

**DECIDING WHAT'S BEST FOR MY CHILD: FACTORS THAT INFLUENCE
PARENTS' DECISIONS ABOUT THE CARE OF
TECHNOLOGY-DEPENDENT CHILDREN AT HOME**

by

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Abstract

Over the past decade there has been an increase in the population of children who are technology-dependent and living at home. This has created new roles for parents who learn all aspects of their child's care, including procedures that have traditionally been within the professional's domain. In the process of caring for their child, parents make many decisions related to that care. The factors that influence parental decisions are likely different from those that influence nurses' decisions. Differences between parents and nurses regarding what is the "best care" for a child can result in conflict between them.

The purpose of this study was to explore and describe the factors that parents perceived as influencing their decisions regarding the care of their technology-dependent child at home. A secondary analysis was performed on data that had been collected for a phenomenological study which explored the role of the nurse in the home care of children with complex health care needs. Transcripts from interviews with ten parents were analyzed, using an interpretivist paradigm and a symbolic interactionism perspective.

Findings revealed that parental readiness for decision-making varied. When parents were first at home they appreciated assistance from nurses to help set up care routines. However, over time, all parents wished to be the decision-maker regarding their child's care. If nurses did not consult parents regarding decisions about their child's care, it created stress for parents or conflict with the nurses.

When making decisions parents considered factors related to their child's medical condition or care needs, as well as their child's developmental stage. Parents also considered factors related to themselves, such as their previous experience, their underlying values, other family responsibilities, or

their level of fatigue or stress. Finally, parents considered factors related to the environment, such as the parent-nurse relationship, the availability and type of supports, and the physical aspects of the home. Seldom did they consider one factor in isolation from others. Rather, a complex web of factors underlay most decisions, and individual factors influenced the resulting decision in various directions.

Three key ideas from the findings are discussed in relation to the existing theoretical and research literature. As well, implications for nursing practice, education, research and program planning are presented.

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Dedication

To Keith and Janet, who help me keep
in perspective what is truly important in life--
relationships with those we love.

Chapter 1: Introduction to the Study

Background to the Problem

Over the past decade several factors have contributed to an increasing population of children who are technology-dependent and living at home. First, advances in medical therapies have resulted in children surviving who, 10 or 15 years ago, would have died. However, many of these children require technologically complex care for long periods of time (Kohrman, 1991; Office of Technology Assessment, 1987; Wong, 1991). Second, medical devices that are usually associated with acute care settings have been adapted or developed for home use, making it possible to care for children with technologically complex needs at home (Bigler, 1990; Foster, 1989; Punch, 1985; Weinstein, 1993). Third, concern about the emotional and psychological impact of long-term hospitalization on a child has contributed to the trend to care for children in their own homes (Feetham, 1986; Kaufman & Hardy-Ribakow, 1987; Wong, 1991). Finally, rising health care costs have led policy makers to look at alternatives to providing care in expensive acute care settings. Several studies have demonstrated the cost-savings associated with home care (Jayabose et al., 1991; Kohrman, 1991).

The increase in the number of families dealing with the complex care of their children at home has created new roles and responsibilities for parents. Parents learn all aspects of their child's care, including technical procedures and emergency care that have traditionally been within the health professional's domain. As well, parents often become the overall coordinators of their child's care at home, organizing the delivery of medical supplies, ensuring that preventive maintenance of equipment is performed, scheduling caregivers for their child, and monitoring the quality of care

provided by others (Cender, 1995; Haas, Gray, & McConnell, 1992; Kaufman & Hardy-Ribakow, 1987; Roemer, 1992).

Because of the specialized and complex care technology-dependent children require, nurses are often hired as caregivers in the home (Roemer, 1992; Scannell, Gillies, Biordi, & Child, 1993; Sherman, 1995). Although the primary purpose for in-home nursing is to provide direct care for a child, thus temporarily relieving the parents of that responsibility, nurses usually function beyond this role. Nurses may monitor a child's overall condition, support parents regarding their child's care, assess the layout and storage of equipment and supplies, and assess emergency preparedness (Canam, Cunada & Bassingthwaighte, 1994; Roemer, 1992).

The few studies that have explored the family's experience of caring for a technology-dependent child at home have invariably identified the family-professional relationship as a major component of the experience (Canam et al., 1994; Cender, 1995; Patterson, Jernell, Leonard & Titus, 1994; Patterson, Leonard & Titus, 1992; Scharer & Dixon, 1989; Thomas, 1986; Youngblut, Brennan & Swegart, 1994). The type of family-professional relationship that parents identify as most positive can be described as collaborative, that is, a relationship in which parents interact with professionals in a manner that respects the knowledge and special expertise of both parties. Parents wish to have their points of view taken into account, and either share decision-making with professionals (Patterson et al., 1994; Thomas, 1986) or be the primary decision-maker (Cender, 1995) regarding the care of their child.

This desire of parents to take a more active role in decision-making is occurring within a health care system that has traditionally viewed the health professional as the decision-maker regarding medical or nursing care. When parents make these decisions they may be based on assumptions, values and

beliefs that are inherently different from those of professionals. Further, although certain assumptions may underlie parental decisions and the resulting behavior, they are generally unspoken, and may even be unrecognized. Professionals, likewise, operate from unspoken, and perhaps unrecognized, assumptions, values and beliefs (Thomas, 1986).

When nurses care for technology-dependent children in the home they are on the parents' "turf", and issues often arise about who should be responsible for decisions around the child's care (Patterson, et al., 1994). If nurses are operating from one set of assumptions, and parents from another, the decisions they make regarding what is the "best care" for the child will likely be different. If the reasons underlying the decisions are not understood, disagreement and conflict can result (Klug, 1993).

It is therefore important for nurses to understand factors that parents perceive as influencing parental decisions regarding their child's care. Nurses will then be able to interact with parents in a manner that respects parental decisions regarding the care of their child, and yet offer support, when necessary, for parents to make decisions.

Purpose of the Study

The purpose of this study is to explore and describe factors that parents perceive as influencing decisions they make regarding the care of their child who is technology-dependent and living at home. This will be done by performing a secondary analysis of qualitative data that were originally collected for a study which explored the role of the nurse in caring for children with complex health care needs at home (Canam, et al., 1994). Symbolic interactionism will provide a perspective for the literature review and analysis of data.

In the following chapter a review of literature that is relevant to this study is presented. Chapter Three focuses on the research method, and includes a description of the data from the primary study, as well as the method of analysis used in this secondary study. In the fourth chapter the findings are presented, and in the fifth chapter key ideas from those findings are discussed in relation to the existing theoretical and research literature. In the final chapter a summary of the study, conclusions, and implications of the findings for nursing practice, education, research, and program planning are presented.

Chapter 2: Review of the Literature

Introduction

Because the population of children who are technology-dependent and living at home is relatively new, little research was found that specifically addressed this population and, in particular, parental decision-making related to the care of these children. However, three main bodies of literature have relevance for this study, and will provide a foundation for understanding the context within which parental decisions are made.

First, because parents who care for their technology-dependent children at home interact with health professionals on a regular and frequent basis, and these interactions help form the meanings that they attach to their situation, literature regarding the parent-nurse relationship will be reviewed. Historical influences on the parent-professional relationship, as well as the current situation, will be examined. Second, the few studies that have explored the experience of families with a child who is technology-dependent will be reviewed, focusing on decisions and decision-making around the child's care. The review will conclude with literature that explores decisions regarding children's health and illness care.

Literature Review

The Parent-Nurse Relationship

Historical influences. In 1769 the physician, Dr. George Armstrong, believed that children should not be admitted to hospitals because "the mothers and the nurses would be constantly at variance with each other" (cited in Darbyshire, 1993, p. 1671). However, views about admitting children to hospitals changed and, certainly by the mid-twentieth century, hospital care

for ill children was seen as superior to that that could be provided in the home by family members. This was due, in part, to increasing technology and drug therapy, as well as the notion of the professional as "expert" in the area of child care (Dixon, 1995). In fact, during the 1940's and 1950's parents were expected to leave their ill children at the hospital, returning to pick them up at the time of discharge, with only infrequent visiting in between (Johnson, 1990). Even as late as the 1960's visiting by parents was often restricted to a few hours per week (Dixon, 1995).

An awareness of the impact of parent-child separation began with the classic works of Bowlby (1953) and Robertson (1953). In 1965, the Association for the Care of Children in Hospitals was founded. This organization, made up of professionals from a variety of disciplines, focused on the psychosocial needs of children and families during hospitalization, and advocated for changes that would increase parents' involvement with their hospitalized children (Johnson, 1990).¹ In particular, the Association introduced the philosophy of "family-centered care" to health care professionals, delineating core elements and suggesting strategies to incorporate the philosophy into pediatric health care facilities. Family-centered care is defined as "care that acknowledges and respects the pivotal role that families play in the care of their children" (Johnson, 1990, p. 236).

Over the past 25 to 30 years the philosophy of "family-centered care" has been increasingly adopted by pediatric facilities, thus encouraging parental participation in children's care (Darbyshire, 1993), as well as decisions around that care. Often these changes have occurred without supports for nurses that would enable them to incorporate the philosophy into existing systems and

¹ The name has since been changed to the "Association for the Care of Children's Health" and parents, as well as professionals, are active members.

practices. As a result, increasing parental participation has sometimes led to the blurring of roles between nurses and parents, and is viewed by some nurses as threatening their authority. These attitudes of nurses clearly influence the parent-nurse relationship that develops either in a hospital or another setting (Brown & Ritchie, 1989; Johnson, 1990) and, in turn, the decision-making process regarding children's care.

The current situation. The nature and range of parent-professional relationships has been explored by a few researchers, from both the professional (Brown & Ritchie, 1989) and the parent or client perspective (Dixon, 1991; Knafl, Breitmayer, Gallo & Zoeller, 1992; Thorne & Robinson, 1988). Because parents of children who are technology-dependent often make decisions that have traditionally been within the health professional's domain, understanding how nurses and parents view the relationship and their respective roles is relevant to the present discussion. The parent-nurse relationship influences and is influenced by decisions that parents make regarding the care of their child who is technology-dependent.

Brown and Ritchie (1989) used a qualitative descriptive method to identify five types of parent-nurse relationships from the nurses' perspective. Twenty-five hospital nurses were asked to describe one satisfying and one dissatisfying relationship they had had with the parent of a child for whom they had cared. Approximately 85% of the relationships described were categorized by the researchers as either reciprocal or adversarial relationships. One major theme that differentiated these two relationship types was the nurses' commitment toward their role of caring for parents, as contrasted with providing direct care for children. When nurses vied with parents for control over the care of the child, rather than assisting parents to manage certain aspects of care, conflict resulted. Power struggles between nurses and

parents were traumatic for all involved. The authors concluded that nurses' difficulties in caring for parents were influenced by their "level of interpersonal skills, ability to deal with anger, understanding of the grieving process, and issues of control" (p. 93).

Dixon (1991), using a symbolic interactionist perspective, developed a Model of Parent-Nurse Interaction, based on research across a number of samples of parents of children with both acute and chronic conditions. The Model described four patterns of parental involvement with nurses: Limited Contact, Recipients of Care, Monitors of Care, and Managers of Care. Parents who were Managers of Care expected to have a high level of control over decision-making, often making decisions alone and using professionals as consultants. Their children often required "high-tech" care and they viewed themselves as the experts on their children, scheduling and managing professional care in the home when they need it.

During interaction between an individual nurse and parent, implicit and explicit expectations were shared, views of one another were formed, and roles related to the care of the child were negotiated (Dixon, 1991). Two concepts that were central to this interaction were control and trust. Nurses who desired high control were more likely to experience conflict with parents who were Managers of Care. As well, the level of trust that parents had in professionals influenced how they interacted with nurses. Parents who were Managers of Care expected to have a "guarded alliance" trust relationship with professionals (Dixon, 1991).

The term "guarded alliance" was coined by Thorne and Robinson (1988). In their model of health care relationships between individuals with chronic illness and health professionals they conceptualized a relationship that evolved over time and consisted of three predictable stages of trust:

naive trust, disenchantment, and guarded alliance. Initially, individuals assumed that health professionals would act in the ill person's best interest, implicitly trusting professionals and the health care system to care for them. Inevitably they experienced dissatisfaction with care and became frustrated, entering the second stage, disenchantment. At this point they often experienced difficulty obtaining information, trust diminished, and an adversarial relationship developed. However, the ongoing nature of their illness necessitated their continuing association with health professionals. The authors described the final stage of trust as follows:

Guarded alliance was accomplished through the reconstruction of trust on an informed, rather than naive, level and enabled cooperative caring that accommodated both the family perspective and the professional medical perspective . . . the participants actively sought the information they needed, demonstrated understanding of the differences in perspective, stated their own perspective and expectations more clearly, and promoted negotiation of mutually satisfying care. (p. 298)

It is this type of relationship that Dixon (1991) suggested parents who were Managers of Care expected to have with health professionals.

In a qualitative study by Knafl and colleagues (1992), parents of children with chronic illnesses described essential components of a successful parent-provider relationship. Included were information exchange and fostering parental competence. Parents viewed themselves as responsible for their child's daily care, and therefore needed accurate, complete information regarding their child's illness and its management. They also wanted to have their own competence acknowledged and fostered by professionals. The authors emphasize the appropriateness of this approach in terms of

strengthening the family's ability to deal with the inevitable demands which having a child with a chronic illness brings. Not only did fostering competence enhance the family's ability to cope, it also increased parental satisfaction with the care provider.

These studies on parent-professional relationships describe an often conflictual relationship with nurses. It is within this kind of social interaction that parents form meanings that the situation has for them. It is within this interaction that they make decisions about the kind of care they want for their child. Following a period of time at home, these parents become Managers of Care, as defined by Dixon (1991). They wish to be given complete information about their child and to have their own competence acknowledged. They expect to make decisions regarding the care of their child with a chronic illness, using the professional as a consultant. Further, they are able to work co-operatively with others, accommodating both their own perspective and the professional perspective, to negotiate care.

Experience of Families who have a Technology-dependent Child

A small number of studies have examined the experience of families whose child is technology-dependent. A child who is technology-dependent is defined as "one who needs both a medical device to compensate for the loss of a vital body function and substantial and ongoing nursing care to avert death or further disability" (Office of Technology Assessment, 1987, p. 3). Children who are technology-dependent may require mechanical ventilation, tracheostomy care, total parenteral nutrition, enteral feeds, or other technological supports.

Patterson, Jernell, Leonard, and Titus (1994) analyzed qualitative data from 48 families who cared for their children who were technology-dependent and living at home. Specifically, they explored the parent-

professional relationship, identifying four positive and four negative characteristics of professional behaviors, as perceived by parents. One positive characteristic was an attitude of "respect and caring" which included a willingness to collaborate with parents, that is, "the staff asked the family about their preferences, took their points of view into account, and shared decision-making with them" (p. 102). This collaborative approach also included a "willingness to share the risks and responsibilities of child care" (p. 104).

A second positive characteristic identified by parents was that of "competence with care". The authors suggest that, not only did parents need to trust the professional's competence, but that professionals must trust the parent's competence with their child's care, in order to "establish boundaries for care and decision-making" (Patterson et al., 1994, p. 104). Mutual trust, therefore, seemed a necessary foundation to resolve issues related to who would be responsible for making child care decisions.

Collaboration was also identified by parents in a study by Scharer and Dixon (1989) as a preferred way of interacting with professionals. In their qualitative study, parents from ten families were interviewed to elicit how they defined and managed the ventilator-dependency of their children. Five families cared for their children at home, and five children were in hospital. One topic in the semi-structured interview guide asked parents about decision-making processes related to their child's care. Parents discussed decision-making in the context of their relationships with professionals.

Parental management strategies used to deal with professionals were classified by the researchers as either passive or active. The three parents in the passive group allowed physicians or other hospital staff to make all decisions regarding their child's care. In the other families, parents spoke of

educating themselves about their child's condition so that they could participate in decisions about care, viewing themselves as their child's advocate. Further, they communicated their expectations to health care professionals. The researchers concluded that, for parents who want to be involved in the decision-making process, the professional must provide the necessary information on which to base the decision, and then must support and follow the parents' choice. Encouraging participation of parents built their confidence and assertiveness, and promoted better care for the children (Scharer & Dixon, 1989).

Cender (1995) also identified collaboration as one characteristic of a supportive professional relationship, as defined by parents of children who had a medically-fragile condition and received nursing care in the home. Parents wanted to be recognized as expert caregivers and "the primary decision-makers regarding the care of their child" (p. 64). Parents spoke of using professionals as a "sounding board" to ensure they had made the right decisions, but not expecting physicians or others to make the decisions for them.

Youngblut, Brennan, and Swegart (1994) interviewed 10 families who cared for their medically fragile children at home, to describe their day to day experiences. One of the areas explored was decisions parents made related to the care of their child. Families were asked to identify two decisions they had recently faced, and who they would go to if they had a question about child care. All children had been home less than six months, which may have influenced the type of decisions that parents needed to make.

Parental decisions were categorized as either developmental or medical treatment decisions. Developmental decisions included such things as allowing the child to play on the floor, using a high chair for feeding, sending

the child to a day camp, and deciding whether to use a crib or a youth bed. Medical treatment decisions included consenting for surgery, deciding whether to go to the hospital, and deciding whether to use a wheelchair or a walker. When making both types of decisions parents sought the help of professionals, primarily physicians and nurses. Nurses were also consulted for questions about the child's health or special treatments, such as nasogastric feeds (Youngblut et al., 1994).

Contrasted with the above types of decisions, when parents needed help with common child care problems, such as toileting, nutrition, discipline, or sleeping, they tended to use informal supports such as relatives, other parents, friends, or neighbours. Youngblut and her colleagues (1994) suggest that nurses need to have greater involvement in decisions regarding common child care problems because the child's medical condition may influence both the problem and the solution. This suggestion that nurses increase their involvement in parental decision-making may be a reflection of what Dunst, Trivette, Davis and Cornwell (1988) refer to as the "dilemma of helping". Certain helping models of health care actually induce parental dependence and a sense of helplessness, rather than strengthen family functioning and feelings of competence. Suggesting to parents that they consult with nurses for all types of decisions, rather than use informal sources of support for common child care problems, may increase their dependence on health care professionals (Dunst, et al., 1988; Thomas, 1986).

Thomas (1986), using an ethnographic approach, conducted in-depth interviews with parents of seven families to elicit descriptions of their experience with childhood ventilator dependence. Consistent with other studies, families described their prolonged interaction with health care professionals as a major component of their experience. They described an

adversarial relationship and a struggle for control over the child's care to be the "most burdensome consequence of childhood ventilator dependence" (p. 198). Thomas places this struggle for control in the context of family adaptation to having a child who is ventilator dependent.

At the time their child was initially diagnosed with a serious condition parents felt overwhelmed and depended on health care professionals for the care of their child, as well as their own emotional support. They complied with whatever decisions were made for them and their child. However, over time they began to adapt to their situation, gain knowledge about their child's condition and care needs, and question the competence of some caregivers. Most wished to contribute to the health care team decision making process (Thomas, 1986, p. 201). It was at this point, when parents became less dependent and demanded greater participation in their child's care, that struggles for control emerged. Thomas points out the irony of control struggles occurring as a result of healthy parental adaptation to having a seriously ill child.

A second major finding in Thomas's (1986) study was the influence of the family's belief system on the health care relationship. Having a child who required ventilator assistance caused families to revise their philosophical approach to life. They were aware their values had changed and were able to articulate their beliefs. These beliefs, if discrepant from the health care professional's belief system, were the source of differences in approaches to care of the child. Thomas gives the following example:

Health care providers were future oriented, with the long term goals for the child reason enough to engage in uncomfortable treatments. For parents, it was exceedingly difficult to see the child in pain or distress. Health care providers also were socialized to believe that they

should control the child's care entirely. Family members wished to control some aspects of the child's care, and to be viewed as a collaborative partner in other aspects of care. (p. 196)

By inviting parents to express their beliefs, health care professionals can lay the foundation for effective communication and collaboration with parents. In fact, Thomas maintains that the family's perspective, or construction of reality, is the *only* perspective from which effective interventions can emanate (p. 212).

The articles reviewed in this section point to the importance parents attach to the relationship that develops between themselves and the professionals with whom they work regarding their child's health care. Parents want a collaborative relationship with professionals who will acknowledge their competence, provide information needed for them to make decisions, and support those decisions once made. The degree of control parents wish to have over decision-making may vary with the stages of adaptation to having a child who is technology-dependent. Also, the family belief system, which is likely different from that of the professional, influences decisions that are made about the care of a child. By eliciting the family's beliefs and values regarding their child, professionals can establish the necessary foundation for a collaborative relationship. In the following section, literature specific to decisions regarding children's health and illness care is reviewed.

Decisions about Children's Health and Illness Care

Literature pertaining to decision-making regarding children's health care primarily addresses decisions made in critical care settings such as neonatal or pediatric intensive care units. Often decisions that must be made relate to medical interventions to prolong life, when outcomes are not

certain. Issues include the roles of the individuals involved, such as the parent, physician or nurse, factors that influence decisions, and ethical principles which influence decisions. Each of these will be addressed.

Who should decide? Some authors discuss decision-making for the care of seriously ill neonates from the perspective of the professional only, thus implying that parents have no role to play (Stern et al., 1991). This lack of involvement of parents is confirmed by studies that explore the parental perspective; some (Able-Boone, Dokecki, & Smith, 1989), or most (Pinch & Spielman, 1989a) parents perceive they have no involvement regarding treatment decisions about their infant, other than signing consent forms without fully understanding the implications. However, parents in an ethnographic study by Able-Boone and colleagues (1989) expressed the desire to have total involvement in decisions, stressing their need to have information about their child's condition, as well as treatment options, in order to participate fully.

Among the three physicians and 33 nurses in the same study (Able-Boone et al., 1989) there were two main viewpoints regarding the appropriateness of involving parents in decision-making. Fifty-six percent believed that parents should be totally involved because the decisions made would affect the family, who would live with the results of the decisions the rest of their lives. Contrasting with this, 43 percent of the professionals advocated minimal parental involvement with decisions. They believed parents, because of their emotional involvement and lack of medical knowledge and expertise, would be further burdened by having to make decisions about their child's treatment.

Not all parents, however, wished to be involved in treatment decisions that were made about their child. Parents in a study by Pinch and Spielman

(1989a) felt comfortable having health professionals make these decisions. Parents in this study were interviewed prior to their infant's discharge from the neonatal intensive care unit. It may be that it is only following a period of time at home, when parents are attempting to integrate their infant into family life, that the consequences of the medical interventions are realized and parents express strong feelings about their intensive care experience (Pinch & Spielman, 1989b). The phenomenon of parents giving over control to professionals during the initial stage of illness is consistent with Thorne and Robinson's (1988) description of naive trust, as well as other authors' descriptions of parents' dependence on professionals when their child is initially diagnosed with a serious illness (Cender, 1995; Hatton, 1992; Thomas, 1986).

Pinch and Spielman (1989b) argue that, even if parents appear to hand over decision-making to professionals willingly, the professional has a moral obligation to include parents in the process because of their long-term investment in the life of the infant (p. 432). The professional's role is to ensure parents have the information and support they need to actively participate in decision-making.

Factors influencing decisions. Research studies that identified factors influencing decisions around children's health or illness care focused on either decisions made by nurses (Hamers, Abu-Saad, Halfens, & Schumacher, 1994) or those made by parents (Harris, 1985; Ruccione, Kramer, Moore, & Perin, 1991; Thompson, 1993). When assessing children's pain and deciding on interventions, nurses considered factors related to the child such as the medical diagnosis, the child's expressions, and the child's age. Other factors that influenced nurses' decisions were related to the nurses themselves, such as their knowledge, experience, attitude and workload (Hamers et al., 1994).

Three studies were found that explored factors influencing parental decisions. In the first study the researchers interviewed employed mothers who had to arrange alternate caregivers for their normally healthy children who could not attend day care due to a minor illness (Thompson, 1993). They were asked what factors they considered when deciding on a substitute caregiver. Mothers experienced feelings of anxiety, as well as conflict between their responsibilities of motherhood and work, when making their decisions. Influencing factors were the severity of the illness, the relative advantages and disadvantages of options for care, job flexibility, and availability of paid leave. Most mothers decided to stay home to care for their ill child themselves, viewing others, including their husbands, as less competent than themselves.

A second study (Harris, 1985) that explored factors influencing parental decisions used grounded theory to develop a cultural decision-making model to predict decisions parents make regarding circumcision of their newborn baby boys. Factors identified in the model are: understanding of the physiology of the foreskin, values of the nuclear and extended family culture, and values of the dominant culture.

Finally, a study that explored factors affecting parental decisions concerning cancer treatment for their children is relevant to the current discussion. Parents whose children are newly diagnosed with cancer are given large amounts of complex information regarding options for treatment. Understandably, parents are experiencing high levels of anxiety at the time this information is given. Ruccione and her colleagues (1991) were interested in exploring how parental anxiety and educational level affected parents' perceptions of the clarity of the explanations, as well as the adequacy of time to consent to treatment. Parents with higher anxiety were more likely to

believe that the explanations were not sufficiently clear. Also, parents with more education perceived that they had not been given sufficient time to consider their decision before consenting to treatment. The authors suggest that, rather than requiring less assistance to understand and participate in decisions regarding the care of their child, parents with more education may have greater needs for information, so as to be able to weigh the risks and benefits of various options.

These four studies suggest that factors influencing decisions regarding children's health or illness care can be categorized as child related and caregiver related factors. Child factors include medical diagnosis or severity of illness, age of child, and the child's response to the situation. Caregiver factors include knowledge, experience, educational level, perceived competency of others, cultural orientation, and anxiety.

Ethical perspectives. Caring for a child who is technology-dependent and living at home presents ethical issues for both parents and health professionals. Parents of well children are morally and legally obligated to provide care for them, and to show good judgement regarding when to seek medical advice if their children become ill. Failure to meet these expectations is considered neglect, or abuse. Physicians and nurses who provide care for children are morally and legally responsible for the outcomes of that care (Lantos & Kohrman, 1991).

Lantos and Kohrman (1991) suggest that, when a child who is technology-dependent is moved from hospital to home, a "reordering of what are 'good' and what are 'bad' outcomes may be necessary" (p. 248). For example, if it means living under conditions of intensive, or uncomfortable treatments, survival may not be the most important outcome. Rather, the psychosocial benefits of living within the family setting, even if it means a

shortened life span, may outweigh other factors. These authors suggest that, because of different values and traditions of parents and professionals, there exists the possibility for legitimate disagreement around decisions about a child's care. The following study is one of the few that examines the ethical principles influencing parental decisions.

Overbay (1991) surveyed 61 parents of well children, using hypothetical situations, to determine what choices parents would make regarding illness care for their children. The questionnaire elicited parental feelings about autonomy (the right to make decisions for oneself), beneficence (doing good for others), and nonmaleficence (refraining from doing intentional harm). Although all three ethical principles influenced the decision-making process, autonomy was significantly more influential than either beneficence or nonmaleficence. Other authors (Rushton, 1990) have suggested that beneficence is the primary ethical principle that should direct both parental and professional decision-making around treatment choices for critically ill infants and children. Clearly, the potential exists for differences between professional and parental perspectives.

In this section, literature pertaining to decisions about children's health and illness care has been reviewed. On the whole, parents want to be involved in decision-making about their child's care. Although some professionals support parental involvement, others believe it would overburden parents who are already anxious about their child's condition. Various factors appear to influence decisions and can be classified as child or caregiver factors. Literature that addresses the ethical aspects of caring for seriously ill children suggests that parents and professionals likely operate from different underlying assumptions, values and ethical principles, thus

confirming the importance of professionals understanding parents' perspectives.

Conclusion

The studies which have been reviewed in this chapter reveal that most parents of children who are seriously ill want to be involved with decisions that are made concerning their child's care. They wish to have a collaborative relationship with professionals, and they go to physicians and nurses for information and support to make those decisions. In particular, because nurses spend long periods of time with parents, parents often consult with them regarding the day to day decisions about their child's care. Although some parents feel comfortable having the physician make all the medical treatment decisions, this may be because those parents are in the initial stages of adaptation to having a child with a serious medical condition; they feel overwhelmed, and are therefore more dependent on health professionals. Parents may later regret not having had greater involvement with decisions that have affected their lives in a significant manner. Therefore, it can be argued that professionals have an obligation to assist parents to make decisions at all stages of the adaptation process, thus empowering parents and strengthening families.

Few studies have examined factors that influence decisions about children's health and illness care. Those that have suggest there may be factors related to the child and factors related to the caregiver that influence decisions. However, none of these studies has looked at the population of children who are technology-dependent and living at home. The parents of these children are likely to be Managers of Care, as defined by Dixon (1991), and therefore expecting to take an active role in decisions that are made regarding their child's care. Rather than assisting parents in their decision-

making role, if nurses vie with them for control over the care of their child, conflict is likely to result. By understanding parental perceptions of factors that influence their decisions, nurses can work with parents in a collaborative manner, thus fostering parental feelings of competence and improved care for children.

The Research Question

The research question for the current study is: What are parents' perceptions of the factors that influence decisions they make about the care of their children who are technology-dependent and living at home? In the following chapter the research method used to explore this question is presented.

Chapter 3: Methodology

Introduction

The research question stated at the end of Chapter two was explored by performing a secondary analysis of data that had been collected for a phenomenological study which explored and described, from both parents' and nurses' perspectives, the role of the nurse who provides in-home care for children who are technology-dependent. Following a description of the data, including pertinent findings from the primary study, methods used for the secondary analysis will be presented. Assumptions of the study, limitations of the study, issues of credibility, and ethical considerations will then be addressed.

Method

Description of the Data

Sample. The parent participants for the primary study were the primary caregivers of children who were technology-dependent and living at home. Mothers of ten children were interviewed; in one family the father also participated in the interview. Five of the mothers were single parents. In three of the families, the child who was technology-dependent was an only child; in the other seven families the child had at least one sibling.

Education of the mothers ranged from grade ten to completion of a graduate degree. Four families had incomes of less than \$25,000 per year, and six had incomes of between \$25,000 and \$50,000 per year.

The ages of the children who were technology-dependent ranged from one year to 16 years of age at the time of the initial interview. Most had been diagnosed with their condition at birth or during the first year of life, and had been living at home from six months to nine years (median of five years).

Medical conditions of the children included spinal cord injury requiring mechanical ventilation 24 hours a day, respiratory conditions requiring a tracheostomy, metabolic conditions requiring vigilant monitoring, and severe broncho-pulmonary dysplasia.

All families received some in-home nursing respite care for their technology-dependent child, provided through a government funded program. The length of time they had been receiving nursing care in the home ranged from four and one half months to nine years (median of two years, three months). Families had between two and seven nurses involved in their child's care at any one time. All children had some Registered Nurses providing care; six also had Licensed Practical Nurses providing some care. Families received between 12 hours and 152 hours per week of nursing respite in their homes (median of 40 hours).

Nurses who provided respite care in the home were also interviewed for the primary study. However, data from the nurses were not analysed for this secondary study.

Methods of data collection. Data were collected through interviews with parents held in a place of their choosing, usually their own homes. Two nurse research assistants, who had attended a four-hour session to learn interview techniques specific to the primary study, conducted the interviews. Parents were interviewed between one and three times; all interviews were audiotaped and transcribed verbatim. As well, for many of the interviews, the interviewers provided field notes that described the context in which the interview took place, and/or other pertinent factors such as interruptions that occurred during the interview, or the general emotional status of the parent.

The nurse interviewers used a semi-structured interview guide (See Appendix A) to conduct the first interview. Following analysis of data from

that interview, a second interview was conducted with the majority of the participants to clarify and expand on emerging themes. Some of the parents participated in a third interview, which was conducted as a focus group led by the principle investigator and co-investigators, to confirm findings. In total, 16 transcripts of interviews with individual parents, representing approximately 24 hours of interview time, and one transcript of the focus group interview, which lasted two hours, were obtained and analyzed for the current secondary study.

Major findings from primary study. Findings from the primary study were categorized into three major areas: organizational variables, family-nurse relationship variables, and professional variables. Both parents and nurses addressed organizational and family-nurse relationship variables; professional variables were discussed only by the nurses.

Organizational variables, from the nurses' perspective, included the setting of care and the impact that had on how care was delivered, agency issues, and other issues related to community resources. From the parents' perspective, organizational variables included issues related to service delivery such as concerns about last-minute cancellations by nurses, non-availability of nurses, and too many agency "rules" about what nurses could and could not do when working in the home.

The second category of findings was family-nurse relationship variables. Themes that emerged from the nurse data included boundaries, trust, control, conflict, communication, collaboration, and fit or compatibility. Parents described a relationship that could be described as collaborative, as the most positive type of relationship; all viewed themselves, rather than the nurse, as having overall responsibility for their child's care. They discussed trust as an important component of the relationship, both from the point of

view of themselves trusting a nurse's competence, and a nurse trusting the parent's competence. Parents also identified conflict as a part of many relationships they had with nurses. Often the source of conflict related to the nurse not acknowledging the parent's expertise, nor consulting with them, regarding their child's care. Lastly, parents identified characteristics of nurses that facilitated the family-nurse relationship. These included competence with the physical care of the child (and equipment), ability to teach, reassure and/or guide the parent, ability to consult with parents as necessary and trust parents' abilities, sensitivity to other family members' needs and to the dynamics of the family, and shared values or philosophy.

The final category of findings was professional variables, which was addressed only by the nurses. Nurses identified sources of stress and sources of support for themselves, as well as ethical issues they confront when working in the home.

Relevance of data for current study. The data for the primary study were collected from parents who were currently caring for their technology-dependent children at home, and who viewed themselves as the ones responsible for the overall care of their children. Therefore, these parents had to make decisions about how care would be provided. Although parents were not asked direct questions about decisions they made related to their children's care, many examples were given of conflictual situations. One of the sources of conflict may be a difference between what nurses and parents decide is "best care" for a particular child. The current researcher was a co-investigator for the primary study, and the theme of "decisions" was not examined during that research. However, a cursory review of the data, as well as discussions with the research team, indicated this might be a fruitful area to explore.

Analysis

Thorne (1994) suggests that one reason for performing a secondary analysis of qualitative data is for analytic expansion. That is, a researcher may ask new questions of an existing data set as new theory develops and is published (p. 266). The question asked in the current study was triggered by an examination of the Parent-Nurse Interaction Model, developed by Dixon (1991), in which she identified certain characteristics of parents who were "Managers of Care". One characteristic of these parents is that they provide "high-tech" care for their children. Other characteristics relate to aspects of decision-making. The parents who were interviewed for the primary research would almost certainly be categorized as "Managers of Care", according to Dixon's Model. Therefore, a rich data base existed which could be analyzed to examine a new research question that had arisen from the literature.

Underlying any research methodology are assumptions about the nature of reality, the relationship between the knower and what can be known, and how an inquirer would go about finding what can be known. These assumptions form a paradigm, which is a "basic belief system or worldview that guides the investigator, not only in choices of method but in ontologically and epistemologically fundamental ways" (Guba & Lincoln, 1994, p. 105). An interpretivist paradigm guided the inquiry for the current study.

The researcher who is informed by the interpretivist paradigm wants to understand the complex world of lived experience from the point of view of those who live it. To understand their world of meaning, the researcher must interpret it by clarifying "what and how meanings are embodied in the language and actions of social actors" (Schwandt, 1994, p. 118). Understanding

through an interpretivist approach can be achieved through a variety of methods, but Schwandt warns that using this approach is more than simply a matter of "mastering a technique, copying a method, or following a model" (p. 132). However, all interpretive inquiry involves watching, listening, asking, recording and examining, with the goal of understanding the meaning of social phenomena (p. 119).

Symbolic interactionism, from the field of social psychology, is one interpretive science (Schwandt, 1994). Although not a method per se, it provided a more specific perspective through which the data were viewed during the analysis phase of the current study. Three major premises underlie symbolic interactionism. The first is that "human beings act toward things on the basis of the meanings that the things have for them" (Blumer, 1969, p. 2). "Things" encompass not only objects, but individual or groups of human beings, as well as guiding ideals, such as honesty. The meanings that individuals attribute to things are central in their own right, rather than merely underlying factors that account for behavior.

The second major premise is that "the meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows" (Blumer, 1969, p. 2). That is, the meaning something has for an individual is formed during the process of interaction between people, growing out of the way others act toward that individual in relation to the thing (p. 4-5).

The third, and final, premise of symbolic interactionism is that "these meanings are handled in, and modified through, an interpretive process used by the person in dealing with the things he encounters" (Blumer, 1969, p. 2). This interpretive process involves two steps. First, the individual points out to himself or herself the things that have meaning. This involves a process

of internal communication, or interaction, with the self. Then, "the actor selects, checks, suspends, regroupes, and transforms the meanings in the light of the situation in which he is placed and the direction of his action" (p. 5). That is, attaching meaning to a thing is a formative process which is influenced by a situation and, in turn, directs action.

The above three premises of symbolic interactionism provided a lens through which the data in the current study were examined. Specifically, they suggested the following in relation to the population of parents who care for their children who are technology-dependent and living at home:

1. Parents' actions are based on the meanings they attach to objects, people, and the philosophical values in their lives.
2. Parents form these meanings during interactions with their child, family members, health professionals, and other individuals in their lives.
3. Parents construct meanings through a process of interpretation that involves identifying what is important, and then interpreting the meaning in the context of the situation.

The meaning of an event, or experience, is embedded in the stories that individuals tell about themselves (Denzin, 1989, p. 62). By examining the stories parents told about their child's care, it was possible to understand the meaning they attached to various components of their experience. Further, it was possible to extract information about actions related to that care, infer the decisions that underlay those actions, and identify the objects, people, or values that influenced those actions. In order to answer the main research question which was stated earlier (p. 22), the following specific questions were

asked of the data:

1. What stories do parents tell that infer they have made a decision about their child's care?
2. What objects, people, or values do parents discuss that could be factors that influence decisions they make, or actions they take regarding their child's care?
3. In what situations do parents make decisions? Does the context of the situation influence a decision? If so, in what way does it influence the decision?

Although symbolic interactionism provided a perspective for examining the data, and the above questions provided a focus for the content that was examined, direction was also needed for the process of analysis. The following steps, developed by Denzin (1989), provided such direction:

1. Locate within the personal experience, or self-story, key phrases and statements that speak directly to the phenomenon in question.
2. Interpret the meanings of these phrases as an informed reader.
3. Obtain the participants' interpretation of these findings, if possible.
4. Inspect these meanings for what they reveal about the essential, recurring features of the phenomenon being studied.
5. Offer a tentative statement or definition of the phenomenon in terms of the essential recurring features identified in Step 4.

(p. 56)

These steps provided direction for the process of examining the data.

In summary, the analysis of data for the current study was guided by the interpretivist paradigm, specifically by symbolic interactionism. The

assumptions of this perspective, namely that individuals' actions are based on the meanings they attach to the "things" in their lives, formed the basis for a set of questions that were asked of the data. Finally, Denzin's (1989) five steps of analysis directed the process of examining the data.

Assumptions

Two assumptions underlay the use of secondary analysis to answer the research question asked in the current study. First, there was an assumption that adequate richness and depth existed in the data to answer the secondary research question about decisions. Because making decisions about a child's care is an integral part of caring for a child who is technology-dependent and living at home, it was assumed that when parents discussed their overall experience of caring for their child they would also discuss decisions they had made related to that care.

The second assumption that underlay the use of an existing data set to explore the current research question was that there would be no systematic bias in the data due to the focus of the original, or primary, study. The focus of the primary study was on the role of the nurse in caring for children with medically-complex conditions in the home. Therefore, families who managed the care of their technology-dependent child without the assistance of in-home nursing respite care were not represented in this data set. It was assumed that factors that influence decisions parents make regarding the care of their technology-dependent children are similar, whether they have in-home nursing respite or manage without.

Limitations

Two limitations of the current study have been identified. First, using an existing data set to answer a new research question presented a limitation. Because the initial trigger questions were not developed to elicit information

about decisions, the current study was limited by the focus of those questions. As well, the nurse interviewers may not have followed a lead that could have further explored a parent's thoughts regarding decisions. It was not possible to return to the participants in the study following secondary analysis of the data. Therefore, the findings from this study were limited to what was in the existing data set.

Second, there were limitations to the generalizability of the findings. The population of parents who care for their children who are technology-dependent and living at home, although increasing, is still small. Parents who have children with chronic illnesses, but are not technology-dependent, may be similar in many ways to parents who were interviewed. However, findings cannot be generalized to that population.

Credibility

The issue of credibility of the findings was particularly important for this study because during the process of analysis the researcher interpreted the meanings of statements made by parents. Further, it was not possible to obtain validation of that interpretation from the participants. Therefore, specific strategies were used to address this issue.

First, thick descriptions from the data were used to illustrate the phenomena (Denzin, 1989). This allows readers to draw their own conclusions about the accuracy of the researcher's interpretations. Denzin offers the following criteria by which interpretive materials can be evaluated:

1. Do they illuminate the phenomenon as lived experience?
2. Are they based on thickly contextualized materials?
3. Are they historically and relationally grounded?
4. Are they processual and interactional?
5. Do they engulf what is known about the phenomenon?

6. Do they incorporate prior understandings of the phenomenon?
7. Do they cohere and produce understanding?
8. Are they unfinished? (p. 63)

The final criterion, which refers to the unfinished nature of the interpretation, reflects the belief that all interpretations are provisional. That is, although conclusions are drawn, future interpretations may be shaped by understandings that were not present during prior examinations.

A second strategy that was used to address the issue of credibility was to have expert nurses review the interpretations. Sandelowski (1986) suggests that a qualitative study is credible when it presents a description of an experience in such a manner that it can be recognized immediately by others who are familiar with the experience (p. 30). Two nurses who had extensive experience working with parents of children who were technology-dependent and living at home reviewed the initial findings. Feedback from these nurses revealed that, with one exception, the findings reflected their experience working with families. One nurse expert identified an omission in the findings. In her experience, the child's expressed wishes played a role in parents' decisions, and this was not identified in the findings as a factor that influenced parental decisions. However, re-examination of the data for evidence of this revealed no explicit examples. The findings in this secondary study were limited to what was in the existing data set.

Ethical Considerations

Care must be taken, when doing a secondary analysis of data, to ensure that the scope of the consent given by participants in the primary study includes permission to explore the question asked in the secondary study (Thorne, 1994). Parent participants in the primary study gave permission to the investigators to examine their experiences related to having a nurse care

for their child with complex health care needs at home (See Appendix B). Ethical approval for the primary study was received from the University of British Columbia Behavioural Sciences Screening Committee. Because the current research question explored an aspect of the parents' experience caring for their child during the time they had nurses in their homes, the original consent includes permission for the secondary analysis.

Summary

In this chapter the research method for this secondary study has been presented. A description of the data from the primary study, including the sample, methods of data collection, major findings, and the relevance of the data for the current study was presented. The method of analysis was described, as well as assumptions of the study, limitations of the study, issues of credibility, and ethical considerations. In the following chapter the findings are presented.

Chapter 4: Presentation of the Findings

Introduction

Each parent who was interviewed for this study had a unique story to tell about living with and caring for a child who was technology-dependent. Within these stories, parents discussed decisions they made regarding their child's care. Although each parent's story was unique, there were common themes within them. These themes will be presented in this chapter.

First, the context within which parents made decisions will be described. Then, an overview of the kinds of decisions parents made will be presented. Both these sections provide background for the main discussion, and final section of this chapter, factors that influence parental decisions regarding the care of their child who is technology-dependent and living at home.

Context of Parental Decision-Making

The children of the parents who were interviewed for this study had a variety of medical conditions and care needs. Children required mechanical ventilation, tracheostomy care, and/or vigilant monitoring of a metabolic or respiratory condition. All parents were fully competent to provide the complex care their children required, which often included identifying subtle changes in a child's condition and considering a variety of factors before choosing an appropriate intervention. Frequently they took on the care of their children without realizing the complexity of what they were doing. As one mother explained:

It wasn't until I actually made those goals and objectives that I realized what I was doing. And it wasn't until I communicated that to

professionals that I got really validated, with the appreciation of, "Yeah, this is a tough thing to be assessing." You know, trying to teach somebody else, all of a sudden, I realized just what I was doing on a day to day basis.

The parents in this study willingly took on the awesome responsibility of caring for their children who were technology-dependent, and were absolutely committed to having them at home. Often this meant making significant changes in their living arrangements, such as using a living room or dining room as the child's bedroom in order to accommodate the large pieces of equipment needed. Some mothers postponed or gave up careers in order to stay home with their children. Siblings were also greatly affected by the decision to care at home for a child who was technology-dependent, often having their routines altered because of their ill siblings needs. The following statement, made by one mother, represents the feelings of many who participated in the study: "It's giving up a lot to have a person that you love in the home, but there is no--I mean, for us, anyway--there is no alternative."

Some of the parents in this study had been caring for their child at home for long periods of time, often before formal supports such as nursing respite were available. A number described themselves as "pioneers" in taking a child who was technology-dependent home, and may have had to fight the existing system in order to do that. In contrast, other parents in this study left the hospital knowing that they would have nurses come in on a regular basis to provide respite for them; these parents had the security of knowing they would have nurses at home with whom they could consult regarding the care of their child. Parents who were interviewed had been

caring for their children at home for periods of time ranging from six months to nine years.

The parents in this study, without exception, expected to make decisions regarding the care of their children at home. One parent was emphatic:

The parents should be the boss. The parents should have the same rights as anybody else. They have the right of directing their child, of disciplining their child, of saying, "This is right and that's wrong." . . . I'm not saying, like abusing them or whatever--within the boundaries of the law, they should have the right to direct the care of the child, the discipline of the child, what's right and wrong, and be totally involved with who takes care of the child, and in the hiring process. . . . It's very important that the nurses understand that if you suction with a twist, then that's the way you do it and that's because the parents want it that way. It's a lot different than being in an institution.

Although all parents in the study expected to make decisions regarding their children's care, some told stories about certain times during their experience at home when they were less able to do that, and were grateful when a nurse took a more active role in decision-making. For example, when parents were first at home with their child, and feeling overwhelmed, they appreciated nurses helping them set up a routine for care.

We needed a few weeks to get adjusted to having him in the house and having this nurse walking around, and getting a routine set up. I was a bit overprotective when he first came home. . . . I had one nurse that set up a good schedule. She'd worked with kids with trachs

(tracheostomies) before so she was really good. She helped out quite a bit. I really trusted her.

However, it was possible for parents to become so dependent on nurses that they were fearful to care for their child themselves. One mother, who had had nurses care for her son at home every night for three years, expressed the following about a time when nursing coverage became less dependable. "It just started becoming much more difficult when we found nights weren't being covered. Well, we don't have a nurse tonight. What was I to do? I was afraid to look after him by myself at night." As nursing hours were decreased gradually, on a planned basis, this mother realized she had to learn to care for her son at night, "and now I don't mind at all, you know, it's fine."

On the whole, though, the parents in this study were more likely to trust themselves, rather than others, to make decisions about the care of their children. One mother described the difficulty she had trusting that nurses in the home would know when to suction her child's tracheostomy. She described it as a "weaning" process for herself, letting others take over some of the decisions for which she, alone, had been responsible. "You were just releasing all trust to them. . . . it was what they thought. Oh, that was really, really tough for me!"

Some parents, who had cared for their children at home for a long time, although no longer feeling overwhelmed with the day-to-day decision-making, were simply tired, and expressed the desire that nurses would use their own judgement regarding their children's care, rather than asking them about every aspect of it. One mother felt that she was "supposed to be the Case Manager, the expert in five hundred different areas--and that creates stress." Another mother told of reaching the point of "wanting . . . to give up my leadership role, to really want to turn it over to somebody." These

mothers were exhausted due to the length of time they had carried the responsibility of caring for their children at home.

On the other hand, when parents did want to make decisions, but felt nurses didn't acknowledge them as the decision-maker, or listen to them, they felt a loss of control. One mother described her experience as follows:

I find you don't have a lot of control over things. You can say things but they don't necessarily get done. They (nurses) will just do things the way they want to do them . . . You set up a certain routine for him and they come in and do their own thing with him and they will just totally screw things up.

Thus, the degree of involvement parents wanted to have with decision-making varied over time. When their child was first at home, parents appreciated having nurses help them with decisions about care, or setting up a routine. Most parents gradually took over the responsibility for their child's care but, when this didn't happen, parents became dependent on the nurses and had less confidence in their own ability to care for their child. Parents who had cared for their children without help, initially found it difficult to turn over that care to nurses. Other parents, after caring for their children for long periods of time, became exhausted and wanted to have someone else take over the manager/leadership role. These accounts indicate that the readiness of parents to make decisions varied over time. When nurses did not recognize the amount of control parents wished to have over decision-making, and either asked too many questions of the parent, or took over too many of the decisions, it was stressful for parents.

Kinds of Decisions Parents Make

In the process of caring for their children at home, the parents in this study made many decisions each day regarding that care. Decisions covered a variety of aspects of care, including decisions about normal parenting issues, those related to the management of the chronic illness, those related to organizing health care supports, as well as those related to sustaining family life.

Although the children of the parents in this study were technology-dependent, their parents were still faced with normal parenting issues. For example, decisions had to be made regarding how much responsibility to give an adolescent son, or how involved to be with problems a child was having at school. The fact that their child had a chronic illness, although adding another dimension to their care, did not eliminate the need for decisions about normal parenting issues.

Parents also made a number of decisions, often on a daily basis, regarding the management of their child's chronic illness. Decisions related to the direct care of the child, such as when to suction a tracheostomy or how to administer a tube feed, were described in the parents' stories. Parents also described decisions they made regarding the level of vigilance, or the type of monitoring that was needed to ensure their child's safety. In addition, they made decisions about the cleaning and maintenance of equipment used for the care of their children at home.

Because of the level of care technology-dependent children require, all the parents in this study received some formal supports to help them manage at home. Types of supports included the provision of medical equipment and supplies, access to a variety of health care professionals, either through hospital clinics or in the community, and provision of nursing respite in the

home. Therefore, decisions needed to be made regarding the organization of these supports. Parents described choosing which nurses would provide care in their home, deciding how nursing shifts could be scheduled to best meet the family's needs, and deciding what the "house rules" would be when nurses worked in the home. Further, parents made decisions about what aspects of their child's care they wanted to delegate to nurses, and what aspects of care they wanted to retain for themselves.

Finally, parents made decisions related to sustaining family life. Decisions about the setting of care for their child, sleeping arrangements at home, or how to balance the responsibilities of a job while still caring for their child who was technology-dependent were described in the stories parents told.

As is apparent from the above discussion, parents made a broad range of decisions regarding the care of their children at home. The wide variety in the kinds of decisions they made provided rich content for exploring the factors that influenced parental decisions.

Factors Influencing Parental Decisions

The parents' accounts revealed that they considered a multitude of factors before making a decision about an aspect of their child's care. A complex web of factors underlay most decisions, and influenced the decision in various directions. For example, when making a decision, parents seldom considered their child's medical condition in isolation from other factors. If a mother were deciding whether her child's tracheostomy needed to be suctioned, she would likely consider factors related to the child's condition, such as how congested he sounded, or whether he had early signs and symptoms of an upper respiratory infection. However, she would likely

consider other factors as well, such as whether he had just fallen asleep and would waken if she suctioned, or how well he was usually able to cough up secretions on his own, or whether he would be able to summon help if necessary. Further, she might consider factors related to herself, such as whether she was wanting to go to bed and would need to waken shortly to suction him if she didn't do it at the present time. In addition, there could be factors related to the environment to consider, such as whether a nurse was booked to come that night. Each of these factors would influence the final decision as to whether she should suction, but in various directions.

Although the factors that influence parental decisions are complex, and often interrelated, it was possible to cluster together similar types of factors into three main groupings. Therefore, the following discussion is organized under child factors, parent factors, and environment factors. While these groupings are not mutually exclusive, they are helpful in explicating the factors, and in describing how they influence decisions.

Child Factors

The stories parents told revealed that they considered a number of factors related to their child when they made decisions about aspects of care. Some of the factors were related to their child's medical condition and/or care needs, while others were related to the developmental stage of their child.

Medical condition/care needs. When considering factors related to their child's medical condition parents were aware of both the underlying chronic condition, as well as their child's potential for developing an acute illness, such as an upper respiratory infection. Both influenced decisions they made about their child's care.

The overall stability of the chronic condition was mentioned frequently by parents as a factor that influenced decisions about the degree of

vigilance required. During a time when her son's condition was particularly unstable, one mother decided to carry a pager with her so that his caregivers could contact her at any time. Another mother, as her daughter's overall condition deteriorated, decided it was time to replace the unlicensed caregivers, who had been caring for her child, with nurses. She explained:

Most of the people that did care for (child) before nursing, or on top of it, were never around her when she was very ill, so they only saw the good side of her. When things went downhill, and she was in the hospital, they didn't see her. When she was headed towards that, they went, . . . "I don't want this!"

This mother's decision to request and obtain in-home nursing respite care for her daughter resulted in fewer hospital admissions because her less stable periods could be managed at home.

As a child's underlying chronic condition became more stable, parents made decisions to decrease the level of vigilance. This might have taken the form of using a baby monitor to listen to respirations from another room, rather than having their child under direct observation or on a heart monitor. One mother thought that, once her infant's condition was stable enough so that he no longer required oxygen, it would be safe to have someone other than a nurse care for him in her absence.

Parents also considered their children's susceptibility to infections when making decisions about their care. One mother made the decision not to let other children kiss her son because of the risk of him contracting an infection.

The complexity of care also influenced parents' decisions about how care would be provided for their children. Parents in one family decided to care for their son themselves at home during the day, but take him back to

the hospital each night because of the complex nature of his care. As well as complexity of care, the frequency of care needs influenced decisions about how care could be provided. One mother moved a second single bed into her son's room so that she could be closer to him, and thus available to settle him to sleep during his frequent awakenings in the night.

The parents of a child who had frequent changes to his complex care regimen preferred to have only full-time staff, rather than part-time staff, care for him at home. The parent explained,

You can't just hire somebody. I've had so many people say things like, "Why don't you just get some retired volunteer nurse to do weekends," . . . but they don't understand that it takes so long to train someone to be able to work with (child) that you can't just call someone in once every two months because maybe in that time he's got a new kind of trach, a new setup for tying the trach in--there's five hundred changes. I mean changes, changes--someone doesn't work a week and there's changes.

In this situation, the frequent changes in their son's complex care regimen influenced these parents' decision to hire regular, full-time staff as much as possible, so that caregivers would be able to give more consistent care.

Finally, consideration of specific aspects of a child's physical condition contributed to parents' decisions. The mother of a boy with a severe skin condition had to make decisions about how to treat his lesions. When deciding whether to remove her son's clothing to incise and drain a blister she considered the size of the blister, how "stuck" it was to his clothing, the mood of her son, and when his next bath was due. Based on these factors, she made a decision as to whether she would deal with the blister at that time, or leave it until later.

The above factors that influence parents' decisions relate to the child's medical condition and/or care needs. Parents also considered factors that related to their child's developmental stage.

Developmental stage. Aspects of development, such as the ability to communicate, or gross motor or fine motor skills, influenced parents' decisions about care. Further, the overall developmental stage, and parents' perceptions of what was normal for that stage, influenced decisions.

A child's ability to communicate influenced parental decisions regarding the choice of nurses, as well as the level of vigilance required. As a child became more able to express his or her needs verbally, or in some other manner, parents generally felt more comfortable about leaving their children with caregivers other than themselves. One mother, whose son had difficulty communicating verbally, had looked for nurses who would be particularly sensitive to his non-verbal cues. However, as he learned to communicate, using a combination of mouthing words and writing, she believed a wider range of caregivers would be able to care for him. She explained, "That's another thing that has helped me feel more relaxed, too, is him being able to communicate with me and with the nurses."

Parents also considered their child's ability to communicate when deciding the level of vigilance required. Infants and toddlers have limited means of making their needs known, thus generally require a higher level of vigilance than an older child. One mother described a recent change in her 3-year old's ability to let her know when he wasn't feeling well. "Now that he's verbal, occasionally he'll just look at me and say, 'My sugar's not right.'" This mother, although not depending on her son to monitor himself, decided he didn't require the same level of vigilance he had needed when he was an infant.

A child's fine motor and gross motor skills also influenced parental decisions about their care. One mother decided to wait to order a particular communication aid for her son until he developed better fine motor skills. This same mother was aware that her son's gross motor skills were delayed, and therefore stayed close to him when he was walking, to prevent him from falling and hurting himself. His developmental level influenced her decision regarding the level of vigilance necessary.

Parents in this study who had adolescents who were technology-dependent seemed particularly aware of developmental issues. This awareness, in turn, influenced decisions they made regarding how care was currently provided, as well as what they wanted for their adolescents as they became young adults. Some parents made conscious decisions to pull back from providing direct personal care for their adolescents, and allow other caregivers to provide the majority of the care, as the following quote illustrates:

I think, especially as (child) gets older, it's becoming more and more inappropriate for his dad and I to do his personal care. . . . If I do a lot of shifts with (child), the way he treats me changes and I don't really like it. So I don't think it is appropriate for parents to do a whole lot.

When they are younger--but now that he's getting older, it's becoming more and more inappropriate.

This mother considered her son's developmental stage when making the decision to have caregivers other than herself and her husband provide most of the personal aspects of his care.

Parents recognized the developmentally normal process of "letting go" as their children became older. However, they struggled with how to handle that process when their adolescent was technology-dependent.

Now we've got to let go. And that's--you know, you do that with any child--but it's harder. It's definitely harder. Because you're not just turning that responsibility over to that child, which we will have to do with (sibling) in a few years. And we do that in some things with him now, but we're also turning him over to somebody else. And (child) has to be totally dependent on other people for his care so we have to feel that we're making the right choices for him. The people that are involved in (child's) care now, and in the next few years--it's going to be the most important part because they're the ones that are making that transition with him and with us. That's not easy.

These parents considered both the developmental stage of their son and his care needs when trying to decide how best to prepare for the future. Both factors will influence their decisions regarding choice of caregivers.

Closely related to the above decisions about choosing caregivers, the parents of the adolescents in this study discussed handing over responsibility for directing their care to their adolescent children. One parent explained, "We are trying to involve (child) in his care and get him more involved in directing the nurses to what he needs and what he wants. That's the future--both at home and at school." However, it's not easy.

I was sitting up here this morning having my coffee and I try to stay out of things and stay out of the way in the morning. And (child) was trying to explain to the nurse how to put something together that he needed to take to school and she was having a hard time understanding that. And I really wanted to go down there and say, "Oh, what's the problem here," you know, and help out. And I thought, "No, I have to let (child) do that. I have to let (child) be the one to communicate with . . . people because the time's going to come,

not that far off, when (child) is independent from us and has to take over his care and be able to deal with his caregiver." So it's really hard for me to just stay out of it, you know. But (child's) getting to an age where--it's not that I'm handing over the responsibility of (child) to a nurse--it's getting where I'm handing over the responsibility to (child). This mother considered her son's developmental stage when deciding whether to assist him in communicating with the nurse, or let him manage the situation on his own.

Another parent considered her son's developmental stage, as well as his care needs, when deciding how much control to give him over his activities. She gave the example of her son not wanting his hair washed, or wanting to stay up to watch a television show.

He's a normal teenager. . . . he should be allowed to have those choices. . . . If it's a school night, it's midnight, he wants to watch another half hour show, if no one was there he would just watch it, like any other eighteen year old. But it was a real dilemma (for his nurses). . . . I'm trying to take the responsibility for every detail of his life away from them (nurses). Obviously, if they think he needs a trach suction and he says, "No," well, they may have to override that, but something that's not medical . . . they need to start giving him some breaks.

This mother was aware of what was developmentally normal for adolescents her son's age, and that knowledge influenced her decisions around how much responsibility to give him over his own activities.

As the parents' accounts explain, factors related to the child played an important role in decision-making. Parents considered both their child's medical condition and care needs, as well as the child's developmental stage when making decisions.

Parent Factors

The second main grouping of factors that parents considered when making decisions about the care of their child who was technology-dependent were those that related to themselves. Parents' stories contained examples of their own previous experience dealing with their child and health care professionals, underlying values they held, other family responsibilities they had, and their own level of fatigue or stress. Each of these acted as a factor influencing decisions they made.

Previous experience. Parents talked about three types of previous experiences that influenced their decisions. Overall experience observing and coming to know their child's condition, experience with their child's responses to specific interventions, and experience working with health care professionals all influenced future decisions regarding their child's care.

Parents were keen observers of their children. They recognized subtle changes in behavior that could indicate a deterioration in their child's condition. They could identify changes in respiratory sounds even from another room, or while they were sleeping. One mother gave a particularly vivid description of the various sounds her toddler made through his tracheostomy, and the meaning those different sounds had for her.

Well, it depends on how he sounds. . . . If he starts coughing and he gets all mucked up in there and he ends up clogging the hole, it makes little noises. When he gets dry, he whistles--it's just kind of a little path that he needs to clear. If he's wet, when he's really wet, usually he'll cough it out. But a lot of times it takes him awhile to do it. You just have to persevere, and just hold off (suctioning) because he will do it. I mean if he's not coughing it out, it's obviously not bothering him--

that's what I feel. . . . 'cause he has a really strong cough. I mean, it flies across the room!

This mother had had enough experience listening to the sounds her son made through his tracheostomy that she knew when it was safe to leave him to try to cough out the mucus on his own, and when she needed to suction. She didn't want him suctioned too frequently because, in her experience, "he gets lazy and he gets worse when you suction him more."

Another mother, having had considerable experience with infections that her son had contracted, explained, "We knew that if (child's) apex went even to 101, we knew an infection was brewing." Based on this knowledge, his parents could take steps to manage the infection early, such as taking him to his physician in the community, and perhaps preventing a hospital admission.

Parents developed specific ways of doing a procedure, or even total regimens for their child's care, based on their child's responses to various aspects of care. Often they had arrived at a particular method of doing a procedure after considerable trial and error, and were reluctant to change any aspect of it once they could see that their child was responding positively. Their experiences with their child's previous responses influenced their decisions about how they wanted care given. For example, one set of parents developed a certain way of cleaning the ventilator and other equipment that they believed had been effective in keeping their child infection-free for two and one half years. Another mother had a particular way of infusing a gastrostomy feed that resulted in less leakage around the tube and, therefore, maintained healthy skin around the site.

A third parent described a strict routine she tried to maintain for her toddler who had a rare metabolic disorder.

His little pancreas is a very stubborn entity and it says, "O. K. if you're gonna give me this much food in this way, then that's the only way I'll take it." So any changes to that, such as when nurses came in, if there was a change in routine, I was excessively concerned about that. I was excessively concerned about when he got his naps, when he got this, when he got that, because my experience and perception was that any change in that, I could not then predict his (blood) sugars.

This regimen was effective in keeping her toddler stable and, as a result, he appeared quite healthy. Therefore, it was sometimes difficult for others, including nurses, to understand the necessity of maintaining the strict routine his mother had developed. To help others understand, this mother wrote out her earlier experiences with her child

. . . so that they could see where we came from. It's very difficult. I find myself, when people ask me, "How is (child) now, as opposed to then?" I'm always focusing on the "then" part . . . I'm always concerned that people won't see where he's come from. And so they don't have the experience of how bad "bad" can get. They don't have that experience or that appreciation . . . so they don't have that level of urgency with him.

This mother used her earlier experiences dealing with life-threatening episodes her son had had, to educate others about the fragility of his condition.

The final type of experience that parents discussed as influencing decisions was that of dealing with health professionals. In particular, past experiences interacting with nurses in the home influenced future decisions regarding how to interact with nurses. One child, who had high care needs, had a number of nurses providing care in the home for long periods of time

each day. Because care was provided in an open area of the house, his parents believed that the nurses became almost "territorial" when other members of the family had to pass through the child's area. As a result of this experience, his mother decided to address the issue when orientating new nurses to her son's care.

So I think it is so important that all these things are gone over before. And now when I am training these people, we do discuss all these things. But I had not had experience. I didn't know. So you need to say--to acknowledge that they are inconvenienced.

This same mother, who looks after scheduling the nurses for her son's care, draws on her previous experiences when hiring and scheduling new nurses.

People come on and say, "Oh, I can do five nights, no problem." But I won't let people do that anymore. Because I know from experience that they're not going to last five nights and pretty soon they'll be coming to me and saying, "Actually, I would like to cut back to three nights." So I just start them off at three nights.

A second mother, whose previous experience included nurses in the home who told her, "We're here to do a procedure and this is the way we're doing it and don't tell us anything--we'll do it the way we want to," was influenced by this experience when choosing nurses to work with her son. When meeting nurses for the first time she noted "how they deal with him (child) . . . whether they turn around and ask questions." It was important to this mother to choose nurses who didn't have the attitude of knowing everything, but were open to listening to both the child and the mother.

These three types of experiences, that is, experience with the child's condition, experience with the child's responses to interventions, and

experience with health care professionals, influenced parents' decisions regarding their children's care.

Underlying values. The second parental factor that influenced decisions was that of underlying values. Parents described such values as guiding them when making decisions about their children's care. Parents' commitment toward and love for their children helped them make decisions when they needed to weigh various options for caregiving arrangements. When deciding what to do regarding her child's care when the regular nurse was not available and she needed to go to work, one mother was prepared to take time off work without pay. She explained her dilemma as being caught between wanting to go to work because she needed the money and didn't want to let her co-workers down, and wanting to be with her child. In the end she concluded, "but my obligation is to (child), of course." This same mother believed that a mother's place is with her child, particularly when a child is experiencing difficulties. When her child was admitted to hospital for minor surgery, and one of the nurses who had been caring for her at home offered to stay with her in the hospital so her mother could go to work, this mother decided against that and went to the hospital herself.

A second underlying value that guided parental decisions, and was discussed by a number of study participants, was that of the desire for as normal a life as possible with their child. Often it was this value that influenced the initial decision to take a child home, particularly for the parents who were the "pioneers". One mother said her seven month old son, who had been in hospital since birth, was "not developing socially and emotionally and mentally and spiritually the way that I want him to." The family decided to move to the Lower Mainland so that they could begin having him at home during the day, and gradually move toward having him

home full-time. The desire for a more normal environment for their son, as well as a holistic view of him, guided this family's decision to have him at home as much as possible.

Parents in a second family, who had had their child home for some time but had few formal supports, were becoming increasingly fatigued and unable to cope with their son's care. They sought supports that would assist them to continue to care for their son at home. "We were just trying to be a normal family, keep our child home, love him, do all that sort of thing." Their desire for a normal life, which included having their son who was technology-dependent continue to live at home, influenced their decision to seek formal supports. They were able to arrange nursing respite care which enabled them to continue to manage at home.

The desire for normalization influenced decisions about which caregiver would provide care in a particular setting, as the following story illustrates.

When we were at the park yesterday, there was a nurse on shift with (child). But when it came time for his cath (catheterization) to be done it was more--seemed more appropriate at the time--for (father) to take (child) in the men's bathroom and do his cath, than the nurse, who is a woman, to take (child) and do his cath.

This family tried to make things as normal as possible for their adolescent son.

One mother, who desperately needed some extended respite, had the option of placing her child in hospital for a short time. However, as much as she wanted time to herself, she believed it would be inappropriate to place her son in "a clinical setting that just simply reinforced all of the things we didn't want to reinforce." She was somewhat dismayed by her own strong

feelings on this point, adding, "I've taught programs in normalization and I never, ever thought I'd get to the point where I'd be a normalization snob!" However, her desire for as normal an environment as possible for her son took precedence over her own need for rest, and she did not admit him to hospital.

The desire for normalcy is closely linked to parental knowledge of the developmental stage of their child. One family, when trying to decide what kind of involvement to have with their son's high school, knew "we want to normalize (child's) situation as much as possible and normalize the family situation." Therefore, the parents came to the following decision:

We try, as far as (child's) academic needs, to get really involved in that.

If there are problems, say with the nursing in the school, then we try to stay out of that. We would like to stay just as parents.

The value these parents placed on normalcy guided them in decisions they made regarding the type of involvement they would have with school staff.

Parental values regarding normalization also influenced decisions about which nurses to have care for their children. In response to the interviewer's question as to whether she thought the nurses tended to promote normalization, this mother replied:

Oh, the nurses are all very gung ho about that and they want to make things as normal as possible for (child). That's why we have the people that we have is because they've all got the same goals for (child) that we have, which is his independence, his well-being, his socialization and, well, the whole ball of wax.

This "whole ball of wax" included such things as having the nurse accompany the child and family to Sunday dinners with extended family

members. It was important to these parents that nurses who cared for their son were able to fit into the usual family activities.

Finally, parents discussed their own religious beliefs, or their lifestyle, as factors that influenced decisions they made about which nurses they wanted to care for their children at home. One mother preferred to have nurses in the home who belonged to the same religion as she did. Another mother stressed the importance of having nurses in the home who understood her busy, and somewhat disorganized, lifestyle.

Thus, the values parents held influenced decisions they made about their children's care. Further, parents were able to articulate and discuss these abstract values, and the manner in which they influenced their decisions.

Other family responsibilities. The third parent factor that influenced decisions was that of other family responsibilities. Although all the children of parents who participated in this study had extremely high care needs, parents had other family responsibilities in addition to the care of their child who was technology-dependent.

A single working mother, whose child usually attended school, decided to change her nursing respite hours from night shift to day shift when her child had an acute illness and had to stay home. This decision made it possible for her child to be cared for by the nurse during the day, while the mother went to work. The competing responsibility of this mother's job influenced her decision to change the nursing hours.

Parental responsibilities toward siblings also influenced decisions regarding care of the child who was technology-dependent. In one family the well sibling was moved out of the bedroom the children shared, so that the child who was technology-dependent wouldn't waken his brother. Another mother, who had to get up early to get her well child to school, decided it was

safe to go to bed before the nurse arrived for the night shift. She had been staying up until the nurse arrived, but her need to get up early for her well child, combined with the technology-dependent child's more stable condition and increased trust in her own ability to waken in response to the monitor alarm, influenced her decision to decrease the level of vigilance she had maintained until that time.

In another family the mother was pregnant. The anticipation of a new baby, and the responsibilities she would have toward that baby, were influencing factors in the mother's decision to actively look for, and train, a back-up caregiver for her son who was technology-dependent.

Level of fatigue/stress. The final parent factor, discussed by a few study participants, was that of their level of fatigue and/or stress in relation to decision-making. Often fatigue was given as a reason for finally deciding they needed some kind of help to manage the care of their technology-dependent child at home. One mother described her level of stress as being so high she was afraid her child was at risk, being cared for by herself.

I felt (child) was at risk. I felt that I could no longer (cope) without assistance fairly quickly--that both of us were at risk. I was at risk of burning out and being totally dysfunctional . . . with the medication and the testing and the nasogastric feeds I could not--I wasn't keeping a handle on that--and that's what, in my mind, put (child) at risk.

This mother believed that her level of stress was affecting her judgment regarding decisions about her child's care; this degree of stress influenced her decision to seek help. Other parents identified fatigue as a factor that influenced their decision to have nurses provide some of the care for their technology-dependent children at home.

Thus, factors related to the parents, themselves, influenced decisions they made about the care of their child who was technology-dependent and living at home. Parents considered their own previous experiences, both those related to their child and those related to health care professionals, the values they held, other family responsibilities they had, and the level of fatigue and/or stress they were experiencing, when making decisions.

Environmental Factors

The third major grouping of factors that influenced parents' decisions were those related to their environment. The interactions parents had with nurses, or the interpersonal environment, influenced decisions they made. Decisions were also influenced by the availability and types of services and supports, as well as physical aspects of the home.

Interpersonal environment. All the parents who were interviewed for this study had had extensive interactions with nurses and other health care professionals. As well, all the families received some nursing respite in their homes. The interaction that parents had with these health care professionals was another factor that influenced decisions they made regarding the care of their child who was technology-dependent. Three aspects of the parent-professional interaction that influenced decisions were the level of trust in a nurse, the attitude or behavior of a nurse, and the information exchanged between the parent and the health care professional.

The level of trust parents had in a nurse influenced their decisions. One mother told a story about the time when she first had her son, who was tracheostomy-dependent, at home. She had been taught in the Intensive Care Unit (ICU) that, when caring for her son's tracheostomy, "'You cannot instill too much.' That's how I perceived it." When at home she frequently instilled her small child's tracheostomy with up to 6cc of saline to loosen his

secretions. One nurse, who cared for him in the home, was concerned about the amount being instilled, frequently without suctioning afterwards. However, when she expressed her concerns to the mother, the mother explained, "I didn't think she knew as much as the ICU staff." The trust this mother had in the ICU staff influenced her decision to instill these amounts of saline. Unfortunately, her son was admitted later to hospital with aspiration pneumonia, and had to be mechanically ventilated for a period of time.

Attitudes and behaviors of nurses also influenced parents' decisions. A mother said about her son, "I was really scared to take him out at first." However, one of the nurses, who cared for him at home, would "just take him out for a walk. Once she started, I got a little better. . . . it helps a lot. If they (nurses) are not scared to do something, then you shouldn't be scared." This mother's decision to take her son out of the house was influenced by the nurse's behavior.

This same mother described another situation in which she may have been influenced by the attitude of a nurse. She described the nurse, who believed the mother wasn't receiving enough in-home nursing support, and "phoned up (agency) and said that this is not fair. Here is this little child that has just come home and his mother is at her wit's end and I want to work with him." The attitude of this nurse may have influenced the mother's feelings of being able to cope with the situation, as well as her decision to ask for more help.

Information exchange was a final factor in the interpersonal environment that influenced parents' decisions. Parents need information to make decisions, and expect health care professionals to provide them with that information.

It would be appropriate, I think, for nurses to bring in those outside resources as part of their job if there was something appropriate for the family. I'm the type of person that really wants a great deal of information. I want as much clinical information about this as possible. It's how I cope; it's how I create control.

This mother recognized her need for information, not only about the management of the physical aspects of her child's illness, but also about the management of the psychological impact of the illness on her child and family. She wanted nurses to provide that information for her so that she could make more informed decisions regarding the care of her child.

Parents expected nurses in the home to share information with them about their child's condition. One mother told of a situation, when she first had nurses in the home, where this was not the case. She had been told that she was not supposed to read the notes written by the nurses in the home. She explained, "But I really, really wanted to know everything to do with my son--and why not? He's my son . . . I have a right. And how can you be a competent mother if you don't?" This mother knew that she needed information if she were going to make good decisions about her son's care.

Two methods of exchanging information with nurses were discussed by parents, the communication book, and team meetings. Parents discussed both these methods as being effective means of exchanging information with nurses in the home. Both parents and nurses wrote in communication books, often about aspects of the child's condition or care. The information was valuable for parents, who could use it to identify potential problems and then make decisions about the management of them, as the following quote illustrates. "It's good for us to go back and say, 'Well, gee, it's been the past

three weeks he's been high pressuring a lot at night, so maybe there's some kind of pattern here.'"

Team meetings, which included both nurses and parents, were a second method of exchanging information. Team meetings were used to . . . exchange ideas and information about how to handle situations with him (child) and see if they (nurses) have similar needs or problems. So, it's very valuable--for (child) especially--consistency, care, working towards his independence; how can we do that? We have to work as a team and you can't work as a team when you don't get together.

These parents used team meetings to exchange information with the nurses, which was then used as a basis for making decisions about their child's care. Parents appreciated information that nurses gave them, and used it when making decisions. "The nurses come up with a lot of really good ideas about ways things can be done more efficiently, and the team meetings have really helped with that." Another mother described her interaction with the primary in-home nurse:

She has a lot of input into . . . how he is feeding, what he is doing, and she's constantly making suggestions for things that might help him. And I really appreciate that because I don't often know everything . . . lots of times we follow the suggestions she makes and it works really well.

The parents quoted above recognized that the nurses who cared for their children had knowledge that the parents might not have, and were open to incorporating nurses' ideas or suggestions into the care regimen. However, they viewed themselves, not the nurses, as the ones who would decide whether an approach to care would be changed, or not.

Thus, three aspects of the interaction parents had with nurses influenced parental decisions. Parents considered the level of trust they had with nurses, the attitudes and behaviors of nurses, and information received from nurses when making their decisions.

Availability and type of supports/services. Many parents talked about the supports and services, or lack of supports and services, that were available to assist them with the care of their children who were technology-dependent. They discussed the availability of both informal and formal supports as a factor that influenced decisions they made about the care of their children.

Often families had few choices regarding caregivers for their children who were technology-dependent; because of their complex care, family members and friends were fearful of caring for them. If informal supports were available, parents could use them. In one family the father had been ill and unable to learn his son's care. When he became well, the parents decided he would learn the care, even though he was not living with the family at the time. This decision enabled the mother to have a back-up caregiver.

A number of parents identified the availability of nurses as a factor that influenced their decisions regarding which nurses to have care for their children. If few nurses were available, parents were more likely to accept a nurse in their home who did not meet their "ideal," rather than have no one cover a shift in the home.

The availability of other types of services also influenced parents' decisions. One family moved from a small town in the interior of the province to the Lower Mainland, where the specialized services they needed for their son were available.

Finally, the policies of support services influenced parents' decisions. Parents sometimes had limited options because of the rules that governed what nurses could or couldn't do. One mother would have liked to have the nurse drive her son to preschool in the nurse's car. However, the existing policy was such that nurses could not be responsible for both driving a car and caring for a child with a tracheostomy at the same time. Therefore, this mother had few options but to take her son to preschool on the bus. The existing policy influenced her decision to manage the situation in this way.

Physical aspects of the home. A few parents described decisions they made that had been influenced by physical characteristics of their homes. For example, when large pieces of equipment needed to be accommodated, consideration had to be given to the amount of space available in the house or apartment. In one family the decision was made to give the larger master bedroom to the child who was technology-dependent, while the mother and sibling shared a smaller bedroom. In another family the child who was technology-dependent was allocated space that had been the dining room. The arrangement of the house was such that, by having him in this area of the house he was able to be closer to family activities. However, as he became older and privacy became an issue, his parents decided to build a suite for him in another part of the house. The fact that there was space to accommodate a small suite in their house influenced their decision, making it possible to give him the privacy he wanted.

The arrangement of rooms in a house or apartment also influenced parents' decisions about their child's care. One mother decided to sleep in a room near her toddler, even when nurses cared for him at night, so as to be able to hear him. Having a room near her toddler's bedroom made it possible for her to do this.

Thus, factors in the environment influenced decisions parents made about the care of their child. Decisions were influenced by the interpersonal environment, or interaction parents had with nurses or other health professionals. Further, they were influenced by the availability of informal or formal supports and services, as well as physical aspects of the home.

Summary

In this chapter the findings have been presented. Parents in this study cared for their children who were technology-dependent and living at home, incorporating their complex care into the day-to-day life of their families. In the course of doing this, they made a wide variety of decisions related to that care. Although all parents expected to make decisions regarding their child's care, some described periods of time during their experience when they were either less able or less willing to do that, and at those times appreciated nurses taking a more active role to help them. However, if parents perceived that nurses did not acknowledge them as the decision-maker, and provided care in a manner different than the parents wished, it was stressful for them.

The stories parents told illustrate the multiplicity of factors that influence the decisions they make. Seldom did they consider one factor in isolation from others. Parents considered not only factors related to their child's medical condition, but also those related to their child's developmental stage. As well, they considered factors related to themselves, such as their previous experiences, the values they held, other family responsibilities they had, and their level of fatigue and/or stress. Finally, they considered environmental factors, such as aspects of their interactions with nurses, the supports and services that were available to them, and physical aspects of their homes. These factors were considered simultaneously, and influenced the resulting decisions in various directions.

Thus, the findings of this study reveal that parental decision-making is a complex, changing process. In the following chapter key ideas from these findings will be discussed in relation to the existing theoretical and research literature.

Chapter 5: Discussion of the Findings

Introduction

The purpose of this research was to increase understanding about parental decision-making regarding the day-to-day care of children who are technology-dependent and living at home. In this chapter three key ideas from the findings will be summarized and discussed in relation to the theoretical and research literature. First, the concept of the parent as overall manager of a child's care will be presented. Then, the notion of parental readiness for decision-making will be discussed in relation to literature that addresses parental adaptation to having a child who is technology-dependent. Finally, aspects of the findings that relate to the parent-nurse relationship will be presented and discussed.

Discussion

Parent as Manager of Child's Care

All parents who participated in this study provided complex care for their children who were technology-dependent and living at home. They were confident in their own caregiving abilities, and expected to make decisions regarding their child's care. They were open to suggestions from nurses who provided in-home care, particularly during the initial stage of caring for their child at home. However, they viewed themselves, not the nurses, as responsible for deciding whether a particular suggestion would be incorporated into their child's care regimen. Further, they expected to be consulted on all decisions regarding their child's care. That is, parents viewed themselves as the ones ultimately responsible for managing the day-to-day care of their child.

These findings support Dixon's (1991) description of parents who she identifies as "Managers of Care" in her Parent-Nurse Interaction Model. The current study provides a strikingly similar picture of parents who are "in control of health-related decisions and use nurses for direct care and consultation. They are frequently involved in providing technologically complex care to their chronically ill child" (cited in Ahmann & Rollins, 1995, p. 935). Dixon describes "Managers of Care" as having an increased sense of responsibility for their child's care, and a high level of control over decision-making, often making decisions alone and using professionals as consultants. Parents who are "Managers of Care" also manage professional care in the home, scheduling it as needed. They have an attitude of, "I am the expert on my child."

Other authors have described similar characteristics of parents who care for children with complex medical conditions over long periods of time. Cender (1995) describes parents becoming expert primary caregivers of children who have medically-fragile conditions. These parents consider themselves "experts in the care and treatment of their child" (p. 148). As well, they may direct others, such as in-home respite nurses, in the care of their child. Hatton, Canam, Thorne and Hughes (1995) describe parents of infants and toddlers with insulin-dependent diabetes as achieving confidence regarding management of their child. Jerrett (1994) also noted that parents of children with juvenile arthritis moved toward "being able to take charge and manage the child's illness on a day-to-day basis" (p. 1054). The current study supports these few studies that describe the parent as manager/director of their child's care, and provides increased detail regarding the health-related decisions parents make.

Parental Readiness for Decision-Making

A second key area from the findings is that of parental readiness for decision-making. The findings from the current study suggest that the degree of control parents wish to have over decision-making related to the care of their child varies over time. When first managing their child's care at home, parents may feel overwhelmed, and appreciate nurses helping them make decisions, or set up a regimen for care. However, over time, all parents in this study became extremely competent with their child's care, and wished to be the ones to make decisions about that care. Two parents expressed the desire that someone else take more responsibility for making decisions, thus relieving them from their role of overall manager, when they felt exhausted.

Parental readiness for decision-making can be viewed as part of the overall process of adaptation to having a child who is technology-dependent. Thomas (1986) describes the families of children who are ventilator-dependent as first being "overwhelmed and dependent on others for the care of the child and for their own emotional support. Family members were willing to be told what to do" (p. 184). However, as parents gradually understood that their child would require on-going ventilator support "they began to learn the child's care, gather information for themselves and gain skills and knowledge" (p. 184). Thomas identifies knowledge acquisition as an indicator of adaptation to having a child who is ventilator-dependent. From that perspective, parents seek knowledge only after they have accepted that their child's condition is relatively permanent. Thomas describes this process as occurring during the child's initial hospitalization.

Hatton, et al. (1995) also identify phases of adaptation in parents who have an infant or toddler with insulin-dependent diabetes. During the period of initial diagnosis and hospitalization, as well as the first six to eight months

at home following diagnosis, parents experienced extreme stress and relied on health professionals for support and advice. However, during the final phase, which the authors label long-term adaptation, parents coped by taking charge of the situation. Also, "because they had established some confidence about diabetes management for their child, the parents found themselves capable of more flexibility in their diabetes management routines" (p. 574).

Cender (1995) also describes stages in the process of the evolution of parents as they move from novice to expert caregivers of their child with a medically-fragile condition. The first three stages take place during the child's initial diagnosis and treatment in hospital, ending with the parents becoming expert caregivers in the hospital setting. Cender describes a fourth stage that occurs after the initial discharge of the child from hospital, as parents assume the primary caregiver role at home. Although they had become expert caregivers of their child in hospital, "they considered themselves as inexperienced in terms of caring for their child at home" (p. 60). It took parents several weeks before they viewed themselves as "the child's primary caregiver, the primary decision-maker regarding the child's care, and as 'supervisors' of respite nurses and other health care workers who provided care for the child in their home" (p. 62). That is, there was a period of parental adaptation and/or learning that occurred in the home.

The current study supports the findings from the above three studies. Parents described needing time "to get adjusted" to the care of their child at home, but they eventually reached a high level of competence with that care. They expected to make decisions related to their child's care and have others follow their directions; that is, they expected to be the primary caregiver and "supervisor" of care.

Parents' accounts from the current study are similar to Cender's (1995) findings in terms of parental readiness to assume the primary caregiver and decision-maker role in the home. However, findings from the current study suggest that parents who have managed the care of their child at home for long periods of time may experience a further stage of adaptation, that of transferring the role of overall manager to another individual. Although neither parent who expressed a desire for someone else to take over their leadership role had been able to arrange that, it is interesting to note that both were willing to give up their role as manager. Presumably, this stage would occur only after parents had become expert managers of their child's care, and were able to evaluate another person's ability to manage the care in a manner similar to themselves. Also, parents would retain overall authority, and therefore be able to reinstate themselves as manager if at any time they were dissatisfied with the arrangement.

Thus, the process of parental adaptation to having a child who is technology-dependent consists of a number of stages, and includes changes to the degree of control parents wish to have over decision-making regarding the care of their child. As described by Thomas (1986) and Cender (1995), during the initial stage parents feel overwhelmed and willingly allow health professionals to manage the care of their child, usually in a hospital setting. Gradually, as parents realize their child is likely to require ongoing care, they seek knowledge and skills needed to provide that care, becoming expert caregivers in the hospital setting. The current study supports the findings of Cender that, following discharge home, parents may once again feel overwhelmed and appreciate assistance from nurses to help them develop a care regimen. However, over time, parents become the manager of care and decision-maker for their child at home, and expect to direct other caregivers.

Finally, findings from the current study suggest that, after parents have managed the care of their child who is technology-dependent for a long period of time, they may be ready to transfer the manager role to another responsible individual.

The Parent-Nurse Relationship

A third key area in the findings from the current study was that of the parent-nurse relationship. Although not explicit, the parent-nurse relationship was an underlying theme in many of the parents' accounts. Health professionals, and nurses in particular, played an important role in the lives of families whose children were technology-dependent. Not only did families have contact with health professionals in hospital and clinic settings, but the children of all parents in the current study received in-home respite care from nurses.

Understanding a family's paradigm. All study participants expected to make decisions regarding their child's care. This, in itself, has implications for the parent-nurse relationship. If nurses did not recognize the degree of control parents expected to have over decisions about the care of their child, and instead provided care based on their own view of what was best for the child, it created stress for parents, and conflict between themselves and parents.

Thomas (1986) emphasizes the importance of the health care provider understanding a parent's world view, suggesting that the interaction between a parent and care provider is based upon this understanding. If a parent and nurse are operating from "divergent paradigms" conflict is inevitable. On the other hand, if care providers operate from a paradigm "convergent" with the family's they are viewed by parents as supportive and caring; understanding,

or "knowing" the family's paradigm, and operating from that basis, results in behavior that is viewed by parents as caring (p. 196-197).

The findings from the current study offer a window through which a family's paradigm can be "known". Being aware of how much control parents want to have over decision-making, as well as understanding the importance they attach to various factors that influence child care decisions, is a specific area of a family's paradigm that can be elicited through discussion with parents. Understanding a family's paradigm, or worldview, creates the basis for effective communication and collaboration with parents.

Type of relationship. As parents in the current study described managing the care of their child who was technology-dependent, several characteristics were evident. Parents were extremely knowledgeable about their child's condition and care needs. They considered themselves the primary caregiver, and expected to make decisions regarding their child's care. They wanted nurses to acknowledge them as the decision-maker and manager of care.

All parents had developed a high level of competence with their child's care, and were able to assess the ability of other caregivers. As well, all parents had had extensive experience dealing with health professionals in hospital, clinic, school, and home settings. They recognized that professionals had information that was helpful to them, and expected to be provided with the information they needed in order to make decisions regarding their child's care. Some parents developed specific strategies for information exchange between themselves and nurses in the home.

These characteristics of parents are remarkably consistent with the findings of other researchers who have explored the experience of parents of children with a chronic illness (Bond, Phillips, & Rollins, 1994; Cender, 1995;

Knafl, et al., 1992; Krepper, Young, & Cummings, 1994; Patterson, et al., 1994; Scharer & Dixon, 1989; Thomas, 1986; Thorne, 1993). The type of relationship these parents prefer to have with health professionals has been described variously as collaborative, negotiative, or co-operative. That is, parents value and need information from professionals, but wish to have it presented in a manner that respects their own areas of knowledge and expertise. They wish to be included in the decision-making process, and to have professionals support their choices. They appreciate professionals being sensitive to their family situation, and interacting in a caring and respectful manner with them. When parents were able to interact with health professionals in this manner, it increased their feelings of competence and empowered them.

The above studies, when outlining the type of relationship parents prefer to have, invariably identify control issues and conflict as recurring problems parents encounter when dealing with health professionals. Parents describe difficulty establishing boundaries for control of aspects of their child's care with in-home caregivers (Patterson, et al., 1994), having information withheld from them and decisions made unilaterally by health professionals (Thomas, 1986), and having their role as expert caregiver discredited (Cender, 1995). Interactions such as these result in parents feeling angry and disempowered.

Dunst, Trivette, Davis, and Cornwell (1988) suggest that health professionals

have been socialized to believe that they and only they are capable of improving their clients' lot, and to suggest that others might be capable of managing events that professionals have been trained to

deal with as experts becomes a direct threat to their sense of competence. (p. 71)

However, there is a major discrepancy between an approach that tries to "rush in and 'fix' children and families" (p. 79), and a family-centered approach to care that promotes the active involvement of parents in the care of their children with health impairments. The authors propose a model for parent-professional interaction that, rather than creating dependence on professionals, enhances feelings of competence in the parent.

Dunst, et al. (1988) identify a number of characteristics of help-givers that are associated with feelings of control, competence and empowerment in the help-seeker. Several of these characteristics have relevance for the parent-nurse relationship in the home and, in particular, parental decision-making within that relationship. First, the authors suggest that an attitude that "assumes help seekers have the capacity to understand, learn about, and manage *all* events in their lives" (p. 73), is competency-producing. The expectation that parents are, or will be, the decision-makers and managers of their child's care represents such an attitude.

Second, the authors identify certain help-giver behaviors that enhance feelings of competence in the parent. Offering assistance that the help-seeker has identified as a problem or need, working in partnership with the help-seeker, and allowing decision-making to rest with the help-seeker are all behaviors that emphasize parental control. Acknowledging parents as the decision-makers, and providing information that parents request is one way of working in partnership and placing control for decision-making with parents.

Finally, the authors suggest that a help-giver's response following a helping interaction influences parents' feelings of competence. The help-

giver must "accept and support the decisions of help seekers" (p. 75).

Providing a child's care in the manner specified by parents respects and supports their decisions.

These attitudes, behaviors and responses described by Dunst, et al. (1988) parallel what parents in the current study described as finding helpful in their relationships with professionals. Findings from the current study offer a specific focus for interacting with parents, that is, communicating with parents about their child's care and decisions they make regarding that care. An attitude that assumes parents are, or will be, the managers of their child's care, behaving in a manner that respects the parents' areas of expertise and offering information when requested by parents, as well as providing care in the manner parents have indicated they wish care given empowers parents and increases their feelings of competence. An approach that includes the client and family in identifying goals for care fits well with a nursing tradition that emphasizes the inclusion of the client in all phases of the nursing process (MacElveen-Hoehn, 1983).

Summary

In this chapter three key areas from the findings have been discussed in relation to the theoretical and research literature. Specifically, the idea of the parent as the manager of care was discussed in relation to Dixon's Model of Parent-Nurse Interaction (1993) and other literature; the notion of parental readiness for decision-making was discussed in relation to literature that addresses parental adaptation to having a child who is technology-dependent; and parent-nurse interaction was discussed in relation to understanding a family's paradigm, literature that describes the experiences of parents of children with a chronic illness, and Dunst, Trivette, Davis and Cornwell's

(1988) Enablement Model for Helping. In the following chapter a summary of the study, conclusions, and implications for nursing will be presented.

Chapter 6: Summary, Conclusions, and Implications

Summary of the Study

Over the past decade an increasing population of children who are technology-dependent and living at home has created new roles for parents. Parents provide all aspects of their child's care, including procedures that have traditionally been within the health professional's domain of practice. Parents also function as overall coordinators of their child's care, organizing delivery of equipment and supplies, scheduling caregivers, and monitoring the quality of care provided by others.

Because of the complexity of care these children require, nurses are often hired as caregivers in the home. The resulting parent-professional relationship has been identified as a major component of the experience of caring for a child who is technology-dependent and living at home. The desire of parents to take a more active role in managing their child's care is occurring within a system that has traditionally viewed the professional as the manager and decision-maker regarding health care. The decisions parents make regarding the care of their child who is technology-dependent may be based on factors that are different from those that professionals consider. If professionals do not understand the factors underlying parental decisions, assuming parents subscribe to the same assumptions, values, and beliefs as themselves, control issues and conflict are likely to occur.

The purpose of this study was to explore and describe the factors that parents perceive as influencing their decisions regarding the care of their child who is technology-dependent and living at home. Understanding parental perspectives will allow nurses to interact with parents in a manner

that respects parental decisions regarding the care of their child, and yet offer support, if necessary, for parents to make decisions.

A secondary analysis was performed on qualitative data that had been collected for a phenomenological study which explored and described the role of the nurse who provides in-home care for children who are technology-dependent. The parents of 10 children who were technology-dependent were interviewed between one and three times for the primary study. In total, 16 transcripts, representing approximately 24 hours in interview time, and one transcript of a focus group interview were analyzed for the current secondary study.

An interpretivist paradigm, using the perspective of symbolic interactionism, guided this study. As such, the goal of analysis was to understand a lived experience from the point of view of those who lived it. Specifically, the process of analysis involved examining transcripts from parent interviews to identify key phrases or statements that related directly to decisions parents made regarding the care of their child who was technology-dependent. These key phrases were interpreted and inspected for what they revealed about parental perceptions of decisions they made, and the factors that influenced those decisions.

Findings from this secondary analysis revealed that, during the process of providing care for their children who are technology-dependent and living at home, parents make many decisions related to that care. However, the degree of control parents wish to have over decision-making varies during their experience of caring for their child at home. When first at home with their child, parents may appreciate help from nurses to set up care routines. As they become more confident in their own ability to care for their child, parents generally take more and more responsibility for decision-making and

overall management of care. If nurses do not realize the degree of control parents wish to have over decision-making, and either make decisions without consulting the parent, or ask too many questions of them, it is stressful for parents and has the potential to create a conflictual relationship between the nurse and parent.

The kinds of decisions parents make include a variety of aspects of care. Parents make decisions related to normal parenting issues, to the management of their child's illness, to organizing health care supports, and to sustaining family life. This broad range of decisions provided rich content for analyzing the factors that influence parental decisions.

Parents often consider a multitude of factors before making a decision about the care of their child, and individual factors may influence the resulting decision in various directions. These factors can be clustered under three main groupings: child factors, parent factors, and environment factors. Factors related to the child include the child's condition and care needs, as well as the child's developmental stage. Factors related to the parent include the parent's previous experience with their child's condition and care, as well as their previous experience with health professionals. Other factors related to the parent are their underlying values, other family responsibilities, and their level of fatigue and/or stress. Finally, factors related to the environment include the interpersonal environment, such as the relationship between the parent and nurse, the availability and type of supports and services, and the physical aspects of the home.

Three key ideas from the findings were discussed in relation to the existing theoretical and research literature. First, the idea of the parent as manager of the child's care is similar to that of Dixon's (1991) description of parents as "Managers of Care". The current study extends Dixon's description

by providing increased detail regarding parental perceptions of decision-making as part of their role of manager.

Second, the idea of parental readiness for decision-making can be viewed in the context of overall adaptation to having a child who is technology-dependent. Thomas (1986), Cender (1995), and Hatton, et al. (1995) describe stages that parents experience when moving from initial feelings of being overwhelmed, to that of being expert caregivers of their child. The current study suggests that, after long periods of time caring for their child at home, parents may experience a further stage of wanting to transfer the role of overall manager of care to another responsible caregiver.

Finally, the idea of the parent-nurse relationship was an underlying theme in most of the parents' accounts. The current study supports the findings of other researchers who have explored the parental experience of caring for a child who is technology-dependent, in that it identifies the parent-nurse relationship as a major component of that experience. Further, parents in the current study describe helpful interactions between themselves and nurses that support the "Enablement Model for Helping" developed by Dunst, et al. (1988).

Conclusions

Some conclusions can be drawn from the findings of this study, and are listed below.

1. Parents expect to be the managers of care for their children who are technology-dependent and living at home, and to make decisions regarding that care.

2. Parents make a number of different kinds of decisions regarding their child's care. Decisions they make relate to normal parenting issues, to the management of the chronic illness, to organizing health care supports, and to sustaining family life.
3. Parents consider a multitude of factors related to their child, themselves, and their environment when making decisions. Individual factors may influence the decision in various directions.
4. Parental readiness for decision-making varies over time. When first at home with their child, parents may appreciate assistance from nurses to set up care regimens. As parents develop expertise in caring for their child, they expect to make decisions about the care and direct other caregivers. Some parents, who have managed their child's care for long periods of time, may wish to transfer the role of manager to another trusted individual, while still retaining overall authority for their child's care.
5. If nurses do not recognize the degree of control parents wish to have over child care decisions, operating from their own perspective rather than the parents', conflict is likely to occur.
6. The parent-nurse relationship is a major component of the experience of caring for a child who is technology-dependent and living at home.

Implications for Nursing

The findings from this study have implications for nursing practice, education, and research. As well, there are implications for planning in-home respite services to support families with children who are technology-dependent.

Implications for Practice

As the number of children who are technology-dependent increases, so, too, does the number of interactions nurses have with the parents of these children. Nurses encounter these children and their families in hospitals, homes, schools, and other community settings. The findings from the current study can inform nurses about the parental perspective regarding their role as decision-maker and manager of their child's care, thus having direct relevance for nurses who work with these parents.

First, the findings from this study can assist nurses to broaden their role from that of provider of direct care, to that of assisting parents to become managers of care. Being aware that parental readiness for decision-making varies, the nurse can assess the degree of control parents wish to have over decision-making, and interact with parents based on that assessment. Thus, the nurse's role may involve teaching parents about aspects of their child's care, including helping them identify critical indicators that would direct them regarding decisions about their child's care. The nurse's role might also include assisting parents to set up an overall regimen for care at home. Or the nurse's role might be to provide care in the manner a parent has indicated they wish care given, thereby validating and increasing the parent's feelings of competence and empowerment.

A further way in which the nurse's role might be broadened is by taking on the role of overall manager of a child's care at home. Parents who

wish to transfer this responsibility to a nurse, however, would likely expect to retain overall authority for their child's care. This expectation has implications for the type of relationship that would develop between a nurse and a parent. Unlike the hospital setting, where the nurse has both the responsibility and authority for the nursing care of children, in the home these are shared. Nurses would need to be able to work collaboratively with parents to plan care, organize equipment and supplies needed for that care, hire and schedule nurses, and monitor care provided by others.

Second, if differences exist between a parent and nurse about some aspect of a child's care, the findings from this study can assist nurses to understand those differences, and work collaboratively with parents to decrease conflict. For example, if a nurse believes a parent is giving unsafe care, or is directing the nurse to give unsafe care, the findings provide a framework to help the nurse understand the factors that influenced the parent's decision. The nurse can explore with the parent factors related to the child, to the parent, and to the environment that may have influenced the decision. In this way, the nurse can identify the source of the difference between parent and nurse, which can then be addressed.

Further, the nurse can differentiate between differences in values, and differences in knowledge, or information. This, in turn, has implications for how the nurse would intervene. If differences are due to value differences, this may need to be acknowledged and either accepted, or a decision made that the nurse and family cannot work together. If, however, differences are due to a lack of information on the part of the parent, the nurse may offer a rationale for providing care in a particular manner, based on nursing knowledge. On the other hand, the parent may have information or knowledge about the child, or the child's condition, that the nurse does not

have, and thus offer a rationale that satisfies the nurse regarding safety of the child.

Thus, the implications of the findings for practice are two-fold. The findings can help nurses who work with technology-dependent children to broaden their role from that of direct caregiver to that of assisting parents to become managers of their child's care. As well, the findings from this study offer a framework for nurses to understand and address differences that may occur between nurses and parents regarding care for a child. In this way, conflict may be avoided.

Implications for Education

The population of children who are technology-dependent and living at home is relatively new, as is the notion of their parents as managers of care. The findings from this study reveal that parents experience stress when nurses do not acknowledge them as the decision-maker, and, instead, provide care in a manner that is different from the parent. However, nurses who work with technology-dependent children may not have an appreciation for the differences between the manner in which their parents expect to interact with health professionals, and the manner in which parents of children hospitalized for acute illnesses expect to interact with professionals. Thus, there are implications for the education of nurses who work with children who are technology-dependent and their families. Ideally, in-service education would be available for nurses before they begin to work with these children and their families in either the home, school or hospital setting.

Findings from this study could be incorporated into course content that addresses the parent-nurse relationship. In particular, introducing the idea of the parent as manager of their child's care, and the implications of that for the relationship, would be valuable information for nurses to have before

beginning to work with children who are technology-dependent and their families. Also, the idea of parental readiness for decision-making, and the need to assess this when working with families, could help nurses interact in a manner that acknowledges the level of control parents wish to have over decisions. Further, informing nurses about the multiplicity of factors parents consider prior to making a decision about their child's care could help nurses develop an appreciation for the complexity of parental decision-making. As described earlier, the findings could also provide a framework for nurses to use if there are differences between themselves and parents regarding child care decisions.

In summary, the findings from this study point to the need for some specialized education for nurses who work with children who are technology-dependent and their parents. Because this is a new population of children, most nurses have not had previous education regarding these children and their families, or experience working with them.

Implications for Research

The stages of parental adaptation outlined in Chapter Five of this thesis are based on the theoretical literature and two qualitative studies, as well as the current study. Further investigation that validates and expands on these stages is needed. As well, information about behaviors of health professionals that parents find helpful at each stage of adaptation would contribute valuable insights that could be applied directly to practice. A model such as the "Enablement Model of Helping" (Dunst, et al., 1988) might be used as a framework for such a study.

A second area for further research is that of decision-making by in-home or hospital nurses concerning the care of children who are technology-dependent. Insight could be gained by understanding both nurse and parent

perspectives regarding the factors that influence decisions regarding child care. Understanding differences between the perspectives could help identify sources of difficulty that so frequently lead to the conflict that is identified in the current study as well as most other studies that explore the experience of parents who care for a child who is technology-dependent.

Because caring for children who are technology-dependent and living at home is a relatively new area of nursing, there is still much to learn. The above two studies would increase understanding about aspects of the parent-nurse relationship, an area that has been identified by parents as a major component of their experience caring for their technology-dependent child at home.

Implications for Program Planning

As well as having implications for specific areas of nursing practice, education, and research, the findings from this study have implications for the broader sphere of program planning for in-home respite services. The findings suggest that parents appreciate specific kinds of help from nurses at specific times during their experience of caring for a technology-dependent child at home. For example, when first at home parents may require assistance from nurses to set up a care regimen. Also, some parents may reach the stage of wanting a nurse to take on the role of overall manager of care. However, for the majority of time that parents care for their child at home they expect to make decisions themselves and direct others who provide care for their child in the home.

During the period of time that parents are the primary decision-makers and directors of care for their child, caregivers other than nurses might safely provide respite care. The nurse's role could change from one of direct caregiver to one of assisting parents to identify and teach suitable unlicensed

caregivers to provide respite care for their child. Nurses could help parents identify specific characteristics that parents believe are important in any caregiver who might care for their child. Characteristics could include personality traits or previous experience caring for children with special needs, as well as knowledge and skills required to provide the specific care their child needs due to their chronic illness. Once an unlicensed caregiver was identified, the nurse could teach that person child-specific procedures. As the overall manager of care, the parent would monitor the direct care provided by the unlicensed caregiver. The nurse might continue to provide some direct care on a regular, but less frequent basis than the unlicensed caregiver. In this way, the nurse would remain familiar with changes in the child's condition, and be able to act as a consultant to both the parent and the unlicensed caregiver if needed.

Clearly, introducing a second level of caregiver for in-home respite would necessitate administrative changes in order to support both nurses and unlicensed caregivers in their roles. First, nurses would likely need in-service sessions that address the topics of delegation of nursing tasks, primary nursing, and/or collaborative working relationships. There are also implications for the scheduling of nursing time. Nurses might have to be given increased responsibility for deciding, with the parents, how frequently they would need to work with a particular child to ensure they maintained familiarity with that child's changing care needs. Further, ensuring that nurses work with the same family over time would be crucial, in order for the nurse to function effectively as a consultant for parents.

Administrative changes would also be needed to support unlicensed caregivers. Educational programs that teach generic information about working with children with special needs in the home would provide

baseline knowledge for individuals wishing to do this kind of work. As well, nursing time would be needed in the home to teach child-specific procedures to unlicensed caregivers, as well as provide on-going skill-checking if required.

Because the health status of children who are technology-dependent can change quickly, flexibility in staffing would need to be built into a respite program that used both nurses and unlicensed caregivers to provide care. For example, if a child contracted an acute infection, or was recovering from surgery, unlicensed caregivers might need to be replaced by nurses for a period of time until the child's condition stabilized. Ideally, a continuum of caregiver abilities would exist between unlicensed caregivers and nurses. As a child's condition changed, the type of in-home respite caregivers would change to provide the appropriate level of care.

Thus, the findings from this study have implications for the planning of in-home respite programs. Because parents function as overall managers of their child's care and are able to direct others in that care, unlicensed caregivers could safely provide some respite care, with nursing support. Rather than having a direct caregiver role, the nurse would act in a consultative role for both parents and unlicensed caregivers. Consistency of caregivers, as well as flexibility in staffing in order to respond to changes in a child's condition would need to be incorporated into such a program.

Summary

The purpose of this thesis was to explore and describe, from the parents' perspective, the factors that influence decisions they make regarding the care of their children who are technology-dependent and living at home. In Chapter 1 the background to the problem was presented. In Chapter 2

literature relevant to the area was reviewed. The focus of Chapter 3 was the research method, and included a description of the data from the primary study, as well as the method of analysis used in this secondary study. The findings were presented in Chapter 4, and discussed in relation to the existing theoretical and research literature in Chapter 5. Finally, in this chapter, a summary of the study, conclusions, and implications for nursing practice, education, research, and program planning were presented.

Reference List

- Able-Boone, H., Dokecki, P., & Smith, S. (1989). Parent and health care provider communication and decision making in the intensive care nursery. Children's Health Care, 18 (3), 133-141.
- Ahmann, E., & Rollins, J. (1995). Family-centered care of the child with special needs. In D. L. Wong, D. Wilson, & L. F. Shaley (Eds.), Nursing care of infants and children (5th ed.) (pp. 933-975). St. Louis, MO: Mosby.
- Bigler, B. (1990). Critical care nursing: Expanding roles and responsibilities within the community. Critical Care Nursing Clinics of North America, 2 (3), 493-502.
- Blumer, H. (1969). Symbolic interactionism: Perspective and method. Englewood Cliffs, NJ: Prentice-Hall.
- Bond, N., Phillips, P., Rollins, J. (1994). Family-centered care at home for families with children who are technology dependent. Pediatric Nursing, 20 (2), 123-130.
- Brown, J., & Ritchie, J. (1989). Nurses' perceptions of their relationships with parents. Maternal-Child Nursing Journal, 18 (2), 79-96.
- Bowlby, J. (1953). Child care and the growth of love. Harmondsworth, Middlesex: Penguin.
- Canam, C., Cunada, L., & Bassingthwaighe, C. (1994). The Nurse's Role in the Home Care of Children with Complex Health Care Needs. Unpublished manuscript.
- Cender, L. M. (1995). The experience of caring for a child with a medically-fragile condition at home: Perceptions of parents. Unpublished master's thesis, University of British Columbia, Vancouver, BC.
- Darbyshire, P. (1993). Parents, nurses and paediatric nursing: A critical review. Journal of Advanced Nursing, 18, 1670-1680.
- Denzin, N. K. (1989). Interpretive interactionism. Newbury Park, CA: Sage.
- Dixon, D. (1995). Parent and nurse interaction during acute care, pediatric hospitalization. Capsules and Comments in Pediatric Nursing, 2 (2), 91-99.

- Dixon, D. (1991). Parent-nurse interaction: A research-based model. Unpublished manuscript.
- Dunst, C., Trivette, C., Davis, M., & Cornwell, J. (1988). Enabling and empowering families of children with health impairments. Children's Health Care, 17 (2), 71-81.
- Feetham, S. L. (1986). Hospitals and home care: Inseparable in the '80s. Pediatric Nursing, 12 (5), 383-386.
- Foster, R. L. (1989). Principles and strategies of home care. In R. L. Foster, M. M. Hunsberger, & J. J. T Anderson (Eds.), Family-centered nursing care of children. Philadelphia: W. B. Saunders.
- Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin, & Y. S. Lincoln (Eds.), Handbook of qualitative research (pp. 105-117). Thousand Oaks, CA: Sage.
- Haas, D., Gray, H., & McConnell, B. (1992). Parent/professional partnerships in caring for children with special health care needs. Issues in Comprehensive pediatric Nursing, 15, 39-53.
- Hamers, J. P. H., Abu-Saad, H. H., Halfens, R. J. G., & Schumacher, J. N. M. (1994). Factors influencing nurses' pain assessment and interventions in children. Journal of Advanced Nursing, 20, 853-860.
- Harris, C. C. (1985). The cultural decision-making model: Focus--circumcision. Health Care for Women International, 6, 25-43.
- Hatton, D. (1992). Parents' perceptions of their experiences of caring for an infant or toddler under three years of age with insulin-dependent diabetes mellitus. Unpublished master's thesis, University of British Columbia, Vancouver, BC.
- Hatton, D., Canam, C., Thorne, S., & Hughes, A. (1995). Parents' perceptions of caring for an infant or toddler with diabetes. Journal of Advanced Nursing, 22, 569-577.
- Jayabose, S., Escobedo, V., Tugal, O, Nahaczewski, A., Donohue, P., Fuentes, V., Devereau, G., & Sunkara, S. (1991). Home chemotherapy for children with cancer. Cancer, 69 (2), 574-579.
- Jerrett, M. (1994). Parents' experience of coming to know the care of a chronically ill child. Journal of Advanced Nursing, 19, 1050-1056).

- Johnson, B. (1990). The changing role of families in health care. Children's Health Care, 19 (4), 234-241.
- Kaufman, J., & Hardy-Ribakow, D. (1987). Home care: A model of a comprehensive approach for technology-assisted chronically ill children. Journal of Pediatric Nursing, 2 (4), 244-249.
- Klug, R. M. (1993). Clarifying roles and expectations in home care. Pediatric Nursing, 19 (4), 374-376.
- Knafl, K., Breitmayer, B., Gallo, A., & Zoeller, L. (1992). Parents' views of health care providers: An exploration of the components of a positive working relationship. Children's Health Care, 21 (2), 90-95.
- Kohrman, A. F. (1991). Medical technology: Implications for health and social service providers. In N. J. Hochstadt & D. M. Yost (Eds.), The medically complex child: The transition to home care (pp. 3-13). Chur, Switzerland: Harwood.
- Krepper, R., Young, A., & Cummings, E. (1994). Pediatric home healthcare: A paradox. Home Healthcare Nurse, 12(4), 15-19.
- Lantos, J., & Kohrman, A. F. (1991). Ethical aspects of pediatric home care. In N. J. Hochstadt & D. M. Yost (Eds.), The medically complex child: The transition to home care (pp. 3-13). Chur, Switzerland: Harwood.
- MacElveen-Hoehn, P. (1983). The cooperation model for care in health and illness. In N. L. Chaska (Ed.), The nursing profession: A time to speak (pp. 515-539). New York: McGraw-Hill.
- Office of Technology Assessment. (1987). Technology-dependent children: Hospital vs. home care. A technical memorandum (OTA-TM-H-38). Washington, DC: U. S. Congress.
- Overbay, J. (1991). Ethical principles influencing parents of well children. Issues in Comprehensive Pediatric Nursing, 14, 93-101.
- Patterson, J., Jernell, J., Leonard, B., & Titus, J. (1994). Caring for medically fragile children at home: The parent-professional relationship. Journal of Pediatric Nursing, 9 (2), 98-106.
- Patterson, J., Leonard, B., & Titus, J. (1992). Home care for medically fragile children: Impact on family health and well-being. Developmental and Behavioral Pediatrics, 13 (4), 248-255.

- Pinch, W. J., & Spielman, M. L. (1989a). Ethical decision making for high-risk infants: The parents' perspective. Nursing Clinics of North America, 24 (4), 1017-1023.
- Pinch, W. J., & Spielman, M. L. (1989b). Parental voices in the sea of neonatal ethical dilemmas. Issues in Comprehensive Pediatric Nursing, 12, 423-435.
- Punch, L. (1985). Pediatric home care expands as new technology is developed. Modern Healthcare, 15 (14), 152, 154.
- Robertson, J. (1953). Some responses of young children to loss of maternal care. Nursing Times, 49, 382-386.
- Roemer, N. (1992). The tracheotomized child: Private duty nursing at home. Home Healthcare Nurse, 10 (4), 28-32.
- Ruccione, K., Kramer, R. F., Moore, I. K., & Perin, G. (1991). Informed consent for treatment of childhood cancer: Factors affecting parents' decision making. Journal of Pediatric Oncology Nursing, 8 (3), 112-121.
- Rushton, C. H. (1990). Involving parents in decisions to forego life-sustaining treatment for critically ill infants and children. AACN Clinical Issues in Critical Care Nursing, 1 (1), 206-214.
- Sandelowski, M. (1986). The problem of rigor in qualitative research. Advances in Nursing Science, 8 (3), 27-37.
- Scannell, S., Gillies, D., Biordi, D., Child, D. (1993). Negotiating nurse-patient authority in pediatric home health care. Journal of Pediatric Nursing, 8 (2), 70-78.
- Scharer, K., & Dixon, D. (1989). Managing chronic illness: Parents with a ventilator-dependent child. Journal of Pediatric Nursing, 4 (4), 236-247.
- Schwandt, T. A. (1994). Constructivist, interpretivist approaches to human inquiry. In N. K. Denzin, & Y. S. Lincoln (Eds.), Handbook of qualitative research (pp. 118-137). Thousand Oaks, CA: Sage.
- Sherman, B. (1995). Impact of home-based respite care on families of children with chronic illnesses. Children's Health Care, 24 (1), 33-45.
- Stern, H. P., Stroh, S. E., Fiser, D. H., Cromwell, E. L., McCarthy, S. G., & Prince, M. T. (1991). Communication, decision making, and

perception of nursing roles in a pediatric intensive care unit. Critical Care Nursing Quarterly, 14 (3), 56-68.

- Thomas, R. B. (1986). Ventilator Dependency Consequences for Child and Family. Unpublished doctoral dissertation, University of Washington, Seattle.
- Thompson, P. J. (1993). Day care for ill children: An employed mother's dilemma. Issues in Comprehensive Pediatric Nursing, 16, 77-89.
- Thorne, S. E. (1993). Negotiating health care. Newbury Park, CA: Sage.
- Thorne, S. (1994). Secondary analysis in qualitative research: Issues and implications. In J. M. Morse (Ed.), Critical issues in qualitative research methods (pp. 263-279). Thousand Oaks, CA: Sage.
- Thorne, S., & Robinson, C. (1988). Health care relationships: The chronic illness perspective. Research in Nursing and Health, 11 (5), 293-300.
- Weinstein, S. M. (1993). A coordinated approach to home infusion care. Home Healthcare Nurse, 11 (1), 15-20.
- Wong, D. L. (1991). Transition from hospital to home for children with complex medical care. Journal of Pediatric Oncology Nursing, 8 (1), 3-9.
- Youngblut, J., Brennan, P., & Swegart, L. (1994). Families with medically fragile children: An exploratory study. Pediatric Nursing, 20 (5), 463-468.

Appendix A

Trigger Questions for Parents

1. Can you think back to when you first heard about the possibility of having a nurse in your home? Can you remember what went through your mind?
2. How did you feel at that time?
3. What did you think it would be like?
4. What is it like?
5. Can you describe a situation that particularly stands out for you since you've had nursing care in your home?
6. Describe an experience that was particularly satisfying for you in relation to the nurse caring for your child.
7. Describe an experience that was particularly frustrating for you.

Appendix B



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PARTICIPANT CONSENT FORM (Parent)

Title of Study: Nurses' and Parents' Perceptions
of the Experience of Nursing in the Home.

Investigators: CONNIE CANAM, RN, MSN, Assistant Professor - 822-7558
CAROLE BASSINGTHWAITE, RN, BSN, Nursing Consultant
LYSBETH CUNADA, RN, MSN, Nursing Consultant

The purpose of this study is to examine parents' experiences of having a nurse care for their child with complex health care needs, in the home. The study will involve interviewing both parents and nurses about this experience. I understand that:

- participation in the study is entirely voluntary and refusal to participate will in no way affect the present or future medical or nursing care that my child receives.
- I can withdraw from the study at any time or refuse to answer any questions or discuss any topic, with no effect on my child's present or future medical or nursing care.
- there will be a maximum of three interviews of approximately one hour each. These will take place in my home or at another location selected by me.
- the interviews will be tape recorded and I can request erasure of any tape or portion of tape at any time during the study.
- the tapes will be transcribed (typed) and any information identifying me personally as a participant will be removed from the transcription.
- the tapes will be destroyed at the end of the study.
- there are no known personal risks or discomforts for me or other family members.
- I will receive a twenty-five (\$25.00) dollar stipend for each interview which will be received after completion of the final interview.
- if I have any questions at any time during the study, I may contact the above researchers.

I acknowledge receipt of a copy of the participants' information letter and consent form.

I do/do not consent to participate in the study.

Signature: _____

Date: _____

CC/pe
CANAM, APPENDIX-B/N