to get him to achieve developmental goals or to maintain them. Another mother felt that her child had not achieved as much as she had the potential for because of difficulties in obtaining various therapies:

> Her life has very little stimulation to it. I have tried desperately to get services for her. And they take away and they take away and they take away and they take away, until the amount of stimulation and the amount of therapy that she's gotten has...it's like a whirlpool, it just goes downward. Everything that you lose, you lose a little more the next time. You never quite get back what you've lost. And so she lives her day, basically with very little stimulation.

However, parents and other family members knew each child's likes and dislikes very well, and used this knowledge to stimulate the child to achieve optimal development.

Several of the children could assist with their activities of daily living and their treatments. The mother of a 10 year old boy with a tracheostomy discussed her son's self-care abilities as follows:

> But suctioning, that's no big deal. And he likes it. Actually, J. can do a lot of this. He comes up here, he knows how to turn all his machines on, put on his collar. He knows how to set up his treatment, he knows to do all of this stuff. In fact, the problem was that he liked to do it too

> much and I really had to put all the medications up because if I was gone for a second he'd come and start monkeying around and try to give himself a treatment and things like that.

In some instances where both parents were interviewed, the researcher noted that each parent had different perceptions of what developmental skills the child possessed or what milestones the child may be capable of acquiring in the future. For example, in one family, the father felt that his 3-year-old son could hear and see to some degree, while the mother was not sure he possessed either capability. Because mothers tended to spend more time with their technology-dependent children as primary caregivers, they generally were more objective in their estimations of their child's actual and potential capabilities.

Other Health Conditions

All of the children in the study had health problems in addition to those that were directly related to their primary reason for dependence on technology. Additional health problems mentioned by families included hearing loss; vision problems; susceptibility to infection, especially ear, sinus, and upper respiratory infections; seizure disorders; asthma or reactive airway disease; and precocious puberty. Two of the children, both of whom had spina bifida, had developed severe latex allergies. Another child, in addition to a tracheostomy, had Type I diabetes, celiac disease, Down Syndrome, and had been born with a congenital heart defect. The presence of these chronic conditions in the children who were technology-dependent often necessitated additional treatments, medications, and cares.

The children in this study had complex past medical histories and most had undergone multiple surgeries. For example, one three year old child was in process of being adopted, and his adoptive mother did not know his entire medical history. She did know, however, that he was born at 27 weeks gestation; had an Apgar of zero at birth; was "coke-addicted and alcohol-exposed and cigarette-exposed and polydrug-exposed"; developed necrotizing enterocolitis and had numerous bowel resections; had bronchopulmonary dysplasia; had an intraventricular bleed; suffered multiple infections, one of which resulted in partial amputation of the digits on one arm); has one leg about an inch shorter than other due to a broken femur in the NICU; and was hospitalized for the first 17 months of his life. Surgical procedures the technology-dependent children in this study had undergone included: myringotomy tube insertion, hypospadias repair, palate and uvula surgery to decrease apnea, tonsillectomy and adenoidectomy, spinal fusion due to scoliosis, removal of salivary glands to decrease drooling, central venous line insertion, repair of broken bones (one child's femur broke in school while a teacher was doing range of motion exercises and another child's femur broke at home when a nurse was doing muscle stretches), repair of hip dislocation, abductor and heel cord release procedures to decrease muscle spasticity, bowel resection, cholecystectomy, open heart surgery to repair a ventricular septal defect, ventriculoperitoneal shunt revision, bladder augmentation, and release of tethered spinal cord. After each surgery, parents needed to learn new cares and develop additional assessment skills.

Changes in Health Status

Another issue affecting the technology-dependent child's care needs related to the additional demands incurred when the child's general condition changed because of acute illness or because of the progression of his or her chronic condition(s). Parents reported multiple instances of "ups and downs" with respect to their child's health status. The mother of a 4.5-year-old described one aspect of her child's frequent changes in health status in this way: "K. has been an inpatient several times, and she's been an outpatient over a hundred and twenty. We're such regular features there that everyone knows us by now, I think. But that's how it is for these kids."

Parents and other caregivers usually needed to institute additional measures (e.g., increased CPT or aerosol treatments, closer monitoring for seizures, increased suctioning) when the child who is technology-dependent became ill, which then increased the time and energy needed to manage daily life with technology. Even when the child was ill, however, most parents preferred to have the child stay at home as long as possible before admitting him or her to the hospital. Hospitalization caused a major disruption in the lives of families with technology-dependent children. One mother said, "...it's harder for me when they're in the hospital, because then I have to ship the girls off to my mother's. Then I juggle being at the hospital and being home with the girls and being at the hospital, and...It's hard when you have a child in the hospital because you just, you want to be there with him all the time."

Several families commented that their child's health status had been stable for several months or years at a time and that this stability made a big difference in their ability to effectively manage daily life with technology. However, keeping the child who is technology-dependent healthy and at home required balancing multiple factors, including the child's physical status. For example, one parent explained, "...we're trying to keep her electrolytes normal and keep her hydrated, because she tends to get dehydrated real quickly. But we don't want to have her gain too much weight, because she has to be carried. And so, it's trying to keep her with everything in balance. I mean, it gets a little touchy sometimes." Participants in this study felt that their child's ability to stay healthy and out of the hospital was primarily due to the high quality of care they received from parents and other caregivers.

In summary, the care needs of the technology-dependent children in this study were quite extensive, and caregivers required a great deal of expertise and time to meet these needs. In all of the families, the child who was technology-dependent needed specific cares such as medications, feedings, respiratory treatments, or suctioning not only during the day but often throughout the night as well. Maintaining and cleaning equipment was also required. These care demands necessitated development of effective time management skills as well as modifications of the home environment.

Time Management

Time management was the second major factor involved in managing daily life with technology. Caregivers of the technology-dependent children in this study, who were primarily mothers, talked about the stress associated with the amount of time it took to care for the child and the constant feeling that they never had enough time to do everything they wanted to do. All of the families felt that they had been forced to become more organized and use their time more efficiently as a result of having a child with special health needs.

Having a set routine and time schedule for daily activities helped families utilize their time most effectively, although the inflexibility and lack of spontaneity engendered by the schedules was sometimes frustrating. As one mother stated, "Those little things, just the little things, like getting up every day because you have to relieve the nurse." Other difficulties associated with time management included: (a) frequent interruptions in the routine, predictable daily schedule;

(b) having to make choices about prioritization of cares; (c) balancing the care demands of the child with the needs of other family members; and (d) the fact that activities always took longer, were more complicated, and required meticulous planning when the child who was technology-dependent was involved.

Schedule Changes

Disruptions in established routines and schedules occurred for multiple reasons, including variations in school and therapy schedules, the child's care needs and health status, and the presence or absence of home health care personnel. In home therapies had an impact on child's care routines and often caused schedules to vary on a daily basis. Even children who attended school had additional sessions with physical therapy, speech therapy, or occupational therapy in the home. Two of the children in the study also had home tutors. The mother of a 7-year-old who was ventilator-dependent described her daughter's variable schedule as follows:

> We usually have therapy at least one to 2 times a day. She gets speech 3 times a week, OT twice a week, PT twice a week, and we also have a tutor come to the house because her immune system is so compromised that if she gets any kind of infection

> it usually ends her up in the hospital....So our house is usually crazy all morning. With therapy, our door is like a revolving door, it's usually going.

Unanticipated variations in schedules also occurred when the technology-dependent child was ill, when home health care personnel cancelled or were not scheduled to work, and when inclement weather prevented the child from attending school. Clinic appointments with the multiple specialists and subspecialists the children needed to see also impacted on the family's daily routines and often required significant alterations in the usual schedule.

Making Choices

The amount of time spent in caring for the technology-dependent child required caregivers to consciously make choices about the prioritization of activities and cares. For example, many of the children in the study received aerosol medications and CPT two to four times per day, which generally took at least 30 minutes per treatment. Parents made choices about how frequently their child would receive these treatments based on the child's health status, developmental needs, and other care needs.

Parents also made choices about prioritizing activities that affected their technology-dependent child in a more indirect way. One parent spoke about the influence of external forces on the choices she made:

> Sometimes I think I put too much towards keeping the house up, and maybe I don't spend enough time terrorizing them (smiles). But with the state, the nursing and stuff like that, you have to try to keep the place as clean as you can. It's not that easy, because these kids can mess a house up in 5 seconds.

Another parent described a decision she had made in response to a bureaucratic paperwork requirement:

> I have to account for his expenses every month, which was just taking me an incredible amount of time until I realized that the state only cared about $40 worth. They didn't care about anything above $40. So now I only report $40 and don't worry about the rest of it. And the same thing with his preschool...they only care about 40 hours a month. So now I do, you know, 4 days worth and sign it, and we're done. So I have been able to streamline things.

One strategy parents used when making choices about cares was to try to have one activity serve a variety of purposes. For example, one mother considered giving her child a bath as not only a time for basic hygiene, but also as a time for range of motion exercises, perianal cleansing and soaking, gastrostomy care, skin care, massage, vocabulary enhancement, and spending quality time with her child.

Balancing Care Demands and Needs of Others

Some parents had difficulty following through with some care activities for their child who was technology-dependent because of the needs and demands of other family members. One family did not perform their child's occupational and physical therapy routines as frequently as the therapists recommended because both parents worked and they wanted to be involved in the school and Scouting activities of their other two children. The parents of four children, including triplets, still fed their 4-year-old, technology-dependent child so that she would get an appropriate amount of intake and also because she was quite slow and messy at feeding herself. As the mother in this family explained, "...we're not very patient with cleaning up a big mess. Which we probably should be more willing to let her make a mess. But dinnertimes are pretty crazy, so we just feed her."

Several of the families had young children or infants in addition to the child who was technology-dependent and the care needs of these children sometimes took precedence. Occasionally, caregivers also needed to take time for themselves, although the demands of all other family members were generally met before the caregivers addressed their own needs.

Increased Complexity of Activities

Activities that involved the child who was technology-dependent were described by parents as requiring careful planning and always taking longer than anticipated. Even a simple trip to the grocery store for one item was a much more complicated procedure when a child with special needs was along. Being away from home for a longer period of time was even more complex. One mother discussed her plans to take her 3-year-old son to visit his grandparents who lived several hours away:

> But there is a lot of stuff that you have to take. You know, in addition to the formula, you have to take the pump, and the charger to the pump, and a pole to hang the bags on. You have to take enough, there's one set of bags for the nighttime feed, and there's a different set of bags for the naptime feed that you have to bring. We use a battery-operated

> pump, so you need extra batteries. And then the syringes, the flush, the tubes, and the extra tubes in case something happens to one of them. And then that's not even talking about, you know, diapers and wipes and lotions and ointments and meds. And every trip I always go through this, "How stable is he? Do I need to take the nebulizer? How far away from the emergency room are we going to be? How likely are they to listen to me when I get there?" Anytime we're going to be gone for more than a weekend, I will actually call the emergency room here and say, "Look. I'm going to be in the middle of nowhere and I want to give your number to the emergency room physician. And all I want you to tell them is, listen to the mother." And they say, "OK, yeah, we can do that.".

Engaging in activities in which the child who is technology-dependent was not directly involved also required parents to do a great deal of strategic planning prior to the event. A single parent described her efforts in this way:

> If I definitely have to do something on a weekend, you know, get a haircut or go to the doctor or whatever, then I usually try to get a sitter. And

> I've got three different people that I call depending on severity. There's a high school kid who can take H. to the park and handle anything less than 2 hours because I don't trust her with the diaper changes. And then there's another guy who can do anything up to about 4 or 5 hours and who has a car that I can trust to pick him up or take him someplace. And then there's a woman who herself is a mother of a disabled kid, who I will leave him with all day. But it's, you know, we go through this every time....So I try to cram as much of my life into lunch hours as possible.

In summary, the parents in this study identified the ability to organize their time as an important component of managing daily life with technology. Despite parents' best efforts to plan carefully and anticipate all possible consequences, however, time management remained problematic at times.

Home Environment

Finally, the home environment also influenced families' abilities to successfully manage the care of a child member who was technology-dependent. Parents identified both positive and negative aspects of their home environments.

In general, parents organized the home environment so that it was conducive to the needs of their child and the child's caregivers. For example, the father of an 8-year-old boy with multiple technology needs noted:

> So I listed all the things we went through, part number, where we store them, and where backup supplies are. So that if a new nurse came in and hadn't been involved with something, that she would know where to go to find these things. And wouldn't get herself caught in the awkward situation, like, where are the diapers if there are none left in the drawers?

Another mother made this statement about her home: "This apartment's really set up for him, and so he gets around real well. And in other environments he doesn't do as well. He runs into things. And he's got really poor depth perception, so he falls a lot."

There were multiple variations in home setup, but the major area where technology was most apparent was the child's bedroom. In this study, most of the children who were technology-dependent had their own bedrooms. Two children shared a bedroom with one other sibling, another child shared a room with two siblings, and two children slept in parents' bedrooms. One child slept on a cot in the living room of the home because he had gotten too big for his parents to carry him up to his former bedroom on the second floor.

All but two of the technology-dependent children's rooms were on the ground floor of the home. Some of these rooms had previously been used as dens or dining rooms and had been modified for use by the technology-dependent child. One mother described the rationale for having chosen a particular room in the home for her daughter who was ventilator-dependent: "This setup works out well, because then the other bedrooms are on the other side of the house. Our living room and bedroom are back there. Then the nurses have a room to sit in, and we're kind of separate from them."

The furniture in the children's bedrooms was arranged to accommodate each child's equipment and supply needs. Some of the children slept in hospital beds, while other beds had been modified to facilitate access to the child and easy transferability from bed to a wheelchair or the floor. Most of the rooms were decorated with children's motifs and contained toys, books, and stuffed animals. Equipment present in the bedrooms included oxygen tanks, cardiorespiratory monitors, humidification systems, portable ventilators, pulse oximeters, suction machines, and feeding pumps.

Evidence of technology was often apparent in other household rooms such as family rooms and bathrooms. Family rooms frequently contained additional equipment such as suction machines, oxygen tanks, and feeding pumps attached to rolling IV stands, or larger items such as adaptive chairs and standing frames. Instructions for emergencies and emergency telephone numbers were clearly posted next to telephones in the homes. All of the homes had televisions and VCRs, and some of the children were also able to use the computers that were present in most of the homes. Modifications in bathrooms included adaptive equipment such as bath chairs, extra large bathtubs and/or shower stalls, and wider doorways to facilitate wheelchair accessibility.

In addition to bathroom modifications, several families had made other changes in the physical structure of their home over the years. The most frequent architectural modification was the addition of some type of wheelchair ramp at either the front or the back entrance to the home. However, some homes contained elements that had not been modified to accommodate the technology-dependent child. For example, one home had steep steps to a basement play area. Another home was being rented, so the family was not able to make any modifications. In this particular home, the child slept downstairs in the master bedroom with her parents.

Some families reported difficulties in fitting all the equipment their child needed into their current home. As one parent commented, "C. has the obligatory medical equipment. Sometimes I think we'll have to build our own barn for her equipment storage." Another parent had this reaction to a physician's recommendation that the family obtain a Hoyer lift for their 10-year-old son:

> Yeah, where am I going to go with that? Or his teacher keeps saying that we should get a standing table at home for him. Sure, you know, what the hell. The whole porch is filled with, he's got his ball out there and 20 boxes of diapers, and you know, all the other stuff. I just don't know in this house where we would put those things.

This mother was also concerned that one of her other children would try experimenting with the lift, especially the youngest one, who was particularly accident prone.

Many parents had concerns regarding the future needs of child as they related to the home environment.

Several families expressed a desire to move, but could not afford a new house at the time the study was conducted. The mother of a 5-year-old commented:

> We've bought a lot, and we're talking about building a wheelchair accessible home. It's just, you know, she's getting bigger, it's getting tougher and tougher to take her up the stairs. You know we had the ramp put in, we had the bathroom modified, and little things.

Many parents demonstrated a great deal of creativity in their modification of the home environment to assist their children. A friend of one family modified a large toy truck so that it could hold the son's portable oxygen tank. Thus, the child could pull the tank behind him as he crawled. One mother developed an apparatus to hold her child's feeding pump so that her child's mobility was not impeded. Another mother could not afford portable IV stands, so she attached clothes hangers to the curtain rods in her living room so that her two sons, both of whom received gastrostomy tube feedings, could watch television while they were being fed.

Summary of Managing Daily Life with Technology

Although managing daily life with technology required skill, organization, and creativity, the families in this study generally were very expert in this area. Families became more knowledgeable about technology and more comfortable with their child's care needs as time went on. Parents acknowledged that the first few months at home with each new technology were difficult, but that for the most part, families could see and appreciate the difference that technological devices such as tracheostomies, gastrostomy tubes and even ventilators made in the lives of their children and in the parents' ability to care for them.

Negotiating with Outside Entities

A second major theme that emerged from the data was the constant negotiation and compromise that occurred when families interacted with systems and individuals outside of the family. For families with children who were technology-dependent, negotiating with various entities outside of the family included the following: (a) relationships with health care providers, including home health care personnel, physicians, and other members of the health care system; (b) school and education-related issues; (c) dealing with other bureaucracies such as insurance companies and government agencies; (d) employment issues; and (e) interactions with the community.

Relationships with Health Care Providers

The families in this study interacted with multiple health care providers. The majority of families used formal home health care services to assist them in providing care for their technology-dependent children at home. Children also saw physicians and other health care providers during clinic and outpatient visits. In addition, families had contact with health care providers during hospitalizations. Families characterized their relationships with health care providers as both positive and negative.

Home Health Care Personnel

Families realized that without home nursing care, it would be very, very difficult for them to function. When one father finished listing the names of everyone who was present in the household, including pets, his 8-year-old son who was technology-dependent added, "And the nurse." The mother replied, "And always a nurse", to which the father added, "Lots of nurses." Parents knew they needed to collaborate with home health care providers as a team. However, their dependence on nurses was frustrating and constraining at times. Issues mentioned most frequently by parents included availability and consistency of staffing, relationships with home health care providers, and agency rules and regulations.

Availability and consistency of staffing. Home nursing was sometimes looked upon as a necessary evil. As one mother noted, "But the strain of having people in your house 24 hours a day. You don't want them but you need them. So you don't have a choice in the matter, because you'd go physically and mentally crazy if you had to do it 24 hours a day." However, families could not always get the amount of nursing coverage the physician had ordered. When speaking about nursing coverage, a parent described the following scenario: "Then of course on Friday, Saturday, Sunday it's just awful because nobody wants to work on weekends...We never have third shift seven nights a week ever. We usually have it 5 or 6 nights a week. So that's kind of the most difficult."

Even when families thought their nursing coverage needs were satisfactory, changes could and did occur without warning. Sometimes nurses called in sick or had other unexpected emergencies, and alternative providers could not be found. As one mother elaborated:

> And the flip side is the frustration when it (all our planning) doesn't work. I mean, then it doesn't matter what plans we might have had and everything

> we do takes extraordinary planning. All it takes is one 30 second phone call before we're ready to walk out the door and the whole thing falls apart.

Working with a large number of health care providers was another common element of home nursing care. Multiple care providers came into the home during the course of a week, and most parents reported cyclic episodes of staff turnover. One parent noted, "I think in an average week we probably have 18-25 people that come in, and that's including therapists and DME people, orientees..." Parents spoke of the disruptions caused by frequent orientations of new people to their child's care and the frustration they felt when new orientees sometimes did not stay on the case for very long. As one mother commented, "Orienting people is a very stressful time. It's like opening up your life. And how many people do you think know the insides of my closets? Or every other personal aspect of our life."

Relationships with providers. Because of the time home health care personnel spent in the home and the close collaboration required to successfully meet the needs of the child who was technology-dependent, parents and other family members often became very close to their home health providers. As one parent explained, "And I know that just having a worker here takes some of my emotional time. I mean, talking with them or dealing with them, and your lives get intertwined, and then you're hearing about their things and their problems. It's a different way of living." Another mother expressed this concern:

> Some people really get attached to my son, and it's nice to see that kind of bonding, but sometimes I worry....I worry if people make really stupid decisions when they get too emotionally tied to him. and so it's like you want to have this closeness but you want to have this line drawn, too, and each person is different so it's very hard to draw those lines.

Lack of privacy was a common concern related to the presence of health care personnel in the home. One mother explained: "It's very uncomfortable for everyone under certain circumstances, like if my husband and I are having an argument or something isn't going right. And if certain people can't accept that or mold into the issue or the wall when they need to, then home care isn't for them." In another mother's words:

> Home health care, once you invite them into your house, you might as well forget normal life. You

> never have a private moment. If you have a discussion with your husband, you don't know if they're listening or carrying it out (of the home).

Because of their desire for privacy, families at times deliberately chose not to utilize all of the nursing care hours available to them. For example, one mother stated:

> And I have 24 hour nursing, we just kind of like not to use it. We don't use the day nursing on the weekends unless we really are spread thin and need somebody or if he's sick then I can get somebody. But when the family is home he really likes to be with us and we do too.

The character and personal attributes of home health providers were important to parents. Parents noted that some of the nurses interacted lovingly with the children, while others just provided physical cares. Parents felt it was essential to be compatible with the individuals who provided home care for their child. Consistency of caregivers was also an important consideration for parents, both for the sake of the child and the sake of the family.

Several parents reported unfortunate experiences with home health personnel. For example, one nurse stole from a family. Another nurse was verbally abusive to the child who was technology-dependent. One family recited a litany of negative experiences with home care nurses. The mother of the family stated:

> We couldn't find anybody in the whole city who had nurses that could staff us. So there were nurses, ah, you would not believe. We had nurses who came in here drunk. We had nurses who came in here and tried to jump into bed with my husband. We had nurses who came in here and walked right back out the door and left me taking care of my daughter...We had days the nurses would call in sick.

The father of this family, who was also present, then added: "We've had nurses have breakdowns here."

Parents generally took an active role in their child's care even when home care nurses were present. For example, the researcher heard one mother telling the nurse that she thought her daughter needed to be suctioned. Other parents checked on the nurse and child occasionally, and many assisted the home care nurse with cares such as bathing, equipment changes, or therapies.

Although the presence of health care personnel in the home posed additional challenges and stressors for families, all families could identify the benefits of this situation. Families also spoke highly of many of the individual nurses who cared for their child.

Agency issues. Some families in the study used nurses who were employed by home health care agencies, while others employed independent providers. There were advantages and disadvantages to each situation. Advantages of agency nursing included better coverage in the case of last-minute cancellations and less family involvement with scheduling and other personnel issues. However, some families preferred to use independent providers because they wanted to have more involvement in hiring nurses who would be compatible with the family and to have more autonomy and flexibility in scheduling. Disadvantages of both types of nursing care included frequent staff turnover, intra-staff conflicts, and differences of opinion between parents and nursing staff regarding cares and routines. One mother discussed one of the disadvantages of independent providers:

> Try to get one of the nurses to keep her AFO (ankle, foot orthosis) on, you know, try to get them to put her splints on. Some of the nurses are religious about it, and others, I mean, they won't do it if you kick them in the face. And what can I do to

> make this nurse comply? The only thing I can do is fire her. To whose detriment?

The bureaucracy associated with home health care nursing also posed a challenge for many parents. In one father's opinion: "The nurses are one of the great assets because they have been extremely caring, well-qualified, and very few problems. Our difficulties over the years have always tended to be in terms of bureaucracy. And this is the third agency that we've dealt with."

Each agency had its own rules, regulations, paperwork, and management style. Although most families dealt with just one agency at a time, at least one family was receiving home care from two different agencies. The mother of a child who had multiple technology needs discussed the difficulties of dealing with the bureaucracy of home health care:

> The big things are understandable: making a ventilator change, making medication change, those things are understandable. It takes umpteen zillion pieces of paperwork to accomplish anything that I would normally as a parent just do over the phone as a matter of course. But because nursing's involved, it's required. And that I can handle most of the

> time. It's the little stuff, simple things, like wanting to use a different facial soap for my daughter, or Clearasil, or changing the manner in which we do things just for variety for her sake, or little things that I might do as a parent because parents are flexible, and in order to make a family work that's how you do things. Knowing we can't do that, you know. If she wanted to have a sleepover, how do you manage something like that? You can't, not unless you have everybody's agreement. And you know very well that doesn't work out....It's a struggle to maintain the balance between what we would do as parents and as a family versus what the agency requires. And I am adamant about, and to my grave I will be, that we are a family first. And we require a lot of assistance, but that assistance has to know its place.

Summary. Overall, families felt that home health care nursing had a major impact on their abilities to successfully manage life with a child who was technology-dependent. The importance of home nursing care is evident in the following words from a parent:

> For our family I believe that the crucial factor in whether our success occurs is not whether school is

> a problem, it's not whether we're having physician changes and problems on that order again, or whether it's true medical emergencies. For all of those things, our coping strategies are in place and intact. The requirement of nursing coverage and all that entails I think has been our make or break point on whether we are successful or not and for any length of time. When that, when the nursing part erodes, or when the focus becomes on nursing, it offsets the balance of the rest of life. Then our success rate crumbles.

Physicians

All parents talked about both positive and negative experiences they had with physicians over the years. Parents recounted interactions with physicians that had occurred from the time of their child's birth to the present. Because of the complexity of their health needs, the technology-dependent children in this study received care from multiple specialists and subspecialists in addition to their pediatrician or family practice physician.

Parents perceived a lack of coordination and communication among their technology-dependent child's various physician providers as a major obstacle to achieving optimal health for the child. In practical terms, the number of physician providers seen by the technology-dependent child posed multiple challenges in terms of transportation, scheduling, and time. One mother described her interactions with her child's multiple physicians as follows: "And to try and make appointments with the physicians, call them and they don't return your calls, or the fact that they say, 'That never happened before', and we've proved them wrong on a number of things."

Another mother felt that interacting with multiple physicians was more difficult than coping with her son's fragile medical status:

> Dealing with him is really not the biggest problem. It's dealing with the system. He sees, now we're up to 9, different groups of subspecialists, and I am his case manager. There's no oversight. Even his pediatrician has no idea of who all he's seeing, or what the different recommendations are.

Negative encounters with physicians had a lasting impact on parents. The mother of a child who survived a near-drowning episode cried as she recalled a painful exchange with a physician soon after the incident nine years ago:

> And I said, "The surgery is dangerous. Her lungs are full. She's such a poor surgical risk." And he said, "Well, I can tell you that it's safer to have this surgery than to let your child swim unattended in a lake." I will never forget that as long as I live.

Another mother recalled learning of her child's diagnosis for the first time:

> We didn't get the diagnosis until she was 6 months old. Although we were suspecting at that point, because the doctors had stopped using words like "optimistic" and "Take her home, she'll be fine" to things like, "well, you know, you need to consider possible adverse consequences" and that sort of thing. You catch on, you see that there's a difference real well. When she was 6 months old they told us, well, the doctor's words were, "There have been apparent neurologic sequelae as a result of the difficult delivery" and then he walked out of the room.

The physicians that families had the most satisfactory relationships with were those who respected the family's expertise and consulted with them in the care of their child who was technology-dependent. The mother of an 8-year-old described her son's pediatrician as follows:

> Actually, I mean, he makes mistakes just like everybody else makes mistakes, and he doesn't do everything correct or whatever, but I will give him 100% credit because he, one, listens to what you have to say and he gives you credit for what you have to say, plus he also considers you a very important team member...he seems to be much more willing to work as a team and you're all the same, you're kind of level, which I think is really what family-centered care is really supposed to be.

Treating the child who was technology-dependent as a unique individual was important as well. The parent of a 12-year-old stated, "I've had some doctors that treat my son like a disease, and not a person. Like, they would talk to me, not even talk to him, like he's not even in the room." In contrast, another parent related this incident:

> There's an ENT who, we don't see him very often, but I tell you, I think he's wonderful, because the very first time he ever saw us he was really good. He came into the room and talked to my daughter. Instead of ignoring her, he came in and said, "Well,

> hello there, beautiful. What's wrong with you today?" He came over and touched her cheek and introduced himself to her and took his time. We get some who won't talk to her. It's just like, she's just a face and a number.

It was necessary for families to feel that they were receiving honest, complete information from physician providers. Even more crucial in parents' opinions, however, was the physician's willingness to admit that he or she did not know all the answers. For example, one mother recalled some good advice she had received from a physician:

> He said, if I tell you that she will never do something, then you'll never try to teach her. And it will become a self-fulfilling prophecy. I'll be able to say I was right. But I was right perhaps only because that's what I told you she would do. But if I tell you that we don't know what she's going to do, even if I think she might not be able to do it, you might try it. And she might be able to do it. And that's the only way we're ever going to find out. So, time will tell. Do as much as you can for her, and wait.

A father spoke about his criteria for gauging the potential for a successful relationship with a physician:

> We find that the single trait that we look for most is the ability to listen. And that if the professional person listens, and does not open with how he knows all the answers to the situation, we're off on the right foot and an excellent relationship. If they come in pretending they're God, they've got all the answers, they've seen thousands of these cases, it's not going to work.

Parents did not hesitate to find providers with whom they could have a good working relationship, even if that meant changing physicians or traveling a greater distance to meet with a provider of their choice. In an unusual example of remaining with a provider in spite of distance, one family said their child's pediatric neurologist had moved to a new position in another state, but the family planned to continue to receive care from her even though it was an 8 hour drive for them. Other parents sought the recommendations of parents who had children with similar needs.

Other Members of the Health Care System

Parents interacted with other members of the health care system such as hospital personnel, pharmacists, occupational and physical therapists, respiratory therapists, social workers, and respite care providers. Parents had both positive and negative experiences with nurses and other health care providers in the hospital setting, just as they did in the primary care, clinic, or home settings. One mother talked about a positive experience with a nurse in the NICU:

> One thing I'll always appreciate is her primary sitting down with me and saying, "What do you think it's going to be like to have her home?" And I will never forget that. That really helped to make it real, and for us to start to organize things at home.

Another family had a more negative interaction with a hospital-based social worker:

> What she told us to go apply for was SSI. And I said, I think we make too much money, because both of us are working full-time...And we went and applied and they laughed at us...And first she was sort of urging us not to keep him. Like put him in foster care or something.

Some parents felt that hospital personnel were not always very sensitive to the technology-dependent child's schedule and developmental needs. In addition, nurses and other health care providers in the hospital setting did not always give parents credit for their expertise or knowledge of their child's needs.

Families also needed time to establish trusting relationships with the multitude of providers they encountered during a hospitalization or clinic experience. One mother recounted her feelings about leaving her daughter in a health care facility for several weeks for evaluation and treatment of the child's gastroesophageal reflux and feeding difficulties:

> But this was people I didn't know, people I wasn't sure if they were going to know all of her little cues. And I worried about abuse, I worried about neglect...So I worried about that, so the first five days I stayed there....And I told them, I was honest. I said, I didn't trust any of you...Then I went home and of course I worried and worried and worried.

Family experiences with respite care also had positive and negative aspects, although very few families used out of home respite care. One family had a respite care worker who took the child to her home every other weekend. For this family, respite care was a very positive experience. It gave them a chance to have the house to themselves, and as one of the parents stated, "You can fight in private, you can let loose!"

Another parent recounted a more negative experience with respite care:

> R. was going to go to the Center for a respite, and last year we got all the way until he was to leave, and I had cancelled all my nursing, and it was right before Christmas...and they cancelled. And my nurses went on vacation. They had a shortage of nursing, and so they left us real high and real dry, and it was a terrible experience.

Another family had a respite worker who left their child with an adolescent babysitter for an evening instead of caring for him herself. Still another family reported problems with having to schedule respite care months in advance.

Summary of Relationships with Health Care Providers

In summary, interacting with health care providers and establishing good working relationships with them were essential components of successfully negotiating the experience of family life with long-term childhood technology dependence. Families were dependent upon health care providers for the life and health of their child as well as the health of the family as a whole. In many instances, the relationships between families and their health care providers were positive and beneficial. However, health care providers were also the cause of a great deal of family stress. Personalities of individual health care providers, family priorities, and agency policies, rules, and bureaucracy contributed to both the positive and negative aspects of family - health care provider relationships.

School and Education-Related Issues

Parents felt that school was very important for their children for a number of reasons. School provided a means of socialization for the child who was technology-dependent and fostered the acceptance of the child by others. It allowed the child to receive needed therapies. Many parents also appreciated the learning that occurred in the school setting, even if what their child learned was not "booklearning" in the traditional sense. The mother of a 12-year-old discussed the advantages of formal education for her child:

> School was a growing experience. I mean, you know, people look at, you know, they don't learn anything. I can say, he increased his tolerance from people handling him, it was varied experiences, some of them are set in their ways. I mean, there's a

> jillion advantages I can cite for these kids in the schools. You know, whether they never learn one iota from it. Because he's just a lot more tolerant.

The technology-dependent children in this study attended a variety of different types of school programs. Since all of them were over the age of three years, all were receiving educational services. A combination of special education classes and mainstream classes was the most common type of education for the school-aged children. The children aged 3-5 attended class with other children with special needs, except for one child who attended a regular preschool. One mother described her daughter's class as follows:

> L. goes to kindergarten. And she has art and music and gym and regular kindergarten stuff. She gets mainstreamed for music and art. She has phy ed with her class. There's 5 kids in her class. A teacher, a teacher's aide, and an LPN. Plus they've got the various therapists. She gets PT, OT, and speech at school.

The primary factors influencing parental choice of a school program were quality of education and the school's ability to deal with the child's special needs. One mother also felt that proximity to her place of employment was an important consideration. Many of the children had changed schools several times over the years because of the child's educational or health needs, because the special education programs had changed locations, or because parents did not feel that the program the child was in was meeting the child's needs.

Most parents were satisfied with the current education their child was receiving, but identified it as constant struggle to oversee and make sure things were being done properly for child. One mother described her present relationship with her son's school:

> Now things have stabilized enough...and he's gotten a lot better, too. And the teachers, their learning curve has improved so that the things that used to send them into a panic don't anymore. And they've come to accept the fact that if there's something really wrong with him, I'm not going to bring him to school. So they've relaxed a little, too.

Parents made frequent calls and visits to the schools, and participated in annual evaluations of their child's educational plan. One mother discussed the time and effort she spent dealing with school issues as follows:

> We are fortunate that we live in an area where I think we have a district that really, really makes an effort so it's not like it's a constant, constant struggle, but there are numerous, numerous hours that have to go into making the school situation functional. And it's a continual, on-going touching base, almost on a weekly if not daily basis, so people can make sure things are coordinated and being carried out and whatever.

Physical cares, medication administration, and attending to technological devices were done for the child at school by a variety of different personnel. One child had her own nurse accompany her to school every day, while other children received feedings, medications, suctioning, and other cares from nurses employed by the school district. Teachers or teachers aides did gastrostomy tube feedings and/or administered medications in some of the schools. One mother whose child was in a regular preschool taught the teachers how to hook him up to his feeding pump at naptime and stop the feeding after naptime was over. Cares were delegated according to legal, practical, and safety issues, and parents were generally satisfied that their children's needs were being met in a timely and safe manner while they were in the classroom.

Most parents thought the persons who taught their children were very good at their jobs and acted as advocates for the children. One mother stated:

> I am extremely happy with what the boys are getting. I feel the teachers know what they're doing. If they don't, they strive to find out the information they need to know....Basically, they do the best they can with what the kids' skills and stuff like that are.

Parents were happy that the classroom personnel assisted the integration of their children into usual school activities such as lunch, music, art, and recess. One parent noted:

> They've started taking the kids down to the lunchroom now and feeding them out with the other kids, hooked up to the tubes and everything...and there's kids that are fighting to come over and sit with them and stuff. It's really neat what's been happening.

Another mother talked about a special program at her daughter's school:

> The PH, Physically Handicapped room, is called the Rainbow Room. And they have a group called the Rainbow Buddies Club....And to join the club, you have to take a pledge that you will always be polite and friendly to the kids in the PH room...it's a real big status thing. They have a reward system in the classrooms, and if you do really well you're allowed to go down to the PH room and read a story or help them with art or something.

Although parents identified many positive aspects of the educational system, they were often frustrated by the rules and bureaucracy of the system. It often took a long time and a great deal of effort to get changes made in the child's educational plan. One mother encountered some resistance to feeding her child at school:

> They will have nothing to do with it. Now, after I went through this program with her and got her the swallow study and know that she's safe to feed and started her on a program, you would think the school would have this instituted already. But they still haven't done anything. So it's almost like I'm going to have to push to get this going.

This parent was hesitant to push too hard, however, because in her words, "I don't want to create any enemies over there, and I want them to treat her well."

Another family related a complex story about their efforts to have their son's school provide him with the amount of time and the appropriate personnel and equipment he was entitled to for physical and occupational therapies. It was the father's perception that children with special health care needs were the ones affected most frequently and most severely by budget cuts, and that parents had to fight for every service their children received.

Parents reported that fighting the system was often necessary, but it took its toll on parental strength and energy. The mother of a 7-year-old described the struggle in this way:

> You don't want to go through lawsuits, you just want the stuff that you're supposed to get. And just provide it. I don't care what you have to do, just provide it. But no, it's almost like you have to go through tons of headaches to get what is supposed to be what you're entitled to. And that's the part that is so hard...And I do think a lot of parents probably get sick of fighting all the time.

Another factor parents identified as stressful was having children in different schools or different school systems. One mother of four children had her children in four different schools in three different school districts. Her primary school district contracted services for children with special medical needs to a larger school district, and children with special education needs to an additional district. Another family sent their healthy children to a parochial school but their child with special needs to a public school. When children were in various schools, the school calendars were different, meaning that each of the children had different vacation times, days off, starting and ending times, and teacher conference times. Parents often found it difficult to be involved in school activities such as home-school associations and volunteer opportunities.

Overall, most parents were pleased with the amount and quality of the educational services provided for their child who was technology-dependent. Individual teachers and activities were generally not as problematic as dealing with the bureaucracy of the system as a whole.

Dealing with Bureaucracies

In addition to dealing with the bureaucracy associated with the health care system and the educational system, families in this study frequently interacted with other bureaucracies such as insurance companies, community agencies, and government bodies. Parents spent a great deal of time and energy dealing with these bureaucracies.

Interactions with insurance providers, which included private health insurance companies, state agencies, and the federal government, seemed to be the most difficult for the participants in this study. In the parents' opinion, insurance companies were notoriously slow at authorizing expenditures and very inconsistent in determining reimbursable expenses for the parents. For example, some insurance companies paid for formula and diapers, others did not. Some paid for supplies that were obtained through a medical supply warehouse but would not reimburse parents for the same supplies if they were purchased at the local discount store, even though the parent's cost was significantly less.

Parents reported difficulties with obtaining authorizations for new equipment for their children in a timely fashion. The experience of a mother's attempts over a 6-month period to obtain a new wheelchair for her son illustrated these difficulties:

> He's got this ratty old manual chair that doesn't fit him, falls apart. When he has an appointment, I have to pick up the manual chair, put it in the back of my van, and then put my son in the car...I mean, it's not even safe...I started doing this in June to get this manual chair. I still don't have it. And they're still giving me the runaround....Like, it's not hard enough having a kid like T., that you have to go through this stuff, too.

Another aspect of bureaucracy that frustrated parents was the amount of paperwork that needed to be done on a routine basis. Many families had one or more types of insurance for their child who was technology-dependent and another type for the rest of the family, and each entity required different forms. And even when families submitted claims properly, snafus occurred on a regular basis. In the words of one parent:

> It's always something. And it started at birth with these kids. I mean, the insurance company couldn't get anything straight from birth. It could not handle twins. They rejected one every time.

> Because they did everything based on birth dates...That went on for years and years. So, the fighting started the day they were born. And it hasn't ended.

One father gave this account of problems with insurance paperwork:

> When you check into the hospital, the first thing they do is take your card, copy both sides of it... The only problem is, after that point I'm not sure that there's any intelligent life that exists that looks at these things. Because what we've found was that our son's records were kept under 12 different accounts. He was then billed twice a month for these things, and we were dunned with these things constantly. I dutifully took them and threw them in the trash can.

A significant number of parents received additional resources from county, state, or federal community-based assistance programs. In these programs, participant families were given a specific amount of money every month that could be spent at their discretion for items that would enable the technology-dependent child to remain in the home rather than be institutionalized. Parents reported using these funds for computers, wheelchair ramps, lifts, and respite care, among other things. The waiting list for this program was very long, however, and other parents in the study were aware of the programs but were unable to take advantage of them. Other parents reported that they wished they had been informed of the existence of this type of program earlier.

Many parents were frustrated in their attempts to obtain therapies for their children who were technology-dependent because of stringent eligibility criteria. One couple complained that they could not ask for additional therapy because not enough progress was seen in their child. These parents felt that maintaining the child's condition and preventing the child from regressing was progress in their situation. Another family related similar feelings: "Because he's not improving, he shouldn't be getting any more therapy. That's the way they're talking to us....Well, I'm sorry. It takes 3 or 4 years for him to improve on something." Yet another mother stated: "We've tried going through eating therapy with him and stuff like that, but the state just said since they're not making any gains with therapy, why should they pay for it?"

In general, most parents in this study characterized their interactions with bureaucracy as adversarial. They did not see bureaucratic systems as being family-centered or concerned with the needs of the family. As one mother commented:

> You have to fight a lot. You have to argue with his doctors to get them to take him, you have to fight to get reasonable appointments because the doctors that will take him set aside, you know, 3 hours a week for Medicaid patients, you know, which may not be the 3 hours that are most convenient in our lives. You have to fight the state with their reams of paperwork....it's just the, it's the systems, you know.

Bureaucracy and lack of coordination between agencies made it difficult for parents to access needed services or even to find out what resources are available for families that include a child who is technology-dependent. In addition, parents felt that health care personnel were not aware of resources to the extent they should be. Many families could have taken advantage of resources sooner if they had been told about them, and some families found out about programs not from health care providers or social service agencies but from friends, co-workers, or other families with children with special needs.

Employment Issues

Since the majority of the parents in the study were employed outside the home, issues related to employment affected family life and were another area where families often needed to negotiate because of their child who was technology-dependent. Overall, the mothers in the study seemed to feel that having a child with special needs had a greater impact on their employment than on their husbands' jobs.

Several mothers were employed on a part-time rather than a full-time basis, sometimes by choice but more often because of the needs of their children. One mother worked 3 part-time jobs as a CAT scan technician. She gave this rationale for her preference for part-time rather than full-time employment:

> When you're working that kind of a position, you have to take call. I don't want to take call. I personally, if I don't have night nursing that night, can't say 'well, I have to leave'. I can't do that, so what I do is pool at different places.

The mother of a 9.5-year-old boy stated, "I used to work full-time up until about four years ago, and then I quit. It was getting too much. Too many doctor's appointments during the day." This mother worked part-time in the evenings so her husband could be home with the children. The father in this family also changed jobs so that he would not have to travel as much and leave his wife alone with the children.

Another mother had a job outside the home but quit because she missed a great deal of work due to her son's unstable health. She explained: "I was working at a grocery store for a while, but I couldn't show up sometimes because one of the boys would be sick in the hospital, or I was sick, or I was so dead tired, and working anywhere from 4 to 8 hours a day. And then working 24 hours at home. It's hard." This mother decided to provide daycare services for other children in her home. However, she would eventually like to have an outside employer again so she would not have to go on welfare if her husband lost his job.

The two single parents in the study also identified the impact that their technology-dependent child had on their employment status. One of the single mothers had a full-time management position. She noted:

> I'm always juggling time at work, you know, just because I have to miss so much with his doctors and

> things. And nobody's ever officially said anything to me, but there's been a lot of grumbling. So I keep intensive records, you know, just to make sure that I always average 40 hours a week no matter what....The office really is, all things considered, they are very cooperative.

This parent also occasionally brought her child to her place of employment, and this enabled her to complete tasks in a more timely fashion.

The other single mother in the study had 3 other children in addition to her technology-dependent son, received some child support from her ex-husband, and worked only sporadically. Her perspective on employment is as follows:

> I've been working at the school (playground duty) every other day. But you know, if I work, who's going to give me off every time Albert is sick? You know, he missed over 35 days of school last year. Or if he is sick, and then you know I've got problems with the nursing care agency. I can't guarantee somebody's going to be there when I get home. And then, for every cent I make, they lose in Social Security. Well, what's the point of that? It's no wonder people stay on welfare....I would

> love to work just to go be with adults and stuff. I would love it. But it's just...

Paternal employment issues were mentioned less frequently than those related to maternal employment. However, one family worried that the father would not be able to find another job if he was laid off because of his age (48); consequently, he felt he had to work twice as hard and not ever use his technology-dependent child as an excuse for taking time off or not wanting to travel.

For the participants in this study, the major issue related to employment was trying to balance employment with the needs of the child who was technology-dependent. Fathers in the study were employed on a full-time basis with the exception of one father who was unemployed. The mothers in the study showed greater variability in employment status and identified a greater number of concerns related to employment.

Interactions with the Community

Family interactions with community entities included issues of access to community facilities, support from community groups and agencies, and the reactions of people in the community to the child who was technology-dependent. Parents described incidents that were helpful and well as interactions that were upsetting to them.

The technology-dependent child's interactions with the community were often limited because of transportation or access difficulties. In one community, for example, the library was not handicapped accessible, nor was the neighborhood school. Another parent spoke of the multiple phone calls and arrangements that needed to be made when she wanted to take her daughter who was ventilator-dependent to the circus. Curbs, lack of convenient elevators, and narrow doorways in public buildings were other barriers to increased interaction with the community for the child who was technology-dependent. One family dealt with the difficulties of taking their child out into the community by keeping him at home most of the time:

> When he was younger, we took him, but now he's so difficult to take anywhere...we have the help, we don't take him as much. So we really aren't out in the community with him the way we would be if we didn't have any help. And so I guess it's just kind of almost a non-issue. It's not something we really have to confront every day.

Parents were generally positive about the support they received from community entities such as churches and businesses. One family said their church was a great source of support for them.

> The church we went to, they did so much for us. They started a freezer bank of food, we had that for over a year...we got several anonymous checks in the mail...and she had lots of visitors, just church people that would come in and see her. Friends, you know, would just do things, stay with the other girls, help out when she had surgery. And then when we came up here and we lost all of that support, so that was hard.

Another family, however, had a distressing experience with the ministers at their former church, who encouraged them to put their technology-dependent child in an institution and never called or visited when the child was in the hospital despite the mother's requests.

Most parents knew and interacted with other parents who had children with special health care needs. One mother found out about a facility where her child could receive a more extensive workup and respite care from a mother who wrote to her in response to a letter she had put in a parent support group newsletter. However, one mother said she did not know many other children who had tracheostomies or other medical needs. Most of the children who were in her son's class were mentally retarded and did not have special health care needs. There was one other boy in his class that had Down Syndrome. This mother said, "Boy, if that's all we had to deal with was the Down Syndrome that would be easy. We could go anywhere, we could do anything."

Several parents commented that acquaintances or co-workers did not really know what it was like to have a child with special needs. They asked about the child's condition when they knew when the child was ill or hospitalized, but did not understand what management of daily life with a child who was technology-dependent entailed. As one mother stated, "People really don't want to hear. They want you to say, "Oh, everything's fine. Everything's wonderful." And then they can tell you about <u>their</u> lives. But they really don't care." Another mother of five children said others did not realize the time and effort it took her to be as well-organized as she appeared: "In fact, you learn to cope with it so well that people do tend to treat you like you can do almost anything. And sometimes you feel like saying, if anyone asks me to do one more extra thing..."

Although most people in the community were either helpful to families who had a technology-dependent child or had neutral interactions with them, families reported instances of interactions that were upsetting or frustrating to them. One mother related the following incident:

> We were at the mall eating lunch one day, and this woman is just staring at my daughter. I mean, I can understand, people look. Because people look at things that are different. That's not a big deal....But this woman was just rude. She finally leaned over and said, "What's wrong with her? And we were just getting up to leave, and I said, "Oh, nothing's wrong with her. She just acts this way whenever she's around rude people." And turned and walked away.

Summary of Negotiating with Outside Entities

In summary, the parents in this study generally felt that negotiating with outside entities was the most stressful aspect of family life with a child member who is technology-dependent. In the words of one mother, "Actually, taking care of my daughter is probably the easiest part. The actual physical taking care of part. The mental part is the worst. Dealing with the doctors, dealing with the nurses...these mental games that you play..." Another parent summarized the feelings of many of the other participants in the study with the following statement: "Attitudes, you know, and having to deal with the system, is far more disabling to a family than the condition itself."

Maintaining a Functioning Family

The third major theme that emerged from the data in this study was the importance of maintaining a family that accepted and incorporated the demands placed on it by technology, but was not consumed or overwhelmed by technology and did not have the technology as its main focus. The major aspects related to the theme of maintaining a functioning family are: (a) meeting the needs of family members, (b) finding time for the family, (c) financial considerations, and (d) involvement of extended family and friends.

Meeting the needs of family members

Parents spoke eloquently about the impact that long-term childhood technology dependence had on the various members of their families. Every member of the family was affected by this phenomenon. Therefore, this section includes data related to: (a) the primary caregiver (self), (b) the spousal relationship, (c) siblings, and

(d) the psychological needs of the child who is technology-dependent.

Self

In this study of fifteen families, the researcher interviewed 15 mothers and 4 fathers. There were two single mothers and no single fathers in the study. All of the parents interviewed identified the need to take care of oneself or else one would not be able to care for other family members effectively. However, they also noted that their own needs rarely took priority because other family members' needs came first, especially the needs of the child who was technology-dependent. One mother stated: "I destroy myself on a regular basis but I put myself back together again. I used to try not to destroy myself but it's impossible. You just have to be ready to put the pieces back together again."

The mother of four children, three of whom had chronic health problems, had this perspective on the relative importance of her own concerns:

> N. comes first, because he's got the most life-threatening needs. And then I'm probably outside with the wastebasket, you know, as far as my needs being met. I mean, my needs are rarely ever met. And my biggest thrill out of the day is if I can

> sleep. That's about as much as I get out of the situation. You know, it doesn't mean you don't love your children, and you wouldn't trade them for anything, but I sure would like to be able to be like my friends, get up, go out shopping with them, have lunch, not have to worry if the nurses are going to show up for a shift...

One of the two single parents in the study sometimes wished she had a partner to help, but at other times felt that it would be just one more person to worry about. This mother noted: "So sometimes it's easier. But sometimes it's like, you know, I just want to take the garbage out. Or I just want to get out, you know. And you can't do it." Other parents thought they would have more time for themselves as their children got older, and that it was possible to postpone some of their own priorities until then. For example, a mother whose technology-dependent daughter was one of triplets hoped that all the triplets could have the same school schedule next year so that she might be able to schedule some activities for herself.

Another concern related to caring for self was attention to one's own physical health. Some of the parents in the study had health problems themselves that needed management. One mother had Graves' disease and asthma, and her husband had back problems. Other parents also identified lower back pain as a common health concern. One mother felt that her physical health problems were directly related to the stress of having a technology-dependent child in the family:

> I've had 13 surgeries, and 10 of them have been since we've had Z....just umpteen hundred problems physically because of the stress and the extra work. And the other kids do add to it, and dad's problems do add to it in the fact that he's gone a lot.

The majority of parents who were interviewed recalled that concerns about their ability to continue to care for their child had surfaced at some point during the years that they had parented a child who was technology-dependent. Several parents felt their own mental health was at stake at particularly stressful times in the past. The mother of a 12-year-old gave this account of the first two years of her son's life:

> And back then, you know, when you start out, you don't have the help and the respite and the workers, and it was just your son and you were doing it on your own and just wearing yourself to a frazzle. And being a nurse, I seriously feared for my mental

> well-being, you know, because I was depressed, cried easily, you know, I suspected I could have an emotional breakdown if I kept up at this pace.

Another parent expressed these feelings: "There were days in the past that I just laid down on the floor and I just...that's all I could do was just cry. You know, I just wanted to, I wanted to die. I didn't want to have to live through this anymore."

One father reacted to stressors of family life with technology dependence by refusing to have anything to do with family financial matters, including paying the bills or even discussing financial concerns. This family identified a need for a bigger house that was more handicap accessible but no action had been taken because the father did not want to deal with the financial ramifications of buying and selling a home.

A father whose 12-year-old daughter was technology-dependent as a result of a near-drowning accident when she was 3 expressed the opinion that there is an increased incidence of mental illness among people who have been the primary caregivers for children or spouses with complex care needs. This father wondered if he might have some degree of mental illness himself because he had spent so much time and so much energy in singleminded pursuit of trying to do what is best for his daughter and striving to overcome obstacles to optimal care provision.

Despite the stresses of family life with a child member who is technology-dependent, participants felt they were coping well and were able to identify strengths or characteristics in themselves that helped them maintain a functioning family or cope with the impact of a child with special needs. Characteristics that were frequently mentioned included organizational skills, perseverance, maintaining a positive outlook, and communication skills. As one mother stated: "Keeping a positive attitude helps a lot. And a sense of humor. Which fail us all from time to time, and then trying to get it back. And trying to let people know how much we appreciate them, really we do, especially those people who've been with us so long." Other parents felt it was their faith in God that helped them survive.

Several of the mothers in the study were nurses, and these mothers generally felt that their profession was an asset because it made assessing their children and understanding their children's medical regimens much easier. One mother also thought that having a medical background made it easier for her to communicate with the school system about her child's special needs.

Approximately one-third of the parents in the study had seen therapists to help them deal with stresses of family life. As one mother explained:

> When I finally got to the point where I just could not cope any longer, I started seeing a psychologist myself. And that helps, too. Just because, for an hour a week, I can vent all my frustrations without having to worry about what effect it's having on the listener. Plus she has a background in child psychology as well, so she can also give me real concrete advice.

Other activities parents engaged in for stress reduction or relaxation included watching movies, reading, and walking. One mother just liked to get out of the house by herself for a little while, even if it was only to go grocery shopping. Another mother played bridge once a month; this was the only thing she said she did that was not related to her technology-dependent daughter.

Employment also provided an outlet for some parents. One mother who was a nurse thought that her family could survive financially if she didn't work part-time, but stated, "But I like my job. I really like my job, and I need that to get out. And I need to interact and be, and I don't want to waste my career that I worked for."

Relationship with Spouse

For the majority of the participants in the study, maintaining the quality of their relationship with their spouse was very important. Most couples identified each other as a source of support, though this was not a universal phenomenon. One husband jokingly said to his wife, "Don't ever leave me, I could never handle this."

All couples in the study felt that their relationship with their spouse had been stressed as a result of having a child with special needs. One mother described the impact on her marital relationship in this way:

> It was real stressful. We're just now getting back to where we're completely in love with each other again after 4 years! And there was never any question that we would split up, that just wasn't an option for us. We just realized all the stressors. We knew having her was stress enough, having 3 babies at once was stress enough, having him writing a dissertation was stress, and then moving, a new job, and the loss of my dad. I want to take one of

> those stress tests and see where we were on that scale...but I think I'm afraid to find out how bad off we were. We did have some counseling, and that helped. I went to it more than he did, but it just helped me through the rest of it.

Another mother offered this opinion: "So far, we've been married almost 8 years, and it's been touch and go. I mean, our marriage has been strong, but it's been stressed, no doubt. No doubt at all."

Other spouses identified that their marital relationship had been permanently damaged because of having a child with special needs. One woman stated, "It's taken a toll on, to be honest, with Dad and I in our relationship. We basically have very little relationship anymore because I don't have the energy to have a relationship. I don't have the time anymore. And it's terrible. I mean, we've both lost out."

Two of the participants in the study were divorced from the biological fathers of their technology-dependent children. Both of these women identified that the marriage had dissolved in large part because of the stresses of having a child with special health care needs. In addition, one couple was in process of getting a divorce at the time the study was being conducted.

Although the wife identified that she thought they would have gotten divorced eventually anyway, she felt the process was hastened because her husband could not handle having a child who was technology-dependent.

Mothers generally felt that they bore the brunt of caregiving and responsibility, not only for the child who was technology-dependent, but for the entire family. One woman who was married for the second time put it this way:

> My husband came in with a very pie-eyed idea of what was going on and he's at the point where he can't deal with any of this anymore. So, I mean it's, there is no privacy that you have. And it's difficult because, there are times where I think, ah, I would love to just say no more nurses, I'll do it myself, but the reality of it is everybody's going to suffer from it too, so you've got to try to look at what's the best for everybody in the long run. And at times I get tired of looking out for everybody, the good for all, and (being) Little Mary Sunshine here. It doesn't always work that way.

One mother wished her husband was home more and would help out more with the children, but seemed resigned to the fact that he was probably not going to change.

Another mother complained that her husband would not help with medical procedures such as changing the gastrostomy tube or drawing blood. She added, "he would change the trachs but he didn't like to because he's very squeamish."

Although mothers were generally the primary caretakers for the children in the family, many fathers did participate in child care. Some fathers provided quite a bit of the physical care for the child who was technology-dependent. In one family, for example, the father fed his son breakfast and got him dressed and ready for school each day. This father was also responsible for lifting his son in and out of his wheelchair and the bathtub because his wife had back problems. In another family, the father provided all of the care for the child while his wife was at work.

In other families, the father's participation in the care of the technology-dependent child was more indirect. Parents reported that it was often the father's responsibility to maintain and repair equipment or investigate possible home modifications. One father assumed responsibility for making his son's home-made blend of formula on a regular basis. In another family, the father did very little physical care of his 10-year-old daughter but spent time talking and playing with her. His wife noted that this pattern of interaction had been the norm with the couple's three older children as well:

> He is the best. He is so supportive and wonderful, but he has never...He's a hands on play and hands on do "extra dad" things. And he was that way as a dad, too, for our big kids, I mean. So I really am the only caregiver when we're apart from nursing care.

Most spouses could identify strengths in their husband or wife that complemented their own strengths, thus enabling them to more effectively manage the complexities of family life with a child member who was technology dependent. One woman spoke about she and her husband's strengths as a couple:

> I think we both have the ability to step back and try to look at the situation objectively, kind of retrench and redirect our energies or come back with a fresher attitude or something. And between the two of us, when one of us really gets bogged down the other is usually then there to be able to bring them up.

Overall, couples negotiated the specific aspects of family life for which each spouse would be primarily responsible. In one family, the parents divided the care of their technology-dependent child fairly equally between them. However, the husband spent more time with the three other boys in the family than his wife did, while the wife was the advocate for the technology-dependent child with respect to the school system, therapists, and insurance companies. The wife in another family commented: "Could I do this without him? No, not really. I might be able to take care of the medical end, but the legal things...I wouldn't know the first thing to do."

Areas of disagreement between spouses included household responsibilities, communication, religion, and child care. One woman told this story that illustrated her frustrations with her husband's reluctance to care for their 5-year-old technology-dependent daughter:

> On Monday evening a friend and I went out. The first time he ever had to put all the kids to bed. He screwed up with A. And my oldest daughter (age 8) told me later, "I tried to show Daddy how it was done." He didn't even start because he didn't know where we kept the bags and stuff for the Kangaroo pump. You'd think by this time he would at least have the interest to find out.

Both husbands and wives agreed that not having enough time to devote to their relationship with their spouse was an area of family life they wished to improve. Spouses identified the need to spend more time with each other, and, as one husband put it, to "take breaks together." However, spending time alone together was often very difficult and required careful planning. Finding childcare was sometimes problematic, since parents sometimes needed to find two different caregivers, one to care for the child who was technology-dependent, and another to look after the other children.

Spouses also found it difficult to spend time alone together even in their own homes. One woman described her feelings about the lack of private time with her husband as follows:

> And privacy, I mean there is no such thing as privacy. And when you were sort of private people to begin with....I guess what should be naturally happening for us as far as being able to do things more spontaneously or have some private time to ourselves, it's just not there. Never being able to finish a conversation, and even a lot more intimate things that you just can't do.

In summary, although spouses admitted that having a child who was technology-dependent placed multiple stressors on their marital relationship, most of the couples in this study were still together. The most frequently mentioned problem was the lack of time husbands and wives were able to devote to strengthening their relationship. Spouses were able to negotiate roles and responsibilities related to maintaining a functioning family with varying degrees of success.

Siblings

Almost all of the participants in this study spoke about the impact, both positive and negative, that having a brother or sister who was technology-dependent had on the other children in the family. There was one family that consisted of a mother and her technology-dependent child; the number of siblings in the other participant families ranged from one to four.

Several families had more than one child with health problems. One family, for example, had four boys: the youngest (age 8) was technology-dependent, the oldest son (age 15) had obsessive-compulsive disorder and depression, and the other two (ages 10 and 12) had ADHD (attention deficit/hyperactivity disorder). In this family, the parents felt that the child who was technology-dependent was not the "sickest" member of the family, but that he received a great deal of attention and care because he "looked different." This family also worried about the impact of the multiple health problems of the family on their one child who had ADHD but was not on any medication for the condition and did not have any other health problems. The parents feared that he was not getting the attention he needed because the needs of the other children were greater, and that he now was starting to act out in school to gain some attention.

Another family consisted of a divorced mother with four children, three of whom had chronic health conditions. The oldest, an adolescent girl, had attention deficit disorder. The second child had progressive leukodystrophy and was technology-dependent, the third child was healthy, and the youngest child had partial trisomy 18 and was mildly mentally retarded. In a family who had twin boys who were technology-dependent, the other two children had speech problems and possible learning disabilities, and the mother felt that all four of the children had discipline problems.

In general, parents felt that siblings who were younger than the child who was technology-dependent tended to accept the child and the family situation because that was the way it had always been for them. So, as one mother stated, "I think they would say that it hasn't been any big deal having a handicapped brother." These children occasionally asked questions about their sibling's health status or developmental capabilities but they did not bring the subject up very often.

In contrast, siblings who were older than the child who was technology-dependent could identify more changes in their families that had occurred as a result of the presence of a member with special health care needs. The mother of four children, three of whom were older than their technology-dependent sibling, said this about her older children:

> And they tell us now that they were grateful they had a family, that we had a time before E., because once E. came into our lives they felt there wasn't any question, E. was always first. and where they understood that it was because of her medical needs and was frequently a matter of life or not, they too were young and growing up...and being emotionally able to deal with it, that's another story.

Parents tried very hard to consider the needs of their other children in trying to maintain a functioning family. In one family where there were only two children, the mother felt that she would like her 2.5-year-old healthy child to have more involvement with children his own age: "I just want him to not develop into a young adult. I want him to be a child, you know, and I want him to interact with children appropriately." One family home schooled their eldest daughter. One of the reasons they decided to do this was because they felt that she had not received the amount of attention from her parents that she needed or deserved because of her triplet siblings' health problems and overall care needs.

Parents tried to participate in as many of their other children's activities as possible, although this was difficult at times because home health nurses were unavailable or cancelled on short notice. Other parents made sure that they spent time alone with each of their children. Parents also tried to ensure that siblings did not feel disadvantaged by having a brother or sister who was handicapped. As one parent explained:

> And so that's why we have a fair amount of help scheduled and all that kind of thing, because we want the kids to be in Scouts, and they want to do this and that, and I don't want them handicapped because they have a handicapped brother. And so we plan for the help and we schedule the help, and it

> may be that all of us, including the worker, are all here. But we at least have that freedom, then, during the time that's she's here, to be able to be spontaneous and say, "Let's go to the Dairy Queen" or, you know, do those things.

Siblings who were present while the researcher was in the home were noted to have varying degrees of interaction with child who was technology-dependent. Several came into the room where the child was to ask their parent a question and did not say anything to sibling, while others said hello in passing or spent a moment or two in conversation. One group of siblings and some of their friends spent time watching television with their brother who was technology-dependent and another group of siblings and friends included the their technology-dependent brother in a game of Nintendo.

Parents frequently described the interactions between their children as "normal" types of sibling interactions such as playing with each other, squabbling over toys, or vying for a parent's attention. Siblings also interacted with their technology-dependent brother or sister in ways that reflected his or her special needs. One mother said, "And if he needs to be on humidity up here we usually have each of the kids come up and take an hour so he stays up here on his humidity. I just give them one hour apiece and they'll come up and play with him." Parents also allowed their other children to perform tasks such as pushing their sibling's wheelchair or gathering supplies for feedings, but were very careful not to make them responsible for providing care.

In rare instances, the presence of a child who is technology-dependent seems to have had little effect on the siblings. In one family, for example, the parents stated that the neither the siblings nor the family dog had much interaction with the child who was technology-dependent. These parents did not feel that their other children's lives were affected one way or the other by the presence of a sibling with special needs.

Most siblings did feel the impact of having a brother or sister who was technology-dependent, however, and parents sometimes wished circumstances would be different for their other children. Parents also worried that having a sibling with special needs was unfair to their other children because they missed opportunities they may have otherwise had. One mother expressed her regrets in this way:

> I can't tell you how many times my kids slept out in the hallways at Children's Hospital, or were left with the neighbors because I nowhere else to leave them because Dad was out of town and I had to take S. to the hospital. I mean, they've been through a lot, and it really makes me sad to think of all the things that they've missed, and all the things that they are going to miss, that they won't have.

However, parents generally felt that having a sibling with special needs made their other children more sensitive to others and more mature than perhaps they would have been otherwise.

Child who is Technology-Dependent

Although a great deal of the time and energy parents spent with their child who was technology-dependent revolved around cares and issues related to the technology itself, the parents in this study were also sensitive to the psychological needs of the technology-dependent child. Promoting normalcy in as many areas as possible while acknowledging the impact of technology on everyday activities and psychosocial issues was important for families. The mother of an 8-year-old gave this example:

> And he always smells so good, he uses cologne and deodorant and the whole thing. And we're pushing him. Not pushing him, but letting him do it, because he is incontinent, and he has a tendency to have more odor that way. So if he wants to smell good, that's wonderful.

Another mother felt it was important for her child to appear as much like other children as possible so that he would be accepted by others: "I work really hard at making him seem as normal as possible. And I try to dress him to conceal the fact that his body is real out of proportion. This shirt he's wearing is a size 8, and the pants are a size 3...we try to like to downplay a lot of that stuff."

Interacting with other children, especially children who were not technology-dependent, was important for the psychosocial well-being of the child with special needs. Participation in school activities, community activities, and informal play with other children were strategies parents used to promote interaction. For example, one child who was technology-dependent participated in Scouting, while several others attended church Sunday school whenever possible.

Each parent thought about their child as an individual who had more than just medical and physical care needs, although the health care needs were certainly very complex. Caregivers tried to find some time in the day when the child was not expected to engage in any therapies or treatments and could just relax, play, or have fun, although this was sometimes difficult to do. The mother of a 4.5-year-old described one way she provided free time for her daughter: "She doesn't get much down time (at school), they're constantly doing things with her. So she needs some down time after school. I'll put her down flat, where she isn't flat ever at school. She needs some time just to relax."

Parents had good sense of their child's capabilities and tried to maximize them. They were also very aware of unique likes and dislikes of their child, and incorporated these into relaxation or play activities. Finally, they were attuned to their child's emotional responses and could identify what types of situations upset the child as well as what made the child happy.

Parents were faced with issues that were universal child development issues but were impacted by the health problems of the child, such as discipline, development of socially acceptable behaviors, and puberty. For example, one parent was concerned about how to explain to her 12-year-old, cognitively-impaired son the changes that were beginning to occur in his body. Another parent of a 10-year-old worried about her child's need for increased independence as she grew older:

> She has so far exceeded any expectations medically that we could have hoped for but yet in our hearts knew was there. And now we're beginning to think about independence for her, what it might mean and how in her it will certainly be quite different from most people. But part of it, for all of us who are involved, we didn't necessarily lay the groundwork foundation as firmly as we might have with an able-bodied child. Or even a disabled or physically-challenged child who had a better prognosis. There were many of these issues that we never dreamed we would have to face. And you really only spend time on those things that you feel are necessary and you try not to waste time on other things...She's missed a lot of developmental stages of all sorts and it's always harder to go back. And in some ways you never do. So that's our next challenge.

Parents also recognized that their technology-dependent children faced some issues that were very different from those experienced by other children. A few of the children in the study received counseling to help them cope with the impact of technology dependence on their lives. In the words of one mother: "We're dealing with a psychiatrist right now with J., to help him deal with his, we call them 'limitations'. To help him deal with his limitations and accept the ones he cannot change, and to do the things that he can do." Another parent voiced the following concern about her child who had been technology-dependent for a number of years:

> But when you're kind of the first, it seems like everything you do is the first time, and that in itself is very, very stressful. Lots of mistakes, we all learn by experience, and unfortunately the person who it affects most is F. I think she continually feels like she's on a roller coaster, but does handle it well.

Many parents commented on their child's spirit and will to live. They felt the child who was technology-dependent and had survived had done so because he or she struggled to survive and did not seem to want to give up on life. A phrase frequently heard during the researcher's conversations with parents was, "He (or she) is a fighter". Parents felt that this character trait was the main reason their children lived as long as they did, in addition to having strong family supports and good physical care.

Summary

In summary, the presence of a technology-dependent member in the family had an impact on each and every member of the family, including the child who was technology-dependent. Families generally attended to the physical care and health needs of the technology-dependent child first, but attempted to meet as many of the needs of other family members as possible. These attempts often required flexibility, creativity, prioritization, and delayed gratification, especially on the part of the primary caregivers.

Finding Time for the Family

For the families in this study, maintaining a functioning family also included trying to meet the needs of the family as a whole and trying to find time for the family to enjoy activities as a group. Again, this was a difficult task to master and finding a balance was often frustrating.

Families tried to find time for family to spend together; frequently this time was the evening meal. The child who was technology-dependent was often included in meal preparations and generally sat at the table with the rest of the family whether it was time for the child to receive a feeding or not. One mother stated: "We always try to make him sit at the table and have supper with us, whether it's tasting a little peanut butter or sometimes we'll give him a plate of whatever we have so he can kind of know what food is...."

All of the families engaged in activities as a family group outside of the home as well. These included church attendance, shopping, eating out, and social events such as movies, school events, and recreational activities. When commenting on the impact a technology-dependent family member had on the activities her family engaged in as a group, one mother commented:

> I don't know how much it's changed the family because he's always...well, he's 10 and my oldest is only a few years older. So I don't know any other way, really. We've really tried to keep pretty much of a normal life with all the other kids. Nothing has been cut back, in fact we probably do too much.

This family included the child in as many family outings as possible, but mentioned that their ability to spend time away from home had been curtailed as a result of this decision.

Other families also noted that family activities outside of the home that included the technology-dependent child were subject to modification or possible cancellation on short notice due to inclement weather, lack of accessibility of community facilities for the handicapped, changes in the child's health status, or the need for scheduled medications or treatments.

Work schedules often made it difficult for families to spend as much time together as they would have liked. Families often arranged their schedules so that one parent cared for the children while the other parent worked. In one family, for example, the mother worked part-time in the evening as well as Saturday mornings and some Sunday mornings so that her husband could take care of the children while she was at work. Another mother stated that her husband worked a shift from 3 a.m. to 1 p.m., and that the schedule worked out well because "then he's home when I have to go to work, so someone's always there. It's rare that we need a babysitter, which is nice. Then it saves money and it's nice for the kids."

Several families had gone on vacation with their child who was technology-dependent. In most instances, this also involved the inclusion of a nurse who could provide care for the child so that parents would not have to attend to the child for 24 hours a day. Although families could not have managed successfully without nursing care, the presence of the nurse still impacted on the family's schedule and ability to spend time on their own as a family. As one mother expressed it:

> It would be nice to even just go anywhere as a family and it wouldn't be the same if we couldn't take G. anyway because he is such a vital part of our lives and family...even so, even to go somewhere and have full-time nursing or whatever, it just doesn't seem quite right.

Most families also spent time together without the child who was technology-dependent. Occasionally, one parent would stay with the child while the rest of the family went out. More often, the child stayed at home with home health care nurses or was cared for in a respite care environment. If parents felt comfortable with the care that was being provided for their child in their absence, most parents viewed an occasional absence from their child with special needs as a positive experience for the family.

However, spending a prolonged period of time away from the technology-dependent child, such as going on a vacation, engendered conflicting feelings in parents. Guilt about leaving the child at home was mentioned by several families as well as sorrow that the technology-dependent child would not be there to share the experience with the rest of the family. One family was very reluctant to take any vacation time without their technology-dependent child and explained the complexity of their feelings in this way:

> You feel, part of you is empty, you know, because she's here (at home)...It's not fair to go and leave her. When you go on vacation, you feel like, I wish she was part of this. I wish we could take her along. It's great to get away, it's wonderful. It's almost, you don't want to do it. It feels so good when you get away, but when you come back, you know that a disaster is going to happen....Either there's some legal action that crops up, or some medical problem, or...And the other thing is, when you get away and you're away from all the things, you have freedom and relaxation. And you come back, and it's so hard. I mean, just coming back and

> seeing the reality of our life is almost more horrible than just living it.

Most of the other families in the study, however, came back from vacation feeling renewed and ready to resume the challenges of caring for the child with special needs.

The presence of child who was technology-dependent also influenced parental decision-making related to having other children. Parents had to make decisions about whether or not to have other children and when the best time for another child would be. Some parents made a conscious decision to limit their family size after having a child who was technology-dependent. Others made an equally conscious choice to have more children, while for a couple of families having other children was described as "accidental". One mother whose technology-dependent child was the second of three children said she and her husband had their third child to see if having another child could save their marriage.

In general, parents reported that the first pregnancy after having a child with health problems was very stressful because parents worried that the next child could have health problems as well. This was especially true when the technology-dependent child's health problems were the result of prematurity.

As with all other aspects of family life with a technology-dependent child, adding additional children to the family was a complex process which necessitated careful planning and negotiation. With regard to one couple's decision to have three more children after their first child was anoxic at birth and eventually became technology-dependent, one woman stated:

> It just has always taken a lot of forethought and planning and arranging and scheduling your life to make it all work, you know, as far as having a baby and where he (technology-dependent child) is going to be, and you start talking to the social worker early and you say, this is what we're planning....you just have to be real assertive and plan ahead. And not react, you know. Act on life and try to make plans and make it work for you instead of waiting until it happens and then say, yikes, what am I going to do?

This mother also reflected the feelings of other parents in the study with her thoughts on the timing of having another child:

> And the main reason we waited that long (3 years) is that if the things we were able to do for M. in those first three years would make a significant difference in his, in what he was able to accomplish, we wanted to give that time to him before we made commitments to other kids. And somewhere along that point, you begin to think...well, or see, or accept maybe, where you're headed as far as what he's going to be able to do and accomplish. And so you start moving on with your life. And so I think that's the main reason we waited the 3 years. And again, him being at school, just the time management situation. Once he started school, I could see maybe being able to manage another child and give adequate time to them.

One couple with two children thought about having another child but were still undecided. The mother in this family thought that another child might be good for the younger sibling of her technology-dependent child, but was not sure that she could mentally or physically handle another child. She described the dilemma she and her husband faced as follows:

> Our whole life has been revolved around raising kids....And our younger daughter will grow up and be

> on her own, but if H. lives long enough she'll be with us forever as long as she is alive. And do I want to have another baby and wait 20 more years to have any time with my husband alone? So there's a lot of issues involved....And then there's the other side that's saying, it's just selfish, because when H. gets hospitalized, we have to dish our kids out....I guess if H. was more stable, it wouldn't be an issue....I would love more kids. I mean, I'd have 6 if I didn't have H., but she's so time-consuming...

In 4 of the 15 families, the child who was technology-dependent was the youngest child in the family, and three of the four families had made a conscious decision not to have any more children. In the fourth family, the father wanted to have more children but the mother did not. In the one case of a family with an only child, the child was in the process of being adopted, and the single parent was considering adopting another multiracial and/or special needs child in the future.

In summary, the participants in this study valued family interaction and devoted time and energy to activities the family could engage in as a whole.

Finding time for the family was not without its difficulties, however, and most families found that their ability to participate in activities that included the entire family was diminished because of the presence of a technology-dependent child member. Decisions related to family size and number of children were also affected by considerations related to the child who was technology-dependent.

Financial Considerations

The majority of families in this study were middle class. The medical expenses of all of the technology-dependent children were covered by Medicaid, and some of them were covered by their parents' private health insurance as well. However, expenses related to having a family member who was technology-dependent still had a considerable impact on family life. As one parent of a child who was ventilator-dependent stated:

> There is no individual more deserving than a child like V. to have all the resources that are available: state, Federal, whatever. She did not choose to be in this position, and that's why we all pay taxes and we all do what we do is to help people who are in such a position. So, I feel, to have her have the benefit of those things is only just. And

> whatever else we can provide in addition is just our good fortune that we've been able to do that....But we have stretched our financial budget to the limit and beyond.

Although many of the child's expenses were covered by insurance, families paid out-of-pocket costs for things that were not covered by insurance. For example, the purchase of a customized van for transporting their child or the cost of installing a motorized lift in a van was not covered by any program. Families paid increased electric bills as a result of monitors, humidification systems, ventilators, heat, central air conditioning, and night nurses. One parent stated: "it is more expensive to run a household. I mean, you have lights on all the time, you have equipment on all the time, your heat is always up, and there's no such thing as turning the heat down at night." Other parents concurred with this viewpoint, as evidenced by the following comments: "It is more expensive to live. Everything you do is more expensive when you have a child with a disability." and, "Everything costs more, you know. Toys with adaptive switches are twice as much as toys without adaptive switches. Puzzles with knobs cost more than regular ones."

A single parent in the process of adopting a 3-year-old child who was technology-dependent made a powerful statement about the financial impact of a child with special needs:

> I just did my taxes. And his direct care, receipts in hand, expenses were $20,000 last year. And Medicaid paid his medical stuff. We're just talking about the rest, you know, and that doesn't even count the intangibles like the fact that all my vacation time went to doctors' appointments and I've had to stop all the free-lance work that I used to do....I've borrowed against my pension and have exhausted all my resources, you know, retirement resources. And again, I was fortunate enough that I do have a good job and I've been working for a long time, and I did have some savings and some equity, but that's just about gone now. And now we're pretty much living day to day, and who knows what the future's going to bring.

In many parents' opinions, some of the financial expenditures they made were justified by the amount of time or trouble they saved. Cleaning services, in-home therapies, and the location and amenities of the family home were examples cited by parents as being worth the expense. A single parent stated:

> I rely a lot more on contractual services. You know, I have a service that comes in to clean the aquarium, and I have a service that comes in to clean the apartment. I take a lot more cabs than I ever used to. Those kinds of things all help, too. But they also cost money. Well, you reach a point where it's like, what's a few more thousand in debt if I can have like 10 minutes of peace? (laughs). And buying a washer and dryer was a big boon, too....So sometimes it's just a matter of finding enough money to buy the things that make life easier.

Another parent commented, "We just pay to get more things done. And we're left with a little more time to spend on the stuff that really matters to us as a family."

For all participant families, even those in which finances were not usually a major stressor, the presence or absence of financial concerns contributed to the family's overall sense of well-being. Families agreed that having financial resources helped to ease some of the stress of having a child with special needs. One family had received a financial settlement from the hospital where their child was born: "Fortunately the state ruled in our favor and the settlement was put in trust for her, so if she needs something, we can get it for her." Another parent noted the strain financial concerns placed on her family during the early years of her son's life with technology dependence:

> The first 4 years, the financial drain, you know, even with having the insurance and stuff. I mean, there were things like cost of respite that we'd have to pay for ourselves, that we had to have. Things like that were difficult, did create additional strain. And there's enough strain on just your relationship and finding time for each other, and if you have kids, the other kids, and all those other things, that if you have a financial strain on top of all of that, I mean all of that can add up. It just stacks up.

Three of the families in the study identified finances as a paramount concern. One of these families was headed by a single parent, in another the husband was unemployed, and in the third the father had a minimum-wage job. The mother in the single-parent family talked openly about her financial problems:

> Yeah, this is a pretty good family. I'm pretty happy with the way things are going. The only thing that bothers me the worst is the money thing. You know, I just wish there was more money. If I had more money, I would run out and go to the grocery store. Two of the boys needs shoes. I don't have a winter coat and my job is outside, so I've just been layering.

This mother also said that she had been using some of a friend's food stamps so that the family would have enough food to last until her next paycheck.

Overall, financial considerations posed an additional though not overwhelming concern for families which included a child who was technology-dependent. All families had some form of health insurance coverage for their children; however, insurance did not cover all of the expenses related to the child's technology dependence. Parents were generally willing to pay for services if it meant they could spend more time with their other family members.

Involvement of Extended Family and Friends

A final factor identified by the families in this study as impacting on their ability to maintain a functioning family was the involvement of extended family and friends. Extended family was generally seen as source of support by most families, especially when family members lived in the area. Only one of the families in the study had extended family members living in the household, as both the father's mother and brother lived with them. The grandmother consistently cared for her two grandchildren and was very comfortable with the special cares her technology-dependent grandson required. This rural farm family also had a male hired hand who lived in their house.

Other parents provided examples of extended family support. In one family where both parents worked, the maternal grandmother babysat 5 days a week for her 1-year-old granddaughter and was present when her other two granddaughters, including a 5-year-old who was technology-dependent, came home from school. Another parent stated: "We have families that are very supportive. That helps a lot, a lot. My parents and my husband's parents both live like within 4 miles each...We wouldn't have been able to do it without them."

Although most of the families who were interviewed had extended family living in the area, two families had grandparents who lived on the East Coast, and one single mother had no relatives in the immediate vicinity. One of the families would eventually like to move closer to their relatives. In another family, both parents had very small extended families and were feeling the burden of having to care for their own aging parents as well as their child who was technology-dependent.

Many of the parents in the study were concerned about the aging and health problems of their own parents. Some were thus faced with becoming caregivers for their parents as well as continuing to provide care for a child who was technology-dependent. Other parents worried about their own parents' abilities to continue to care for their technology-dependent grandchild. One father felt guilty having his parents watch his technology-dependent son for any length of time because his mother worried so much, did not sleep well while caring for him, and had difficulty lifting him.

Although the grandparents of technology-dependent children were the usual extended family members to assist with cares, one family used the father's brother and sister-in-law for respite care and paid them occasionally through a formal respite care program so that the parents could take a vacation with their other children. Another family felt that the mother's sister was a special source of support for them.

Two families in particular felt that they received minimal support from their extended families and were quite bitter about the situation. For example, the mother of a 12-year-old related her husband's family's reaction to her daughter who had become technology-dependent as the result of an accident:

> And then his family is saying, "Put her away. Put her away. She's a gork. She's a vegetable. Put her away. What are you doing with her? What about your family?" If it wouldn't have been for Aunt E and some of my friends, we would have, we had no supports. We had no support system. It was disgusting. It was like, all of a sudden, this child who was so wonderful to her grandfather was dead. He still talks about her like she's dead. He won't go in to see her, he just treats her like she's a nonentity.

Other families related specific instances where they wished they could have received greater support from their extended families or friends. One mother stated that her own siblings did not visit her son when he was hospitalized and also did not wish to learn any of his cares. A single mother who was adopting a son with special needs said her parents thought it was a ridiculous idea. They were also bothered by the fact that the child was black.

Parents also received support from friends and neighbors. One mother commented, "I have been lucky to have a lot of good friends and family and home care to help me through." This woman felt her husband did not have as much support outside the family as she did, primarily because he was not as social as she was. She stated, "And I try to be there for him but I can't always be there for him. And I think sometimes he's just going to have to find people to get his support from."

A few parents reported receiving minimal support from friends. The mother of a 3-year-old who was fed by gastrostomy stated, "There's always people that could watch him, but there's only 4 of us (mom, dad, grandmother, and uncle) that know how to feed him. Nobody wants to learn." A single mother who was adopting a technology-dependent child said this about her friends:

> Most of my friends are single and childless and they think that this is like the most insane thing I've ever done in my life. And people are real uncomfortable hearing about it. And I tend to be real cautious about, not talking a lot about how sick he gets just because I don't want people to

> treat him different. So I tend to be guarded in what I say to people, and people tend to have real low thresholds of comfort because they just don't want to hear about it.

Many parents received support from other parents who had children with special needs. Some parents met through formal support groups, while others met while in the hospital or clinic setting. One parent belonged to several support groups because there was not a single group that met all of her needs. She was not able to go to many of the meetings but enjoyed getting newsletters and corresponding with other parents via mail. This mother said she was waiting for an all-purpose, single parent, adoptive parent, multiracial, multihandicapped support group.

Parents were not always able to actively participate in support groups because of several factors: the time of day meetings were held, the child's health status, finding child care for the technology-dependent child as well as for any other siblings, or the difficulties associated with taking the child and his or her assorted equipment along to the meetings. Interactions with other parents of children who were technology-dependent enabled parents to exchange information about the latest treatments, the reputations of health care providers, and strategies for coping with family life and technology.

Summary of Maintaining a Functioning Family

In summary, a third major theme of life with long-term childhood technology dependence for the participants in this study was maintaining a functioning family. Aspects related to this theme included meeting the needs of family members, finding time for the family, financial considerations, and involvement of extended family and friends. Maintaining a functioning family required attention to multiple issues, weighing and prioritizing family needs, and being willing and able to compromise.

Making Sense of Life

The final major theme that emerged from the data was the theme of making sense of life. Participants in the study struggled to find a reason for their child's disability and to incorporate the changes in their lives into their overall beliefs about and schema of life.

Families' ability to make sense of life was influenced by health care providers' opinions about the life expectancy of the child who was technology-dependent. Almost all of the families in this study said they were told that their child would not survive very long. The mother of an eight-year-old child with cerebral brain atrophy described this experience when her son was an infant: "They taught me how to gavage feed him and they sent him home. And that's where I started from, basically. And they gave him probably about three months to live."

Another mother, as she looked at her 3 year old son who was walking towards her and asking if he could play with his train, said: "He's actually lived longer than they said he was going to. But now we've disproven a lot of the things they originally said. You know, they said, he's profoundly retarded, he's not going to talk, he's not going to walk, he's not going to do much." In a similar vein, the mother of a 12 year old who is ventilator-dependent stated:

> And her initial prognosis was not good and when we brought her home from the hospital there was quite a variety of thoughts from her physicians on the possibility of her survival. The prognosis was grim. But thankfully they proved to be wrong. And although the prognosis is still very guarded, certainly we have overcome a number of hurdles, and we are seeing some real positive strengths.

All of the technology-dependent children in this study exceeded the life expectancy that had been predicted for them by health care providers. Some parents initially accepted what health care providers said about life expectancy and then had to readjust their beliefs when the child continued to live, while others said they "knew" their child would live and would also "know" when their child was going to die.

Parents were also influenced in their efforts to make sense of life by factors other than the predictions of health care providers. Additional subthemes in this section include: (a) reconciling the past and present, (b) changing priorities, and (c) imagining the future.

Reconciling the Past and Present

When asked to tell the researcher about their child, parents invariably started at the beginning. They told the stories of when their child was born or first diagnosed with the health problem that led to the child's dependence on technology.

Most parents had gone through a phase of wondering what had caused their child's condition: for some children, the exact cause was known; for others, the cause remained uncertain. In one family, one of the twin boys had contracted meningitis when he was 10 months old and was left severely brain damaged; the other twin did not get the disease at all. These parents felt that it was a freak accident, "just something that happened." The mother of a three-year-old with severe developmental delay of unknown etiology talked about her son's diagnosis as follows:

> They don't know if that, while I was carrying him, if somewhere along the line he got a drop in oxygen, they don't know that. They don't know exactly what happened, but the labor and the birth went good....and it was nothing I could go back and say "the doctors did something" because they didn't. I had good prenatal care, too. I never had an ultrasound, though. And at 6 months we found out that he might have, well, as she put it, the kindest diagnosis she could give us was cerebral palsy.

Several parents thought something was wrong with their child but were told not to worry by others, including pediatricians, nurses, family members, and friends. The parents of one child commented on their early suspicions, with the father stating: "He never squeezed hands...he'd seem to almost try to roll and do a few things early on, and then went backwards."

Whether or not parents knew the etiology of their child's health problems, all felt it was important to search for something that would help them understand why this situation had occurred in their family. One mother spoke about she and her husband's beliefs about the reason for their daughter's health problems:

> I don't know what it is, and God and I are going to have a great talk when I get there, but there's a reason for everything. Whether I have to pave the way for another family, or that He just wanted her to get a good, loving family. I don't know what the answers are but there's a reason for it. And my husband just, he hasn't gotten to that side of it yet. He doesn't care what the reason is, it's not right and it's not fair. Period. And you're right, it's not right, it's not fair, but it is.

Another mother felt this way:

> And everything happens for a reason, too. I don't believe in the "God doesn't give you things you can't handle" thing. That doesn't wash with me. But I think everything happens for a reason...I also believe in past lives. And I believe that there was a time in the past that X. took care of me. And it's just coming around, and it's just my turn to take care of him.

The families in this study believed that the best thing to do was to accept the situation of having a technology-dependent child and make the best of it. Most parents eventually came to believe that having a child with health problems could have happened to any family, and they were not singled out to be the parents of a child who was technology-dependent. In fact, several parents resented other people telling them that they had a child with special needs because they were special or extraordinary people. As one mother stated: "People would come up to me and say, 'oh, you must be such a good person to have a child like this.' And I'd say, if I were a little more rotten, she'd be OK?"

Although parents did feel children with serious health problems could be born to any family, they recognized that the unique care they gave their children was one factor that kept them alive. One mother described her feelings as follows:

> We don't drink, we don't do drugs, the worst I do is smoke and swear. We don't go out hardly at all, you know. We're family people. And if he was with somebody else he wouldn't get what he's getting from us. So that gets me through a lot of days.

Another mother discussed her perspective about this issue:

> And these kids happen to anybody...there are people that aren't able to do it. They get them just as much as the people that are good and able and equipped and trained to be able to handle it and stuff....maybe some of those things and skills and attributes is what has enabled them to keep their kids home. How many of them out there that weren't so well-equipped or educated didn't thrive, didn't survive?

A final example of the difference parental care made for a child who was technology-dependent is the following statement: "A lot of people told me I should have put them in an institution. But they wouldn't have survived. And they sure wouldn't be where they are today. They would have died."

Many families made comparisons between the past and the present, particularly with aspects of the child's condition that had stabilized or improved over the years. The mother of 6-year-old twins compared the past with the present in this way: "The hardest part is over. That's when they had the trachs. Every night, I didn't know. I didn't know if I would come down or go upstairs and find them dead. Find them not breathing." A father had this perspective on his child's progress: "If you see one little improvement over a few years, that's something, you know. And sometimes it happens so gradually that you just think, oh, wow, gee, 3 years ago I wasn't able to do this, and now he's letting me do it."

Parents also identified changes in the child's health status or behavior that made care easier. For example, one mother of a 7-year-old girl stated:

> And I would say, when she was probably about 3, we were able to actually really dig in to therapies. And her health started to get better that we could actually, she would tolerate therapy. In the beginning, she wouldn't tolerate them. She wasn't even off the vent at all, she was on 24 hours a day. So it has gotten better over the years.

Another mother said this about her daughter:

> She's not as bad as she used to be. I mean, anytime we'd even touch her face or her lips she would try vomiting. It was terrible. She wouldn't even, we couldn't even hold her for a year after she was home. She wasn't affectionate, she was real closed in....So she had a really hard time, but she came out of it very well.

Although most of the parents had accepted their child's dependence on technology and adapted quite well, the past continued to be a source of sorrow. One father mentioned that having a daughter with disabilities and doing long-term home care for a number of years continued to be painful because the situation never goes away; it is always there.

Many parents cried while recounting their stories and talking about negative incidents that happened in the past. One mother of a child who had a near-drowning incident cried many times as she talked about the accident that had disabled her child 9 years ago and the events that had transpired since that time. This mother spoke about the impact of having a technology-dependent family member on the entire family over the years:

> I mean, we had no life. And here's my baby, who is 7 months old. Her infancy...one day she was breast fed, and the next day it was history. One day I didn't show up for a month....And here's this little baby who's getting shifted around all over the place from one person to another, anybody who would take this kid....We were like, we were like maniacs. We had no life. And then we brought her (the child who

> was technology-dependent) home, and we still have no life.

Parents all recalled instances over the years when their child's health status deteriorated and the child was in danger of dying. Parents recounted their struggles to make decisions about continuing treatment at these junctures, and wondered at times about the quality of life for their child. One mother gave this account of an incident that required her husband to make a difficult decision about the care of her son:

> He took A. to the hospital with the nurse and he threatened to sue the hospital if they didn't put him on a ventilator. And so they did put him on the ventilator, and then he's kicked himself ever since thinking, if I hadn't put him on the ventilator then he wouldn't be here and we wouldn't have all this stuff going on. But there have been too many times where they've told me, well if you don't do this he will die, and he doesn't die. So I've gotten to the point where I stop kicking myself.

A father talked about decision-making related to his technology-dependent daughter and his wife supported this view: "We made decisions at the point in time when we had made them based on the information that we had. If I knew then what I know today, obviously a lot of decisions that we made would be a lot different."

For the parents in this study, one of the most important factors in being able to accept having a child with special needs was faith in God or a higher power. The parent of a four-year-old stated:

> I think the main thing, I can say this now, I couldn't say it right in the middle of everything, is probably our religious faith and belief in God. You know, during everything you get kind of angry at God. You know, why us? Or why our child, or whatever. But now I know that's really the main thing that got us through it.

One family in the study belonged to the Wiccan religion (a pagan nature religion whose members practice witchcraft), and the mother gave this explanation of how her beliefs helped her: "But it all comes out in the end. That's my philosophy. It all works out. And what goes around comes around, and it comes around three times, three fold....that's why everybody should be nice to everybody else, because you never know." Other parents were able to accept the uncertainty of their child's lifespan because they believed God had a purpose for their child and only God would decide when the child's life was over.

In summary, one of the ways parents tried to make sense of life was to review the past and place it in perspective. Finding a purpose for the events that had occurred was instrumental in this process, as was being able to make positive comparisons between the child's past condition and present condition. Seeing family growth and adaptation over the years was also helpful for parents in their efforts to view life as making meaningful sense.

Changing Priorities

Parents reported that having a child who was technology-dependent had changed their lives to a greater degree than they had ever imagined. The experience enabled them to develop their own talents and strengths, and caused them to re-examine their priorities. In the words of one father, "it's brought us closer in a lot of ways, too, because it gives you a different set of values, your career's not as important and things like that. It's more emphasis on your family, and it changes your outlook on life a little bit, I think."
Another mother stated:

> And on really, really bad days, I just remind myself that if he hadn't found me when he did, he probably would have died by now. And he does help put things in perspective about my life. I don't worry about a lot of things that I used to worry about.

Overall, family life with a child member who is technology-dependent was much more difficult than most families anticipated it would be when they were first dealing with it. As one mother put it:

> It's harder than I ever would have dreamed. And a lot of it was just ego, I think, on my part. You know, it's like, I can handle this. I deal with a multimillion dollar budget, I deal with a professional staff. What's one little kid? Not the same --- at all.

The experience of family life with a technology-dependent child led parents to change their opinions of what was important in life and helped them reflect on the positive outcomes of the experience, not just the negative ones. One mother listed all of the things her child with special needs had taught her:

> He's taught me strengths about myself and he's taught me how to examine your coping mechanisms and to try to preserve your energies...if he hadn't been

> there I never would have taken the time to do that....He's taught me that you can learn just about anything you want to learn, and that's there's lots of different ways to go about doing something, and sometimes it really matters which of the ways you go about doing things and sometimes it doesn't.

In another mother's opinion, "There are so many blessings. When you get past the anger and the frustration and all of that stuff, and if you just have some time to count the blessings, there are so many blessings really involved."

Parental expectations and priorities for the child who was technology-dependent were also modified over the years. This was reflected in one mother's statement of her priorities for her son's education:

> (Reading is) the one thing that I would like him to get out of school. I mean, I'm a realist. I mean, he's not going to be a college graduate or whatever. I want him to learn to read. His mind is functional, I want him to be able to have the world open to him through reading, whether he's using his computer, reading a book, or whatever.

Parents put a high priority on their technology-dependent child's happiness, lack of suffering, and achievement of optimal quality of life. It was especially important for parents to raise the child with special needs in a loving environment and to feel that their child knew he or she was loved.

Participants in the study felt that they were able to set priorities and that each "just did what I had to do." They did not question the fairness of the situation for the most part. One parent explained her feelings in this way:

> So, you play the cards you're dealt. I just feel like there's no control over it in any way. I mean, the fact that she's lived 5 years longer than they told us. Who's had control over that other than taking good care of her and getting antibiotics or whatever when we need it. It's been either pure luck or pure fate, I don't know, one or the other.

The words of other parents supported this view: "It's just, you do it. You love him, and you do what you gotta do to get you through. If he's having a good day, you're having a good day. If he's having a bad day, well, you're going to have a bad day.", and "You don't have a lot of choice. You either learn to cope with it or completely fall apart."

In summary, participants in this study found that having a child who was technology-dependent led them to rearrange and change their priorities. Changing priorities assisted families in their efforts to make sense of a life that had changed dramatically with the addition of a child with special needs.

Imagining the Future

Parents had multiple questions and concerns about their child and their family's future. Only one mother said she deliberately tried not to think about the future because it was too uncertain. Concerns mentioned frequently by participants in the study included: (a) the technology-dependent child's length and quality of life, (b) who would care for the child in the future and whether the child would have the financial resources he or she needed, (c) the impact of growing up with a technology-dependent sibling on the other children in the family, and (d) concerns about parental health and well-being.

The primary uncertainty expressed by parents when trying to imagine the future was the health status of their child who was technology-dependent. Parents wondered how much longer their child would live and what the quality of that life would be. For example, the mother of a 3-year-old stated: "He's got a lot of brain damage that nobody is real sure what it's going to mean yet. If other parts of his brain will compensate, because he was so young when it happened, or if he's always going to have significant impairments." Other parents knew their children needed additional surgical procedures and treatments in the future if they were to survive. One mother was not as worried about her child needing further treatment as she was about her child's response to his uncertain health status:

> He's lost two friends that he knew very well that had similar problems to his. He's not a dumb child. Because he has a lot of physical limitations doesn't mean his brain doesn't function. Which makes it harder. If he was retarded, it would make it so much simpler to care for him. You know, because he wouldn't be questioning his limitations, he wouldn't be thinking about dying. That's a terribly heavy subject for a 7-year-old to have to deal with.

More concrete concerns such as which school the child would go to in the next several years or what specific skills could be learned in the future related to the quality of life parents hoped their child could attain. One mother, who said she never thought she would have to think about what high school her son would go to because he had not been expected to live, would have to make that decision in the coming year. Another mother expressed these feelings about her child's need to change schools in two years:

> He's got to go to some middle school, but I don't know where. Sometimes I think about moving, but, you know, how many school districts in the state really are equipped to handle the severely handicapped child? I don't know. So I mean, you can't even move. You can't even buy a new house out of the city unless you check out what they have.

Parents had future-oriented goals for their children who were technology-dependent; some of these goals were realistic, others were more questionable. One mother expressed her conflicting ideas about her son's future as follows:

> In my fantasies, I see him having independent living skills with just an administrative type person to come in and take care of ordering supplies and handling the finances, paying the rent and doing the bookwork. But I see him holding down some kind of repetitive, routine job at McDonald's or at an assembly type place. And being independent in

> living skills. But, the realities are, I don't know that he'll ever be able to have independent living skills...And he may very well always need to live in some kind of a sheltered care with a resident houseperson to help with personal care...And of course, on our worst days, I can't even see him as a grownup, you know. I don't see him living that long. And in my <u>real</u> fantasy world, he becomes a lawyer and he sues a lot of the doctors that did things to him during the early part of his life.

The mother of an 8-year-old discussed her hopes for her son's future in this way:

> I have lots of dreams for him when I let myself think about that. I have a dream that someday he would be able to live in a place of his own. I know it won't be totally independently, but maybe with an attendant and a service dog....People think that he wouldn't know where he was or that a dog like that wouldn't mean anything to him, but I know he knows more than we can tell. Sometimes I like to think that there's really a lot more in his brain than he can let us know about, and that he just sits there and takes everything in and has an opinion about everything.

Most parents had not made final decisions and plans regarding who would become their child's guardian if something happened to them. One mother said she often wondered what would happen to her child if she got hit by a bus, but had no definite answer to this question. Another mother deferred her concerns to the future:

> I think as she gets older I'll worry more, only because I can't rely on family. I will have to rely on someone else...my parents are both overweight and their health isn't that great. And I can't rely on them, and I don't want to have to rely on them because I want them to enjoy their life, too.

In general, parents hesitated to discuss the possibility of guardianship with extended family members, and most of the other children of the families in this study were too young to be able to take on that responsibility.

In addition to questions of guardianship, a few parents worried about the financial expenses of caring for the technology-dependent child after the parents had died. Two parents mentioned trusts that had been established for this purpose. Another parent, who was adopting a child who was technology-dependent, stated:

Once the adoption goes through, there's a subsidy. The subsidy comes to me and not to him, and if I precede him

> in death the subsidy stops. So I have to set up some kind of trust, and that involves naming somebody who will be in charge of his financial affairs, and somebody who will be in charge of his physical well-being, and I think it's an incredibly complicated thing.

Although families had multiple concerns about the future for their child members who were technology-dependent, most also found some aspect of the future that was positive. For example, as one mother was recounting the progress her 7-year-old twins had made over the years, she noted that the physicians had told her that by the time the boys were 10 years of age, all the damage from the high doses of oxygen they received after birth would be reversed.

Parents also worried about the impact family life with a technology-dependent member would have on their other children's futures. One parent considered the possible ramifications of having health care workers in their home for so many years:

> But it's just different when you have somebody in your home. And you sometimes worry about the long-term effect of all of that. You know, you <u>do</u> do things differently whether you're conscious of it or not. and I wonder whether that's good or bad. You

> know, the impact of that. And time will tell. You wonder that even with you kids, you other normal kids, too, is what kind of impact is all of this going to have on them as far as growing up. I don't know. I can't worry about it, I guess. You do what you have to do. Hopefully, there are enough other benefits that they will reap, you know, so that whatever inconveniences or differences that they experience as a result of it will be outweighed by the good.

Another mother expressed her concerns about her other children in this way: "We don't have the money to give them a college education....They're going to have to work like we did to get a college education. Which isn't bad...In fact, they might get a lot more out of their education if they're paying for it." Other parents were concerned about the possible consequences for siblings if they took on the responsibility for guardianship of their technology-dependent brother or sister after the parents could no longer do so.

Finally, when parents imagined the future, they mentioned concerns about their own physical and mental health as well as the status of their relationship with their spouse. One mother expressed her concerns in this way:

> Even now, sometimes, I worry a little bit about my emotional person, because I really pride myself in being ruled by my intellect, not by my emotions. But I wonder what's happening with all these emotions sometimes. Am I dealing with them in a constructive way at all or all of a sudden are they going to crop up like in a Pandora's box and eat me alive or something.

Parents also stated concerns about their physical health and its impact on their ability to continue to care for their technology-dependent child in the future. Other parents wondered how caring for a dependent child long after his or her siblings had grown up and left the home would affect their marital relationship. One mother summarized a discussion she and her husband had about the future as follows:

> He and I have always said, we don't know how long we'll be able to even keep him. I mean, I don't know if we'll make it to age 21, who knows? So in that sense we live day by day. By the same token, I don't think that we could completely rule out that institutional care would never happen. That could

> be possible. And again, you would have to assess the situation at the time, given the choices of bouncing from foster home to foster home, or mediocre care or care that you can't monitor....Maybe a group home, eventually, in the community, would be nice. It would be nice not to have him far away from wherever we were. Or even in the event of after we were gone.

Parents hoped they would never be forced to choose between their marriage and their child who was technology-dependent, but were realistic in their assessment of the effects of cumulative strain on their relationships with each other.

It is interesting to note that when parents tried to imagine what life would be like if their child died or was suddenly cured, they realized that their lives would change very dramatically. As one mother commented, "I worry about, if and when anything happened to J., that our other daughter would feel a big void because the house would be empty....And our life would change dramatically. I think it's scary, almost, to think of what would happen." The mother of a 12-year-old son who had been technology-dependent for eight years made this observation: "My whole life is built around this system.

And if that system changed tomorrow, there would be a certain degree of crisis and readjusting my life and how I was going to function. Because I don't function as any other normal mother."

Summary of Making Sense of Life

The final theme that emerged from the data for this study was making sense of life. Families were influenced in their ability to make sense of life through multiple factors, including resolving discrepancies between predictions about their child's length and quality of life and actual outcomes and being able to accept and grow from past experiences. Parents were uncertain in many ways about the future, but tried to plan for it as well as they could. In general, they tried to accept the circumstances of their lives that could not be changed and make the best of those that could be. The view expressed by one mother recurred throughout many of the stories told by parents: "This is reality, this is the way things are. You know, you just build around it, you do what you can do, and give it your best."

Summary of Construction of Family Experiences of Long-Term Childhood Technology Dependence

This completes the presentation of the four major thematic areas of concern in family experiences of long-term childhood technology dependence. Each theme has been explored in isolation; however, this experience is a process. Hence, none of these four thematic aspects of family experience with long-term childhood technology dependence occurs independently of one another.

Each family who participated in this study had a unique experience, yet when these experiences were examined in comparison to one another, certain commonalities emerged. The goal for families that contain a technology-dependent child member is to achieve some degree of stability so that optimum child and family development can be attained. The four themes discussed in this chapter were essential components in the lives of these families, and a change in any one of those areas altered the balance and forced the family to restructure. Unfortunately, a change in balance is a constant element of family life with a child who is technology-dependent. The mother of a 4.5-year-old daughter stated:

> As far as her stresses upon our family, it just a constant, you know, it's never ending. You know, if it's not school-related where they want you to be involved in this program and that program and go on this field trip or whatever, then it's doctor appointments or her AFOs need to be revised, or this

> feeding consultation out of town. It's just everything is constant. It's not like a typical child.

All four of the major thematic areas identified in this study were characterized by frequent change, unpredictability, and feelings of lack of control and frustration on the part of families. Families reported multiple and frequent changes in family life over the course of time, especially in the areas of child health status, schedules and routines, relationships with health care providers, school and therapy issues, and family roles and responsibilities. One parent described her life in this way:

> And you can never really sit back and say, "OK, now you've done all this work. Now let's just leave it alone and it will work." It doesn't work that way. It's daily, or there's always something that comes up that you gotta jump on somebody for. It gets very frustrating and very tiring.

Families in this study were not only faced with frequent change, but were also often unable to predict when and in what area of family life those changes would occur. The two areas that seemed to be the most unpredictable were the health status of the child who was technology-dependent and the home health care personnel who cared for the child.

Parents gave multiple examples of the unpredictability of their child's health status. For example, one child with a seizure disorder required multiple medications to control his seizures. Each medication would work for a few weeks or months, and then the seizures would start again. Another child's respiratory status was very unstable; sometimes a virus would only cause a cold and other times he would develop pneumonia quite rapidly. Other parents made statements such as: "When it can't be, he does it. He doesn't stick to the normal patterns of things.", and "every time they tell me, 'no, that will never happen', it does."

The unpredictability of home health care personnel was also a source of consternation for parents. When speaking about home health nurses cancelling on short notice and the agency not being able to find a replacement, a mother stated:

> It doesn't happen as much as it used to and it happens in cycles. Things seemed to have been going well lately, and I was getting used to it, and that was a mistake. I shouldn't have, you know, because

> it, without any warning, without anything, it just falls, it can fall apart. And it does.

Because the availability of home nursing services was sometimes unpredictable, parents could plan activities far in advance only to have their plans disrupted at the last minute. Parents also recounted instances of having to stay up all night to provide care and monitor the child's condition because the night nurse called in sick and then having to work or care for their other children the next day.

Unpredictability and frequent change contributed to feelings of lack of control and frustration on the part of families. In the words of one parent, "The minute you bring them home from the hospital, there's no instructions. Especially with a special needs child. There's no way they can put instructions with them. With special needs kids it's all trial and error." Parents often felt that no matter how carefully they planned, something unexpected could, and generally did, happen.

The construction of family experiences with long-term childhood technology dependence in this chapter provided an attempt to analyze the phenomena in terms of its constituent elements (Denzin, 1989). It is through the process of construction that the groundwork for the final step of the interpretive interactionist method is laid. This final step is referred to as contextualization. Contextualization interprets the structure provided in construction and gives meaning to the structure by returning it to the natural social world. The contextualization of family experiences with long-term childhood technology dependence is explored in the final chapter of this dissertation.

CHAPTER FIVE

FAMILY LIFE WITH LONG-TERM CHILDHOOD TECHNOLOGY DEPENDENCE: CONTEXTUALIZATION, CONCLUSIONS, AND RECOMMENDATIONS

In this final chapter, a contextualization of the experience of families which include a child who is technology-dependent is presented. Contextualization is the final phase of the interpretive interactionist process. It is through contextualization that the themes and structures revealed in the bracketing and construction phases are interpreted and given meaning within the naturalistic social environment in which the phenomenon occurs (Denzin, 1989). The main themes of the individual stories are synthesized so that a reformulated statement of the process can be made. Thus, contextualization attempts to reveal how the phenomenon is experienced by those who are living it. Once the contextualization of the phenomenon is completed, a brief summary of the study, conclusions from the study, and recommendations for nursing research, nursing education, and nursing practice are presented.

Contextualization of the Experience

For the families in this study, the experience of living with a child member who is technology-dependent was characterized by a sense of fragility. Families experienced a constant struggle to sustain a tenuous equilibrium that could shatter at any time. Parents felt that their daily life involved maintaining a delicate balance between the need to assert control and the need to remain flexible. They reported that the stability of their daily lives was tentative at best, although they did their utmost to establish routines and continuity. Ironically, the factors which enhanced family stability were often the same as those that undermined it.

Because of the continuing effort needed to successfully manage the care of a technology-dependent child at home and the ease with which the equilibrium that the family had worked to achieve was disrupted, the metaphor of "living in a house of cards" most accurately described the experience of life with long-term childhood technology dependence for the participants in this study. A single parent who was employed on a full-time basis described this feeling as she spoke of her efforts to arrange for care for her technology-dependent son while the child's school was closed for eight weeks:

> You have these convoluted setups, and one person doesn't show up, or one person's late, and then the person who's there is calling me at the office and

> saying, "I gotta go", and you're like, well, what can I do? That really impressed me, you know, with how fragile the whole system is. You know, we've got our lives going, and one little piece falls out, and then splat!

Another parent observed the following:

> My life has been out of control. I live on the edge. And when disaster comes, all you do is just zero in on that disaster and you take care of it. And meanwhile, it's like constellations spinning all around you...And yet you're in the middle of it, and you're trying to gather it all into some solar system of sense. You're trying to gather it in and give it structure.

Finally, the mother of a 10-year-old daughter who had multiple technologic needs provided this perspective:

> All in all, I think we have done well. Our daughter has certainly done well. We have survived. We have survived a lot of the ups and downs. I would like to think that we are more settled now and in some regards I believe that to be true. But I am not so unrealistic to know that everything hangs together by a thread. It really does. And as we try to build stability into our future, we still have, we

> always have, that component of everything hanging together by a thread. And it's like a house of cards. It does not take much and it all crumbles.

Families attempted to increase the stability of their lives through three main strategies: vigilance, advocacy, and reframing. As one family put it, they survived by "being an advocate and not buckling under and not letting things slide." Each of the three major strategies used by families in this study to increase stability is examined in light of the four themes addressed in the last chapter: (a) Managing Daily Life with Technology, (b) Negotiating with Outside Entities, (c) Maintaining a Functioning Family, and (d) Making Sense of Life. The overall contextualization of the phenomenon of family life with a child member who is technology-dependent is depicted in Figure 1.

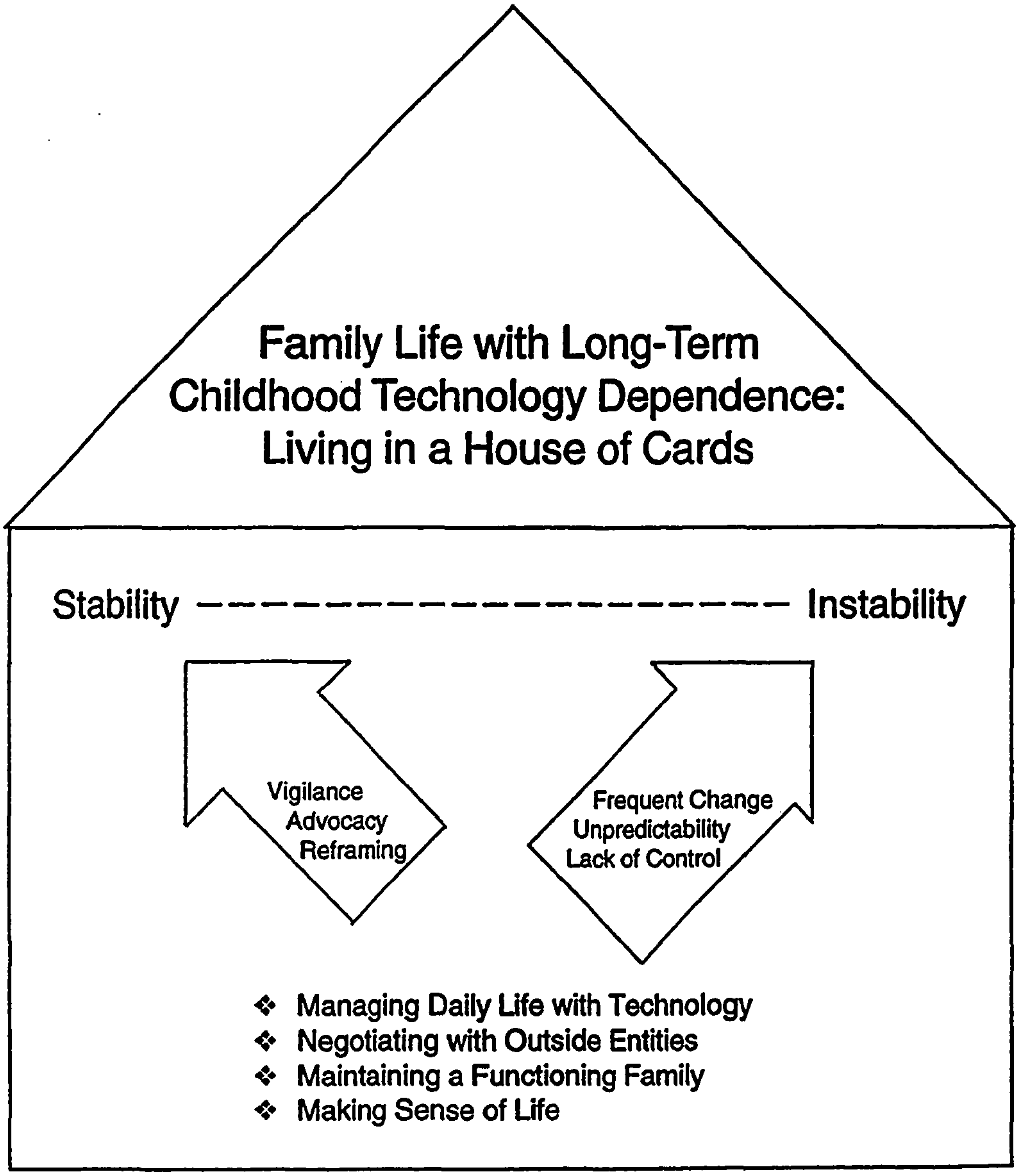

Figure 1. Contextualization of family experience with long-term childhood technology dependence.

Vigilance

Vigilance was a universal strategy used by the families in this study to promote family equilibrium. Vigilance consisted of multiple aspects, including constant monitoring of the technology-dependent child's condition; close attention to the proper and timely performance of physical cares and prescribed treatments; careful selection of home health care nurses, physicians, and other providers; overseeing all entities who interacted with the child who was technology-dependent; attention to the needs of other family members; and regarding vigilance as a positive element in family life with a child member who is technology-dependent.

Parents and other caregivers engaged in constant monitoring of the technology-dependent child. The physical status of the child was one area parents worried a great deal about. For example, one mother stated:

> I'm pretty positive she's probably got a viral pneumonia going. I wouldn't doubt it, because I listened to her before and she sounds real cruddy. She just got off her Supra. I'm almost tempted to call and get her right back on it. It's like, you know, how do you make these decisions? You're supposed to bring her in and let the doctor make the

> decision, but you're only in the office for a minute, and is that enough?

Another mother described her vigilance in this fashion:

> And it's just the little things, you know. When he starts waking up in the night screaming, it's like, is this a phase, is this nightmares? Or is he having g-tube complications, is he bleeding in the brain again? So you have to go through the normal kid questions plus all the others.

Parents felt they needed to be especially alert to potential changes in their child's health status when the child was nonverbal. The mother of a 5-year-old noted:

> And then there's also the element that she can't tell us what hurts and what bothers her. You know she's not feeling good, you know she has a temperature. What is it? She can't tell us where it hurts. And so you end up doing a lot of guess work and probably running a lot of tests that you might not run on other kids.

In addition to close assessment of the technology-dependent child's health status, parents were very exacting as far as proper performance of physical cares and strict adherence to procedures, treatments, and medications. One mother, when speaking about recent changes in her child's medication regime, stated:

"That's the way it is all the time. There's always something changing. You know, you always have to really think about what you're doing. It never can get really routine."

Being vigilant helped families feel more in control of their child's health, since they could recognize subtle changes early and sometimes prevent major health crises. As one parent noted, "As you take care of the problems, you become very knowledgeable about what's going on, which takes away a lot of the fear. The fear is the worst thing."

Interestingly, some parents reported vigilance on part of the child who was technology-dependent or the child's siblings in addition to the expected parental monitoring. The father of an eight-year-old stated: "He just has that incredible extra sense to know what's good for him. And, it's almost like from the day he was born, he's already been through this." Another parent related the following example:

> I want to tell you, no matter what health care professional, whether it's a dentist, a neurosurgeon or whoever he goes to see, the minute they glove up or whatever, "Are those latex?". He asks. First thing he ever asks. He never forgets his latex

allergy, because he knows how he feels when he was paralyzed.

Families were also vigilant in their supervision of other caregivers, such as home health care personnel, therapists, and physicians, to ensure adequate care and treatment of the technology-dependent child. Although families chose nurses and respite workers carefully, they continued to monitor the performance of the personnel who cared for their child closely. If parents did not feel comfortable with a particular home care nurse, for example, they might not leave the house while that person was there. Families did their best to maintain home health care personnel who were responsible, competent, and willing to help families in their vigilance regarding the child who was technology-dependent.

Many of the technology-dependent children had never spent any time away from their primary caregiver except for hospitalizations. One family sent their child to a respite care provider's home every other weekend, and several children had spent short periods of respite time at an institution that specialized in the care of children with developmental delays. In two of the families, the biological parents of the technology-dependent child were divorced, and the children occasionally spent time with their fathers. Although camping opportunities are available for children with special health care needs, even for children with ventilators, none of the children had ever gone to camp. Several parents mentioned that they had not sent their child to camp because they were not sure they could trust the camp personnel to know how to properly care for their child.

Parents reported the need for increased vigilance when the technology-dependent child was hospitalized, since the child was exposed to multiple health care providers in that setting, many of whom did not know the child well. A parent described her feelings about her child's hospitalizations in this way:

> There's so many specialties that nobody looks at the whole person....All they're concerned with are the areas they've taken care of...and they let the rest of it go to hell. So then you have to be there. And you have to keep beating them over the heads with, "this is his routine." Every time he goes in to the hospital, whether it's for routine or for a surgery, we go in with his complete schedule, his meds, what his routine is for the day. And it's always some do-gooder that thinks that they know

> better than we do, that will completely ignore and change it. So basically you're there most of the time when he's in the hospital making sure that the things that are supposed to be done are done....And it's constant. It's a constant battle.

Another aspect of vigilance related to keeping the needs of the family as a whole in perspective. Parents strove to balance the needs of technology-dependent child with the needs of the rest of the family. They were alert to signs that one family member or another might be in need of some extra attention. For example, one participant's goal for the coming year was to do a better job of spending time alone with her spouse, since she felt they needed to pay increased attention to their spousal relationship.

Parents reported increased vigilance towards the other children in the family as well. One mother expressed an acute awareness of her child who was not technology-dependent: "I look at my daughter and I think, OK, I see a bruise on her, how'd you get that bruise. Because we've met cancer kids."

Although parents tried to be sensitive to their own needs and the needs of other family members, they were always cognizant of the child who was technology-dependent. As one mother described it, "You never go anywhere. You don't go out to dinner without your child, the child that isn't there, going along with you." In a similar vein, another mother stated: "We try and maintain our outside life as much as possible. But it's hard, because no matter if you go, you always have to be aware something could go wrong."

In summary, the constant vigilance parents reported was difficult and fatiguing at times. In the words of one father: "You can try to set things on the back burner, and you can try to kind of place them out of your mind, and you can displace them with other things but the reality is, it's still there. And it's always there." However, the parents in this study felt vigilance was a positive strategy that enabled them to foster the well-being of the child who was technology-dependent. As one mother commented, "And I think, what about these parents that aren't in tune to all this? Those are the kids that probably don't make it, I don't know." Vigilance also allowed families to ascertain potential problems and intervene in situations before they became serious, thus preserving family stability.

Advocacy

An advocate is one who argues or defends a cause. The families in this study were advocates for the child who was technology-dependent and for the family as a whole. Many parents also engaged in activities that were directed towards advocacy for other children with special needs and their families.

Because parents were experts in the care of their technology-dependent children, they were able to identify their child's needs and functioned to keep the best interests of the child as a primary concern. As with many other aspects of managing life with technology, advocacy was a continuous process. One father expressed his opinion of the importance of advocacy in these words:

> One of the strongest things that we have found and continually rings through here, is being the child's advocate. And until you've done it, there's no way of telling just how critical that is. And whether that's dealing with the hospitals, dealing with doctors, dealing with schools, dealing with agencies, bureaucracy, nurses, home supply agencies, manufacturers, you have to really be prepared to go to the mat with these organizations.

Another parent described her efforts in the following way:

> It takes a tremendous amount of energy just to fight to keep him alive and keep him growing and keep him learning. And literally, everything we do has to be a therapeutic intervention....And so you've got this going on in the foreground, while in the background, you know, every time he needs new braces Medicaid says, "Well, it's too soon by our tables." Well, your tables are irrelevant to his growth spurts.

The advocacy skills parents developed were of critical importance when interacting with entities outside of the family. Parents struggled to gain the respect of physicians and to have physicians consult with them regarding the care of their child. One mother described her feelings in the following way:

> I just hope that everybody that's involved can actually listen to what the families want and need for their kids...And when families have new suggestions or other ideas, I wish they would be more open to them, because we're learning as well as they are along the way. And they're learning on our kids, and I think they should be a little more open to that.

Another mother discussed what it was like to really be an advocate for her child with health care providers:

> Asking questions and not thinking that every physician is a god, and saying, "well, you know, I don't really agree with what you're saying. You'd better explain to me exactly why you're saying this. And you're not touching my child until I understand and I think it's the best thing for him to have done."

Parents wished to be considered equal partners in decision-making concerning the technology-dependent child. For example, the mother of triplets thought that the one triplet who was technology-dependent had stayed in the hospital longer than necessary because health care providers felt that she and her husband would not be able to provide proper care for a child who was on total parenteral nutrition (TPN) and antibiotics in addition to the two other triplets and an older child. This parent felt it was presumptuous of the health care team to assume what would be best for the family without ever discussing it with the family themselves.

Families also made extra efforts to receive appropriate therapies and other services for the technology-dependent child. They tried to be knowledgeable and current about the types of programs and services available for children with special needs and their families, although many parents stated they found out about community resources only by chance.

In addition to advocating for the child who was technology-dependent, parents also defended the integrity of their family as a unit. They did what they felt was necessary to increase the amount of time available for family activities and maintain family stability, including increased use of services to assist with household maintenance such as cleaning services, lawn services, and car repair. They became more skilled at articulating their need for respite care or for increased nursing care hours so that they could maintain family stability.

Parents believed their ability to take on the role of advocate had been strengthened as a result of having a child with special needs. As one mother explained:

> I would say the best thing for assertiveness training is to have a handicapped child. That makes you more assertive, it makes you fight for stuff, because you have to...because it's your kid. Your kid can't speak for himself, and if you know anything about the school system, you know your kid doesn't get what they need. Or even in the medical

> system a lot of the time, unless you go, "Excuse me, this is the way it needs to be and it's going to be this way and I'm going to raise holy hell until it gets to be that way."

Several families expanded their advocacy efforts into the political arena and worked not only for their own child but for other children with special needs as well. The mother of a twelve-year-old described how she became involved in her local community:

> My perception over the years is that the County Human Services Agency is totally inept...they have a very bad reputation from people that have to use their services. I view that as an education problem, that they need to be educated and more sensitive to the needs of families, of people who are trying to keep special needs kids at home. And the only way they're going to know that is to be around one. So here I am, I'm on the Human Services Board! With the idea of helping to change some attitudes and to educate, and maybe get a more caring delivery system in the long run. And one that's more sympathetic and supportive of the needs of families.

Another mother expressed her feelings about becoming politically active as follows: "Never in my whole life did I ever dream that I would need to lobby before the Legislature and continue to do so, and that it wasn't just that one time could do it and it would be resolved. It's just an ongoing struggle."

Although some families lobbied on behalf of the population of children with special needs in the public arena, they could understand why other families were not active advocates in the community. As one mother stated:

> I think why some of the parents have had such a hard time, is that you're so consumed with the care of your child that you really don't have the time or the energy to do that. And it's only because I've had stable help and the financial support and all those things that I'm able to become an activist myself. And if my home health care worker quit tomorrow, heaven help me! My whole life would change overnight again...So it kind of all depends on where you're at in this cycle of things. And right now I'm in a place where I can do some of this, so I'm grabbing the opportunity.

In acting as advocates for children who were technology-dependent, parents felt they had an impact on other people's perceptions of individuals with special needs. This attitude was reflected in the words of one parent whose son had multiple needs for technology:

> If we want to affect long-term attitudes, the attitude of the next generation towards people and being inclusive of differences, whether it's his handicaps or just any differences, people need exposure to them....I would like to see my son function in a capacity of helping people realize that people like him are approachable, that they're people first...That there's a benefit to having them around, that they can enjoy having them around.

In summary, the parents in this study generally became more outspoken and more assertive as a result of their efforts to advocate for their child who was technology-dependent. This increased assertiveness applied to efforts to strengthen overall family functioning as well. For some families, advocacy efforts were expanded to encompass social or community issues pertinent to the population of children with technology needs and their families.

Reframing

A third strategy for promoting stability in families that included a child member who was technology-dependent was that of reframing. Family members adjusted to a new and different way of living, reexamined their beliefs and values, and changed some of their priorities in life. Reframing was the most prevalent and most dynamic strategy used by the families in this study.

The longer families lived with technology and the more expert they became in the care of the technology-dependent child, the more comfortable families felt in managing daily life with technology. Most parents could identify ways in which the care of the child who was technology-dependent had grown easier over the course of the years. For example, the mother of a 12-year-old boy with spastic quadriplegia, gastroesophageal reflux, and severe developmental delay said:

> He was a hard kid to take care of that first four years. Today he's a breeze in comparison. Though he's bigger now, and that creates a problem. But back then...he was fussy and irritable...there wasn't 5 minutes in the day somebody wasn't tending to him.

The care of the technology-dependent child also became easier in some ways because parents became more sensitive to their child's needs and preferences. Many parents felt their continuing efforts to promote optimal child development enabled the child to make progress, which in turn made the child's care less demanding. For example, the parents of a 9.5-year-old spoke of the child's increased tolerance for touch and sound. As the father of this child stated: "He'll sit in his wheelchair for a long time, where he never would in the past. So in little things like that he's come a long way...It's things that someone like a therapist or something might not consider that much progress, but it helps a lot around the house."

Identifying a reason for technology made it easier to reframe the technology as something acceptable to the child and family. One parent described her family's acceptance of increased dependence on technology over the years as follows:

> Although every surgery and every acquired dependency upon technology was certainly a major adjustment, it has always been an added plus for us because we knew the difference between survival and not survival were the factors....we resisted and struggled, I think, as most parents and families do. It is very difficult to see your child go through these things, and I don't know that any parent would accept it willingly except that the ultimate is that this is what your child needs and then it makes the decision

very, very easy.

Overall, parents identified that taking care of a child who is technology-dependent was not easy, but of all the things they needed to do, it was one of the most manageable aspects. This feeling was reflected by one mother who stated: "I think that physically taking care of them isn't easy, but it's probably the easi<u>est</u> out of the whole situation. The real problem is the people you have to deal with to get everything done. Every day."

Families made conscious choices about reframing their perspectives about life with a technology-dependent child member. Family decisions regarding family roles, responsibilities, activities, and even family size were influenced by family perspectives about life with technology. Many families used humor to help them cope with difficult situations. As one mother stated: "You have a choice, laugh or cry. I choose laughing. It makes me feel better." Other coping strategies frequently mentioned included focusing energy on outcomes that were attainable and trying not to worry about the entire array of alternate options, looking for the positive qualities in people or situations, and maintaining hope for the future. As one mother noted: "I guess what we try to develop and work on is to really enjoy and appreciate those times when things are going well. And hopefully that, in turn, when things aren't going well, that other people will be flexible also to help us get back on track."

Reframing also included instances of thinking about the technology-dependent child's purpose in life and why he or she had exceeded health care providers' predictions about life expectancy, as well as trying to resolve the question of "why did this happen to our family?". Often, family attempts to solve these quandaries led to changes in philosophies, religious beliefs, political views, and values related to quality of life and life itself. One mother correlated a change in her philosophy of life with her increased involvement with other families of children with special needs:

> I think, well, if I'm here for these people, maybe there will be somebody like me for my son. So it's opened up a whole bunch of different dimensions for me, and helped me see how we're pretty much all the same....It's because we're so busy trying to hide our own disabilities that we're not willing to become friends with these people that can't hide them. And they need that friendship just as much as we need their friendship.

Several parents had definite opinions about the roles of the medical profession and society as a whole in making life-and-death decisions about children with severe health and developmental problems. One family was very bitter about much of their nine year experience with childhood technology dependence. The mother in this family stated: "Society will not provide these children with individualized care. There is no family-centered care, or minimal. It's just something to be managed. And to be managed in the most efficacious financial way that you can." Her husband advocated for families to be able to make choices regarding the life or death of their children:

> If we want to go to the wall to take care of our daughter, then in my opinion we should be allowed to go to the wall. If there's another family that wants to walk out on the kid and leave him in the Pediatric Intensive Care Unit, the family should be allowed the opportunity to let the child die.

Another mother commented: "But I don't think when they save these kids that they realize the stress that they're putting on a family situation. And I guess I can understand that because in the beginning I didn't think about that aspect of it either."

Reframing involved changing the way parents viewed life in general and how families structured their lives. One way parents gained some perspective on their lives was by comparing their family to other families. Comparisons were made with other families who had a technology-dependent child member as well as with families who did not.

Parents spoke of the common stresses and experiences they shared with other families that included technology-dependent children. However, they often emphasized the areas of strength in their own families and frequently compared their child to other children who were technology-dependent, especially to children who had even greater needs. For example, parents identified factors such as: "he doesn't need all of the medical attention that some kids do", or "she doesn't get sick as often." Other parents knew technology-dependent children who had greater health problems or were more unstable than their own child, and this knowledge influenced their perceptions of family life with a technology-dependent child. The mother of a 4-year-old expressed this viewpoint as follows:

> Now it's like, we look at her and we say, well, if she didn't have CP she'd be just about perfect.

> Because, you know, her bowel movements are not pleasant but she's learning to control it and we can deal with that part now. And she's eating, she eats fine now. And her blood work is always normal, so...right now I don't see any long-term major problems with her short bowel. I mean, there might be something in the future, but right now it's her CP. I mean, she can't sit up. She can't walk or crawl, so that's our biggest issue right now. But she's pretty smart, we think.

Another mother compared her family with other families that included a child who was technology-dependent in this way:

> And perhaps the impact for our family was a little different in some regards in that we did come into this more slowly. It wasn't as though we had a child who at birth had severe problems and then all of a sudden we were thrust from what we anticipated to be a normal situation to one that included lengthy hospitalizations and equipment and all of those things. So I do think our transition into becoming a family that includes a technology-dependent child has certainly been a more gradual one...we did have a chance, we have always had a

> chance to know her prior to the equipment needs. And so we don't have a problem separating the two, as I've observed some other families have difficulty doing.

The families in this study felt they were substantively different from most other families by virtue of the inclusion of a child who was technology-dependent. In the opinion of one mother:

> We are a family in crisis, and most families that have children with special health care needs are in crisis...frequently. And that's OK, because of what's going on. Acknowledging that, yes, there are going to be crises, and sometimes you're not going to make it through the crises, and sometimes you are. And it's not always, well, fix the problems, because you can't always fix them.

Another parent talked about the differences between her child and other children: "A lot of it is frustrating, and you try and look at the bright side. You think, on the one hand she's not going to have a lot of the experiences that the other kids will, but she'll be spared some of the bad ones, too."

Finally, a parent offered this summary when asked what having a child with special needs meant to her family:

> Knowing a different kind of love, I guess. Knowing that life is not perfect and that there are special people out there that need just as much love, this is what it means to me. For my family, it probably means dealing with more stress. I guess it's for our family knowing a different kind of love, because our son is going to grow up with his sister knowing that she's handicapped, that she's different, and I think that's really neat. Because I was never exposed to any of these kids until I was in college. I never knew, and we always shied away from them. Every time I saw a child or a person in a wheelchair I always looked away. And now I never look away...I guess for my husband it means more responsibility. He knows that she will be with us for the rest of our lives.

Although families which included a technology-dependent child perceived themselves to be different from those that did not, the families in the study became accustomed to a lifestyle that accommodated the child with special needs and essentially viewed it as a "normal" life for them. Many parents were very matter-of-fact when discussing their everyday lives. As one mother commented: "I guess it's just a matter of having a routine. And having flexible child care." To which her healthy 7-year-old daughter added, "And flexible children."

Another mother described her perspective about her family's life as follows: "It's kind of like, he's been there for years so your family just molds to it. You can't think of what it was without it. And with the other children, they don't know anything other than that." Further illustration of reframing one's life with an emphasis on a changed or different definition of normalcy was provided by the parent who recalled:

> I remember when he was born, another mother with a child with Down Syndrome came to see me and she said, "You know, he's just a baby that needs his mom." And I really just accept that as all he is to me --- another child that needs a family and a home. We don't really think of his limitations and I think all the kids have been brought up around that and I don't think that anyone really thinks about it. It just is, and if anything, we really through the years have become more grateful to have this experience because it's really taught so much....I think as the years go by you really start to stop

> regretting what he <u>isn't</u> and are just grateful for what he is. And really, with his health history, we really feel fortunate that he's still here.

Without a doubt, experiences with long-term childhood technology dependence had a major impact on the philosophies and world views of the families in this study. Parents reported that their perspectives had changed over the years and could conceivably change again in the future. As the parent of a twelve-year-old son described this process:

> It kind of depends where you catch me in the cycle. Right now my life is not hindered by having my son at home. To me, I view it that it's enriched, it's better for having him here. But if you'd asked me that first five years, I could have listed innumerable hindrances to having a handicapped child, and wondering seriously whether I would survive it.

Interestingly, all parents, even those who had recounted negative or frustrating incidents during the interviews, were able to identify some positive aspects of the experience of having a child who was technology-dependent in the family. Many families felt their experiences contributed to personal growth and character-building in individual family members.

The mother of a twelve-year-old offered this perspective:

> It's been a growing experience, I guess. Again, it means something different today than it did when he was five years old. But today, I think my husband and I would both look back on it in that it's changed us considerably, it's helped make you a better person. In that you're more sensitive to people that have needs, that you're probably doing more contributing and giving back....It makes you rethink your priorities. It makes you rethink what you really believe in life...it's a time of reexamining and maybe reworking your spiritual beliefs and your beliefs about people and things and the world. I guess it's a time to just reassess and you see things from a different point of view. It changes your point of view. And so, out of all of that, I think that's good and that you become then a stronger person.

The same parent continued:

> On the flip side, it means stress, hard work, pain, sorrow, strife. It's been all those things, too. But maybe you don't have the growth without those....So it's certainly not anything you'd ask

> for, I wouldn't ask for it again. But if it happens, I guess that I'm glad that we've been able to live with it and deal with it and that we're doing as well as I perceive that we're doing.

Other parents also felt the experience of having a child with special needs made them better and stronger individuals. In addition, family experiences with long-term childhood technology dependence generally made siblings more sensitive to the feelings and needs of persons who were handicapped.

In order for parents to stabilize their family lives to the greatest extent possible, they needed to be persistent, assertive, educated, and even aggressive on occasion. They wished to be considered partners in the care of their child, and for their expertise to be respected by others. Families felt it was important for them to have as many options and as much self-determination as possible so that they would be able to make informed choices for the good of the family as a whole. Being an advocate for the child who was technology-dependent and, in many cases, other children with special needs, was important to parents as well. Finally, parents were able to reframe their experiences so that many were perceived as positive and/or growthproducing for family members. It was in these ways that families were able to manage life with a child member who was technology-dependent.

Summary of Study

The purpose of this study was to explore the experience of families which included a child member between three and twelve years of age who was technology-dependent in order to provide a deeper understanding of family experiences as they relate to the phenomenon of long-term childhood technology dependence. A qualitative approach known as interpretive interactionism was the method used in this study's exploration of the phenomenon. Kazak's (1986, 1989, 1992) systems and social-ecological model, which is a synthesis of family systems theory and Bronfenbrenner's (1979) model of the ecology of human development, was the conceptual orientation that provided a sensitizing foundation for the study.

The specific research questions addressed in this study were:

1. What does it mean to families to have a child member who is technology-dependent?

2. How do families that include a child who is technology-dependent adapt to and manage daily life with

technology?

3. What do parents perceive as factors which hinder their abilities to adapt to life with a child who is technology-dependent?

4. What do parents perceive as factors which enhance their strengths as a family?

5. How do parents with children who are technology-dependent perceive their family's relationships and interactions with members of the health care system?

A purposive sample of fifteen families which included a child who was technology-dependent was obtained through family response to an introductory letter about the study distributed by health care agencies, social service agencies, and parent support groups. The child member who was technology-dependent was between the ages of three and twelve years, had been technology-dependent and living at home for at least one year, and was medically stable at the time of the study. Sample selection continued until there was evidence of thick data description and the point of redundancy was reached.

After informed consent was obtained from adult members of the family and assent obtained from applicable child members, the researcher began the data collection process. Two methods of data collection were used in the study. Family experiences with childhood technology dependence were explored using unstructured parental interviews (see Appendix A) and participant observation in the home (see Appendix C). Sociodemographic data were also obtained from participants during the interview (see Appendix B).

Interviews were audiotaped, and observations were recorded as field notes or audiotaped in narrative form. All audiotaped materials were transcribed verbatim by the researcher into typewritten format as soon after data collection as possible. Descriptive statistics were used to describe the sample as a whole, and demographic data were incorporated in the qualitative analysis where appropriate. Transcribed interview/observation data and field notes were analyzed using the interpretive process outlined by Denzin (1989).

Four themes emerged from the interpretive interactionist data analysis: (a) Managing Daily Life with Technology, (b) Negotiating with Outside Entities, (c) Maintaining a Functioning Family, and (d) Making Sense of Life. The theme of Managing Daily Life with Technology encompassed factors such as the child's care needs, time management, and the home environment.

Although managing daily life with technology required skill, organization, and creativity, the families in the study were generally very expert in this area. Families became more knowledgeable about technology and more comfortable with their child's care needs over time.

For families with children who were technology-dependent, Negotiating with Outside Entities included relationships with health care providers, school and other education-related issues, dealing with bureaucracy, employment issues, and interactions with the community. Parents reported frequent conflict, uncertainty, and difficulties with communication in their interactions with others. As a result, the theme of Negotiating with Outside Entities was the most stressful aspect of family experiences with long-term childhood technology dependence for the families in this study.

The third theme, Maintaining a Functioning Family, involved meeting the needs of family members, finding time for the family, financial considerations, and issues related to extended family and friends. Families expressed the need to structure family life in such a way that incorporated the demands placed on it by technology but was not subsumed by them. Efforts to maintain a functioning family required family members to pay close attention to multiple, complex issues, to prioritize family needs, and to be willing and able to compromise.

The final theme of family experience with long-term childhood technology dependence was Making Sense of Life. Aspects of this theme included reconciling the past and present, changing priorities, and imagining the future. Participants struggled to find a reason for their child's disabilities and to incorporate the changes in their lives into their overall belief systems and perspectives on life. In general, families which included a technology-dependent child member attempted to accept the circumstances of their lives that could not be changed and make the best of those circumstances that could be altered.

Families felt that the potential for frequent and unexpected change, unpredictability, and limited parental control inherent in each of these major thematic areas contributed to the fragility and instability of family life with technology. The contextualization of the phenomenon of family experience with childhood technology dependence revealed that families felt as if they were "living in a house of cards." Major strategies used to increase stability were vigilance, advocacy, and reframing. Families utilized these strategies with a fair amount of success, although they realized that even these strategies could not totally mitigate the cyclic and changeable nature of family life with long-term childhood technology dependence.

Conclusions

Today, an increased number of families provide care for a child who is technology-dependent in their homes than in the past (OTA, 1987; Teague et al., 1993). The experience of family life with long-term childhood technology dependence is complex and multifaceted. This study attempted to provide insight into this phenomenon through an exploration of family experiences with long-term childhood technology dependence from the family's perspective.

Several conclusions can be inferred from the findings of this study, although the findings must be interpreted with caution due to the qualitative nature of the study and the characteristics of the sample. The sample of participants in this study consisted of parents who were willing to be interviewed and to have the researcher come into their homes. All of the families had health insurance for the child who was technology-dependent, and all could be considered middle class. Generalizability of the study findings is limited to the participants in the study, as the findings reflected an interpretation of the participants' experiences with long-term childhood technology dependence. If this study was conducted with another sample of families which contained a child member who was technology-dependent, their experiences with long-term childhood technology dependence might be different from those of the families in this study. However, certain commonalities related to the major thematic areas of concern may be found.

The first conclusion is concerned with general family adaptation to life with a technology-dependent child member. Overall, the families in this study coped remarkably well with stresses that had accumulated over the years. Parent strategies for managing life with a technology-dependent child involved being flexible, making adjustments as necessary, and doing the best you can. Parents believed they did not have a choice about having a child with complex health care needs, but they did have choices about how to deal with life and the situations they encountered.

This study supports the contention that families of children who are technology-dependent share feelings and experiences that are similar to many of those expressed by families who have children with other types of chronic health problems. For example, parental vigilance was a dominant strategy used by parents in this study in their attempts to manage life with a technology-dependent child member. Similarly, vigilance was found to be an important component in studies that examined other populations of children with chronic conditions (Miles, D'Auria, Hart, Sedlack, & Watral, 1993; Ray & Ritchie, 1993). Balancing the care needs of the child with the needs of the family and the other individuals within the family, parental advocacy, and reconceptualizing family priorities and values are other common elements of family life with childhood chronic illness, regardless of the particular diagnosis (Austin, 1991; Burke & Roberts, 1990; Christian, 1993; Diehl et al., 1991).

Families in this study, however, did not generally use normalization as a strategy for management of life with childhood chronic illness, unlike many other families affected by childhood chronic illness (Christian, 1993; Miles et al., 1993; Robinson, 1993; Scharer & Dixon, 1989). Normalization involves defining family life and the social consequences of the child's chronic condition as normal while concurrently acknowledging the presence of the chronic condition (Deatrick, Knafl, & Walsh, 1988; Knafl & Deatrick, 1986;

Krulik, 1980). The parents in this study viewed the lives of their technology-dependent children and of their families as different in many respects from those who were not affected by technology dependence. These families did not attempt to make their lives like those of the majority of "normal" families. Instead, they tried to establish environments and routines for themselves that incorporated and accommodated the complex aspects of life with a technology-dependent child member.

The major stressor reported by families in the current study was related to interacting and negotiating with entities outside the family. Physical cares and cares related to daily management of technology were not considered to be as stressful as interacting with physicians, home health care providers, school personnel, insurance representatives, and members of the community at large. This is in contrast to a study by Teague et al. (1993), in which 62% of caregivers cited the physical demands of providing care as the most difficult aspect of the situation of caring for a technology-dependent child at home. As a related issue, parents had multiple concerns about the bureaucracy associated with caring for a child who is technology-dependent. Interpretation of the stressful nature of negotiating with outside entities in the context of the systems and social-ecological model (Kazak, 1986, 1989, 1992), which was the sensitizing framework for this study, suggests that microsystem issues were less problematic for these families than issues involving the systems more peripheral to the family, most notably the mesosystem.

Next, financial considerations were not a major stressor for the families in this study, unlike reports elsewhere in the literature (Fleming et al., 1994; Wegener & Aday, 1989; Youngblut, Brennan, & Swegart, 1994). There were two or three families that expressed concern about finances, but their concerns were related to overall financial constraints and not just the financial impact of having a child who was technology-dependent in the home. Perhaps because the families in this study were middle class and had been providing care at home for a range of two to nine years, they were more aware of financial resources or had developed better financial planning skills than families who had begun caring for technology-dependent children more recently or had greater financial stressors. Although home care is a viable alternative even for families who have significant financial constraints, these families may need more intensive support, information, and resources to be successful.

Another conclusion involves the fact that the technology-dependent children in this study had all survived longer than had been predicted by health care providers. Parents attributed their children's survival to the home environment, the involvement of family, and meticulous attention to the child's physical needs, technology needs, and medical treatments. This remains an area that is largely unexplored in the literature, although there is some evidence that technology-dependent children who have greater family involvement, increased access to normal developmental experiences, and are in a home environment have improved psychological outcomes (Hamlett, Walker, Evans, & Weise, 1994). However, families need to be valued and respected for the contributions they make to the quality and length of life achieved by their children who are technology-dependent.

Yet another conclusion of this study is that health care providers have an enormous influence on families. Parents recalled specific instances where physicians, nurses, or other health care providers had provided support or discouragement for families in great detail, even when the incident had occurred years ago. Home health care providers, in particular, impacted on the family's ability to successfully manage life with a technology-dependent member. Quality parent-professional relationships in the home setting were considered to be essential by the parents in this study, and this view is supported by the results of other research with families affected by childhood chronic illness as well (Patterson, Jernell, Leonard, & Titus, 1994; Sherman, 1995).

This study supports the conclusion reached by other researchers (Smith, Layne, & Garell, 1994; Wegener & Aday, 1989) that someone other than a parent needs to be well-versed in the history, health problems, and needs of the individual technology-dependent child. Health care providers expect parents to serve as the care coordinators for their child; however, some families do not have the time, the inclination, or the ability to perform in this capacity. Even if a parent is identified as the best person to coordinate services and provide care management, someone else should have the same degree of knowledge and ability to serve as a backup resource.

An additional conclusion of this study is that the cyclic nature of caring for a child who is technology-dependent must be realized. It is important to assist families to identify areas they feel are most crucial for them to achieve the type of family life they desire, and for families and care providers to recognize that these needs will change as the family changes, as the child grows older, or as the child's health status changes. The components of caregiving and/or the situational factors influencing family activities may vary over time (Ray & Ritchie, 1993). Thus, families may have increased needs for support, care management, or respite at particular points in the trajectory of family life with technology dependence.

The final conclusion reached in the study is that having a child member who was technology-dependent in one's family significantly changed individual family members as well as the family as a whole. In Denzin's (1989) words, this was a major epiphany, an experience that is transformational and makes one's life never the same again. The experience of epiphany was especially true for the parents in the study. This phenomenon is similar to the theory of transformed parenting suggested by Seideman and Kleine (1995) in their study of parents of children with developmental delay/mental retardation.

The conclusions reached in this study raise several significant issues that should be addressed by the health care system in an attempt to improve the quality of family experiences with long-term childhood technology dependence, and indeed, the quality of family experiences with childhood chronic illness in general. In the final section of this chapter, recommendations are presented to assist nursing in resolving these issues.

Recommendations

The findings and conclusions of this study support several recommendations regarding nursing research, nursing education, and nursing practice related to families which include a child member who is technology-dependent. These recommendations are presented in the following section, as are implications for family policy.

Recommendations for Nursing Research

Based on the findings of this study, the following recommendations for nursing research are made:

1. A similar study using a sample of single-parent families should be done in order to further explore these families' experiences with long-term childhood technology dependence. There were two single-parent families in the current study, and although their experiences were similar to those of two-parent families in many respects, issues related to finances, employment, and support would merit additional investigation.

2. The current study consisted entirely of European-American parents, and all of the children who

were technology-dependent were European-American with the exception of one African-American child who was in the process of being adopted. Little research has been conducted which explores the needs of ethnic minority families which contain a child member who is technology-dependent. Therefore, families who are African-American, Hispanic, Asian, and Native American should be interviewed to provide a deeper understanding of their experiences with long-term childhood technology dependence and to provide insight into culturally appropriate health care services for these families.

3. A further exploration of the phenomenon of long-term childhood technology dependence from the perspective of the home health nurses who work with children who are technology-dependent and their families would be helpful in attaining an alternative perspective on the theme of negotiating with outside entities, which the families in the current study described as the most problematic area of their experience.

4. Research with families that contain adolescent children who are technology-dependent is essential. Parents of several of the older children in this study mentioned the need to begin thinking about developmental issues of adolescence such as pubertal changes,

sexuality, peer relationships, and independence. Past research has not addressed the specific needs and strategies used by families of adolescent children who are technology-dependent.

5. A study could be done with siblings to gain their perspective of family life with a brother or sister who is technology-dependent.

6. Parents in this study identified managing the technological aspects of their child's care as generally the easiest aspect of family life with a child who is technology-dependent. Longitudinal studies to ascertain factors involved in the process of becoming comfortable with technology and how long it takes for parents to achieve this level of comfort should be undertaken.

7. Continued exploration of the cyclic nature of family experiences with long-term childhood technology dependence and other chronic conditions, as well as the factors which increase or decrease the stability of family life, would be worthy of further investigation.

8. The perceptions of families who have chosen not to provide home care for their children who are technology-dependent should be explored in an effort to illuminate their experiences as well as to gain insight into possible differences between those families and

families who care for children who are technology-dependent at home.

9. There were multiple similarities between families which included child members who were technology-dependent and families which included child members with other types of chronic conditions. Continued research to explicate the similarities and differences among families affected by childhood chronic illness is recommended. In particular, further exploration of the concept of normalization as it is experienced in families with technology-dependent children is warranted.

Recommendations for Nursing Education

Based on the findings of this study, the following suggestions are made for nursing education:

1. Nursing programs, especially programs that prepare advanced practice nurses, should include increased content related to the management of children with complex yet stable chronic conditions, including the population of children who are technology-dependent.

2. Home health nursing services and other health care services must be acceptable to clients. In order for this to occur, health providers must be more attuned to the needs and the cultural backgrounds of the clients

they serve. Nurses should be educated on the concepts of family-centered care and home health care as well as on the importance of providing care which focuses on the individual needs and concerns of families with a child member who is technology-dependent.

3. Nurse educators should provide nursing students with opportunities to obtain theoretical knowledge of children who are technology-dependent and clinical experiences with technology-dependent children and their families in multiple settings (e.g., hospital, clinics, and home) so that they can better understand the implications of long-term childhood technology dependence and its impact on family life.

Recommendations for Nursing Practice

Based on the study findings, the following recommendations for nursing practice are made:

1. Many families wished that there was a professional who shared their knowledge of their child and could provide service coordination to help them negotiate the various systems and circumvent some of the repetition and bureaucracy. Advanced practice nurses who specialize in the care of children with special health and developmental needs would be qualified and capable in this type of position (Consensus Committee, 1994). In

addition to performing competent physical assessments, advanced practice nurses are educated to focus on psychosocial support, counseling, anticipatory guidance and child and family education.

2. Nurses need to examine their personal values and philosophy of care in order to interact most effectively with families and children in the client's home. Nurses need to understand that they are partners with the family and must be sensitive to the implications of providing care to the child who is technology-dependent in the home setting. Nurses must be cognizant of the family's needs as well as those of the child.

3. Nurses should actively develop, support, promote, and implement health policy that will provide comprehensive, developmentally appropriate, and family-centered care for children who are technology-dependent and their families. Nurses should become politically active and support the passage of legislation on the state and national level that will ensure that the needs of children who are technology-dependent and their families will be met.

4. Nurses need to become more comfortable with interdisciplinary collaboration. A multidisciplinary approach is essential in providing optimal care for

children who are technology-dependent. Nurses need to increase their knowledge of the skills of other disciplines, be able to clearly articulate and implement their own unique skills, and engage in care that has as its goal the best interests of the technology-dependent child and his or her family.

Implications for Family Policy

Based on the findings of this study, the following recommendations for family policy-makers are made:

1. The parents in this study had multiple concerns about the bureaucracy they encountered in trying to manage life with a technology-dependent child member. Simplification of the entire care system would be helpful in order to reduce the amount of paperwork, the delays and miscommunications associated with bureaucracy, and the multitude of agencies and programs involved with children who are technology-dependent and their families.

2. Families must be respected and supported in their efforts to negotiate with various systems and to advocate for their children who are technology-dependent. The principles of family-centered care must be considered the foundation upon which family policies are constructed and implemented. Continued efforts and increased emphasis must be placed on preparing family advocates who

can teach families how to access community services and how to negotiate with the multiple bureaucracies with whom they interface, including the health care system, the school system, the insurance industry, and the government.

3. The potential impact of family and health care policies on families which include a technology-dependent child member must be considered. Changes in Medicaid reimbursement, welfare criteria, school inclusion policies, funding for community-based resource programs, and family leave policy are examples of issues that may have a profound effect on these families, and their perspectives must be included in the debate.

Summary

In recent years, more and more children are surviving with significant needs for and dependence on technological devices. Families can and do provide competent, safe care for their child members who are technology-dependent, but the psychosocial burden on families remains significant. It is time for health care providers, especially nurses, to examine the quality of services being provided to this population. In this study, the researcher attempted to illuminate some of the complex issues experienced by families who are living with a child who is technology-dependent. It is hoped that increased knowledge of this phenomenon will enable families and the health care providers who interact with them to better understand the effects of technology on family life, will aid nurses in planning and implementing more effective and holistic care for these families, and will serve as an impetus for additional research with families that contain a child member who is technology-dependent.

APPENDIX A

INTERVIEW GUIDE

Grand Tour Question:

How would you describe what having a child who is technology-dependent child in your family means to you? To your family as a whole?

Additional probes will be used to elicit information pertinent to the research questions if needed. Examples of these questions follow:

1. Tell me about a typical day in your family.
2. How has your family life changed over the time that your child has been at home? What was it like before your child became technology-dependent?
3. What sorts of things interfere with your family's ability to adapt to having a child who is technology-dependent? What makes it difficult for you to have the kind of family life you want?
4. What sorts of things help your family in living with a child who is technology-dependent? What do you see as your family's strengths?
5. Tell me about your family's relationships and experiences with your child's health care providers.

APPENDIX B

DEMOGRAPHIC DATA

1. Family members (name, age, gender, relationship to technology-dependent child, ethnic background, health status, marital status, living in the home?)
2. Information about technology-dependent child (age, gender, type of chronic condition(s), prognosis, technological devices and daily cares needed, length of time technology-dependent, length of time cared for at home since technology-dependent, changes in health status over time, source of medical care, education)
3. Parental education, occupations, employment outside of home
4. Type of insurance/reimbursement mechanisms utilized by family
5. Number of nursing care hours per week, types of nursing care providers if applicable (RN, LPN, etc.), availability and use of respite care

APPENDIX C

GUIDE TO PARTICIPANT OBSERVATION

The focus of the participant observation portion of this study was family adaptation to technology and the impact of technology on family members' activities of daily living. Data were collected using the following categories as an initial guide:

1. **Space**: the physical environment of the home, with particular attention to modifications that have been made to accommodate the child who is technology-dependent;
2. **Actors**: the people involved in interactions with the child who is technology-dependent or who are engaged in activities related to the technology (e.g., cleaning equipment, conversing with health care providers);
3. **Objects**: the physical things present in the setting that are pertinent to living with technology (e.g., technological devices, extra equipment);
4. **Acts, Activities, and Events**: interactions between the child who is technology-dependent and other family members, including conversations, play, and routine treatments/cares; observations of usual activities of daily life that may be affected by

technology such as meals, leisure activities, and family member roles and responsibilities;

5. **Time**: the sequencing that takes place over time; the amount of time spent in acts, activities, and events related to technology;
6. **Goal**: the things people are trying to accomplish as a result of their acts, activities, and events;
7. **Feelings**: the emotions expressed by the individuals being observed, especially those related to living with technology.

APPENDIX D

FAMILY DEMOGRAPHIC CHARACTERISTICS

Family A: Blended family, residing in urban/suburban area, step-father unemployed, mother employed full-time (FT); technology-dependent child member male, age 7, 3rd of 4 children, has cerebral brain atrophy, tracheostomy, and gastrostomy; other children in family healthy.

Family B: Nuclear family, residing in small town, father employed FT, mother at home; technology-dependent child member female, age 4, one of triplets and has one older sibling, has cerebral palsy (CP), gastrostomy, and has received total parenteral nutrition (TPN); other children in family healthy.

Family C: Nuclear family, residing in rural area, father employed FT, mother employed FT; technology-dependent child member male, age 3, 2nd of 2 children, has neurological disorder of unknown etiology, gastrostomy; other child in family healthy.

Family D: Single-parent (divorced) family, residing in urban/suburban area, mother employed part-time (PT); technology-dependent child member male, age 12.5, 2nd of 4 children, has progressive leukodystrophy, gastrostomy; oldest child has attention deficit disorder (ADD), youngest child has partial Trisomy 18.

Family E: Nuclear family, residing in urban/suburban area, father employed FT, mother employed PT; technology-dependent child members twin males, age 6, 2nd and 3rd of 4 children, both have complications of prematurity, gastrostomy, tracheostomy; other children in family have speech and discipline problems.

Family F: Nuclear family (parents in process of divorce), residing in urban/suburban area, father employed FT, mother employed PT; technology-dependent child member female, age 5, 2nd of 3 children, has complications of birth asphyxia & CP, gastrostomy, oxygen dependence; other children in family healthy.

Family G: Nuclear family, residing in small town, father employed FT, mother employed PT; technology-dependent child member male, age 8, 4th of 4 children, has spina bifida, tracheostomy, gastrostomy, oxygen dependence; oldest child has obsessive-compulsive disorder, other 2 children have ADD.

Family H: Nuclear family, residing in urban/suburban area, father employed FT, mother employed PT; technology-dependent child member male, age 9.5, one of twins and has two younger siblings, has residual effects of meningitis, gastrostomy; other children in family, including twin, healthy.

Family I: Nuclear family, residing in small town, father employed FT, mother at home; technology-dependent child member male, age 12, oldest of 4 children, has complications of birth asphyxia, gastrostomy; other children in family healthy.

Family J: Nuclear family, residing in small town, father employed FT, mother employed PT; technology-dependent child member female, age 4.5, 1st of 2 children, has complications of prematurity, gastrostomy; other child in family healthy.

Family K: Nuclear family, residing in urban/suburban area, father employed FT, mother at home; technology-dependent child member male, age 10, 3rd of 5 children, has Down syndrome, diabetes, tracheostomy, gastrostomy, oxygen dependence; other children in family healthy.

Family L: Adoptive, two-parent family, residing in urban/suburban area, father employed FT, mother at home; technology-dependent child female, age 11, 4th of 4 children, has spina bifida, tracheostomy, gastrostomy, oxygen dependence, is on ventilator; other children in family healthy.

Family M: Nuclear family, residing in small town, father employed FT, mother employed FT; technology-dependent child member female, age 12, 3rd of 4 children, has residual effects of near-drowning, gastrostomy, oxygen dependence; other children in family healthy.

Family N: Nuclear family, residing in rural area, father employed FT, mother employed PT; technology-dependent child member female, age 7, 1st of 2 children, has complications of prematurity, tracheostomy, gastrostomy, oxygen dependence, is on ventilator; other child in family healthy.

Family O: Single-parent, adoptive family, residing in urban/suburban area, mother employed FT; technology-dependent child member male, age 3, only child, has complications of prematurity and maternal substance abuse, gastrostomy, TPN.

APPENDIX E

INTRODUCTORY LETTER

Dear Parent,

My name is Maureen O'Brien, and I am a pediatric nurse with a special interest in children who are technology-dependent and their families. I am currently a doctoral student in parent-child nursing at The University of Texas at Austin School of Nursing. My dissertation is a study of how families adapt to and manage long-term childhood technology dependence at home.

I would like to invite you to participate in this study. By doing so, you will have the opportunity to help other families meet the challenges of family life with a child who is technology-dependent. Your family's participation in this study will also be helpful in providing nurses and other health professionals with a better understanding of the actual experiences of families who care for a child who is technology-dependent at home.

Your participation in the study would involve an audiotape-recorded interview and an observation of your family during a portion of a "typical" day. The interview and observation will take place at a mutually agreed upon date, time, and location. If you decide to participate, your responses will remain confidential. Furthermore, you have the right to withdraw from the study at any time without penalty.

Responding to this letter does not imply consent to participation in the study. If you are interested in participating or would like further information about the study, please complete and mail the attached postcard or call me at [redacted]. I welcome your interest in this study and look forward to your response. Thank you for your time in considering your family's participation in this study.

Sincerely,
Maureen E. O'Brien, M.S.N., R.N.

Addressed Stamped Postcard

CHILDHOOD TECHNOLOGY DEPENDENCE STUDY

I WOULD LIKE TO BE PROVIDED WITH MORE INFORMATION ABOUT THIS STUDY. MY NAME IS ______________________________

AND YOU MAY CONTACT ME AT THE FOLLOWING TELEPHONE NUMBER: _____________. BEST TIME TO CALL: _________________.

APPENDIX F

CONSENT FORMS

PARENT CONSENT FORM

Title of Study: Family Adaptation to Long-term Childhood Technology Dependence

You are invited to participate in a study of family adaptation to and management of childhood technology dependence. I am a doctoral candidate at The University of Texas at Austin School of Nursing. Through this study, which is my doctoral dissertation, I hope to learn more about the experiences of families who are caring for a child who is technology-dependent at home. You were selected as a possible participant in this study because you are the parent of a child aged 3-12 who is technology-dependent and living at home, and would provide valuable insight regarding family life with childhood technology dependence. Your family will be one of approximately 15 families chosen to participate in this study.

Participation in this study will involve an audiotape-recorded interview session and an observation of a typical day in your family's life. The interview will concern your family life and your family's experience with having a child member who is technology-dependent. Some demographic information about your family will also be asked at the beginning of the interview. The interview will be scheduled at a date, time, and place of your choice. The interview will last approximately 2 hours and will be audiotaped. The tapes will be coded so that no identifying information is on the cassette tape and they will be kept in a locked file cabinet and will only be heard by the investigator. The tapes will be transcribed using only the code numbers. No names or personally identifying information will appear on the transcriptions.

In addition to the audiotape-recorded interview, you will be requested to allow the investigator to observe a portion of a typical day in your family. During this observation, the investigator will not interfere with or interrupt your usual activities. Written or audiotaped field notes will be made by the investigator during this observation period, which is anticipated to be approximately 4-6 hours in length. The observation information will also be coded with a number so that no names or personally identifying information will appear on the field notes or transcriptions. Records of completed observations will be kept in a secure locked file cabinet and will only be seen by the investigator.

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission. All information will remain unidentifiable within any published or unpublished papers or presentations. Confidentiality of participants will be protected by using coded audiotape cassettes, coded transcripts, and coded observation field notes. Privacy during the interviews will be maintained by conducting the interview in a place you select. All audiotapes will be erased upon completion of the study.

Parents who participate in this study may benefit from sharing their experiences about coping with their child's technology dependence by discussing strategies for managing the child's care, sharing feelings about family life experiences, and discussing issues related to the health care system, financial concerns, or community resources. Nurses and other health care professionals may benefit through a deeper understanding of the family's experience of life with a child who is technology-dependent.

There are no anticipated risks or discomforts to you or your family from participation in this study other than the inconvenience of time. The investigator is an experienced pediatric nurse with clinical expertise in caring for families and children with complex health problems, including home nursing care for children who are technology-dependent. If you experience discomfort during the study, the investigator will be able to discuss your discomfort and provide information and referral as appropriate. If families request assistance with home management of their child, the investigator will be able to refer parents to appropriate community resources. There is no cost to subjects for participation in this program and no compensation will be made to individuals participating in this study.

Your decision whether or not to participate in this study will not affect your future relations with The University of Texas or your child's health care providers. If you decide to participate, you are free to discontinue participation at any time without repercussions. You will have the opportunity to ask the investigator any questions about the study at any time during the study. You may decline to answer any particular questions during the interview or may decline to participate in the observation phase of the study.

If you have any questions, please ask us. If you have any additional questions later, the chair of my dissertation committee, Alexa Stuifbergen, Ph.D., R.N., or I will be happy to answer them. You may contact:

Alexa Stuifbergen, Ph.D., R.N.
The University of Texas at Austin School of Nursing
[redacted]

OR:

Maureen E. O'Brien, M.S.N., R.N.
[redacted]

At the conclusion of this study, a summary of the results will be mailed to all participants. Thank you for your interest in this study. Your family's time and participation are appreciated.

You will be offered a copy of this form to keep.

You are making a decision whether or not to participate. Your signature indicates that you have read the information provided above and have decided to participate. You may withdraw at any time without penalty after signing this form, should you choose to discontinue participation in this study.

______________________________ _____________
Signature of Participant Date

______________________________ _____________
Signature of Investigator Date

OBSERVATION CONSENT FORM: ADULT

Title of Study: Family Adaptation to Long-term Childhood
Technology Dependence

You are invited to participate in a study of family adaptation to and management of childhood technology dependence. I am a doctoral candidate at The University of Texas at Austin School of Nursing. Through this study, which is my doctoral dissertation, I hope to learn more about the experiences of families who are caring for a child who is technology-dependent at home. You were selected as a possible participant in this study because you are a family member, caregiver, or trained health care provider of a child aged 3-12 who is technology-dependent and living at home, and would provide valuable insight regarding family life with childhood technology dependence. This family will be one of approximately 15 families chosen to participate in this study.

If you decide to participate in this study, you will be requested to allow the investigator to observe you during a portion of a typical day in this family. During this observation, the investigator will not interfere with or interrupt your usual activities. Written or audiotaped field notes will be made by the investigator during this observation period, which is anticipated to be approximately 4-6 hours in length. The observation information will also be coded with a number so that no names or personally identifying information will appear on the field notes or transcriptions. Records of completed observations will be kept in a secure locked file cabinet and will only be seen by the investigator.

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission. All information will remain unidentifiable within any published or unpublished papers or presentations. Confidentiality of participants will be protected by using coded audiotape cassettes, coded transcripts, and coded observation field notes. All audiotapes will be erased upon completion of the study.

Persons who participate in this study may benefit from sharing their experiences regarding childhood technology dependence. Nurses and other health care professionals may benefit through a deeper understanding of the family's experience of life with a child who is technology-dependent.

There are no anticipated risks or discomforts to you from participation in this study other than the inconvenience of time. The investigator is an experienced pediatric nurse with clinical expertise in caring for families and children with complex health problems, including home nursing care for children who are technology-dependent. If you experience discomfort during the observation, the investigator will be able to discuss your discomfort and provide information and referral as appropriate. There is no cost to subjects for participation in this program and no compensation will be made to individuals participating in this study.

Your decision whether or not to participate in this study will not affect your future relations with The University of Texas, your employer, or the child's health care providers. If you decide to participate, you are free to discontinue participation at any time without repercussions. You will have the opportunity to ask the investigator any questions about the study at any time during the study. You may decline to participate in any particular aspect of the observation phase of the study.

If you have any questions, please ask us. If you have any additional questions later, the chair of my dissertation committee, Alexa Stuifbergen, Ph.D., R.N., or I will be happy to answer them.

You may contact:

Alexa Stuifbergen, Ph.D., R.N.
The University of Texas at Austin School of Nursing
[redacted]
[redacted] [redacted]:
Maureen E. O'Brien, M.S.N., R.N.
[redacted]

At the conclusion of this study, a summary of the results will be mailed to all participants. Thank you for your interest in this study. Your time and participation are appreciated.

You will be offered a copy of this form to keep.

You are making a decision whether or not to participate. Your signature indicates that you have read the information provided above and have decided to participate. You may withdraw at any time without penalty after signing this form, should you choose to discontinue participation in this study.

______________________________ ____________
Signature of Participant Date

______________________________ ____________
Signature of Investigator Date

OBSERVATION CONSENT FORM: MINOR CHILD

Title of Study: Family Adaptation to Long-term Childhood Technology Dependence

Your child is invited to participate in a study of family adaptation to and management of childhood technology dependence. I am a doctoral candidate at The University of Texas at Austin School of Nursing. Through this study, which is my doctoral dissertation, I hope to learn more about the experiences of families who are caring for a child who is technology-dependent at home. Your child was selected as a possible participant in this study because he or she is a child aged 3-12 who is technology-dependent and living at home, or is a sibling of such a child, and would provide the investigator with valuable insight regarding family life with childhood technology dependence. Your family will be one of approximately 15 families chosen to participate in this study.

If you decide to allow your minor child to participate in this study, the child will be asked to allow the investigator to observe him or her during a portion of a typical day in your family. During this observation, the investigator will not interfere with or interrupt your child's usual activities. Written or audiotaped field notes will be made by the investigator during the observation period, which is anticipated to be approximately 4-6 hours in length. The observation information will also be coded with a number so that no names or personally identifying information will appear on the field notes or transcriptions. Records of completed observations will be kept in a secure locked file cabinet and will only be seen by the investigator.

Any information that is obtained in connection with this study and that can be identified with your child will remain confidential and will be disclosed only with your permission. All information will remain unidentifiable within any published or unpublished papers or presentations. Confidentiality of participants will be protected by using coded audiotape cassettes, coded transcripts, and coded observation field notes. All audiotapes will be erased upon completion of the study.

Persons who participate in this study may benefit from sharing their experiences regarding childhood technology dependence. Nurses and other health care professionals may benefit through a deeper understanding of the family's experience of life with a child who is technology-dependent.

There are no anticipated risks or discomforts to your child from participation in this study other than the inconvenience of time. The investigator is an experienced pediatric nurse with clinical expertise in caring for families and children with complex health problems, including home nursing care for children who are technology-dependent. If your child experiences discomfort during the observation, the investigator will be able to discuss your child's discomfort and provide information and referral as appropriate. There is no cost to subjects for participation in this program and no compensation will be made to individuals participating in this study.

If you allow your minor child to participate in this study, you are free to discontinue his or her participation at any time without penalty. You and/or your child will have the opportunity to ask the investigator any questions about the study at any time during the study. You may decline to have your child participate in any particular aspect of the observation.

If you have any questions, please ask us. If you have any additional questions later, the chair of my dissertation committee, Alexa Stuifbergen, Ph.D., R.N., or I will be happy to answer them. You may contact:

Alexa Stuifbergen, Ph.D., R.N.
The University of Texas at Austin School of Nursing
[redacted]
OR: Maureen E. O'Brien, M.S.N., R.N.
[redacted]
[redacted]

At the conclusion of this study, a summary of the results will be mailed to all participants. Thank you for your interest in this study. Your time and participation are appreciated.

You will be offered a copy of this form to keep.

You are making a decision whether or not to allow your minor child to participate. Your signature indicates that you have read the information provided above and have decided to allow your child to participate. You can choose to discontinue your child's participation in the study at any time without repercussions in your present or future relations with the University of Texas or your child's health care providers after signing this form.

______________________________ ____________
Signature of Parent/Legal Guardian Date

______________________________ ____________
Signature of Investigator Date

CHILD ASSENT FORM

Title of Study: Family Adaptation to Long-term Childhood Technology Dependence

I agree to participate in a study that is interested in the everyday lives of children who are technology-dependent and living at home. I understand that this study has been explained to my mother/father/guardian and that she or he has given their permission for me to participate. I understand that I may decide at any time that I do not wish to continue this study and that it will be stopped if I say so.

I understand that I will be watched by the investigator, Maureen O'Brien, during part of a typical day in my family. I understand that I will do the things that I usually do during this time and that I will not be interrupted. I also understand that nothing bad or wrong will happen to me if I decide to stop my participation in this study at any time.

When I sign my name to this page I am indicating that this page was read to me and that I am agreeing to participate in this study. I am indicating that I understand what will be required of me and that I may choose to stop my participation at any time.

Child's Signature	Date
Signature of Investigator	Date

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