

# Caregivers' perceptions of nurse-led discharge education interventions: Knowledge needed for adequate care of a technology-dependent infant in the home setting

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Boston College

William F. Connell School of Nursing

CAREGIVERS' PERCEPTIONS OF NURSE-LED DISCHARGE EDUCATION  
INTERVENTIONS: KNOWLEDGE NEEDED FOR ADEQUATE CARE OF A  
TECHNOLOGY-DEPENDENT INFANT IN THE HOME SETTING

a dissertation

by

BRIAN M. FRENCH

submitted in partial fulfillment of the requirements

for the degree of

Doctor of Philosophy

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Running head: CAREGIVER PERCEPTIONS

**Caregivers' Perceptions of Nurse-Led Discharge Education Interventions:  
Knowledge Needed for Adequate Care of a Technology-dependent Infant  
in the Home Setting**

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**Abstract**

**Background**

Advances in clinical care over the past 40 years have saved the lives of many infants who previously would not have survived. However, a substantial proportion of these children need on-going technological support and are cared for at home by family caregivers with or without the assistance of home care services. Existing studies describe the experience of family caregivers of technology-dependent children post-discharge, but there is a gap in knowledge related to caregivers' perceptions of nurse-led discharge teaching.

**Purpose**

To describe caregivers' perceptions of nurse-led discharge education designed to prepare them to care for their technology-dependent infant in the home setting and to uncover factors that facilitate or hinder its effectiveness.

**Method**

A qualitative descriptive study design was employed to explore caregivers' perceptions of nurse-led discharge education efforts. Demographic data were collected



prior to conducting a semi-structured interview. Interview data were analyzed in an iterative fashion using qualitative content analysis.

### **Sample**

Recruitment was via purposive sampling aimed to find caregivers of technology-dependent infants under the age of three. Nine participants completed the study.

### **Results**

An overarching theme, *caregiver learning and self-advocacy is enhanced by positive nurse/caregiver relationships and team cohesion, especially during anxiety-producing transitions in care*, emerged from the data. The overarching theme encompasses five major themes and several major themes. The five main themes are: *the nurse/caregiver relationship enhances learning; the complexity of care presents challenges to the learning process; team performance affects caregivers' level of anxiety/uncertainty; caregivers' level of expertise improves self-advocacy; and transitions in care settings contribute to caregiver anxiety*.

### **Conclusion**

Insights that contribute to nursing knowledge of the caregivers' experience of nurse-led discharge education and their perceptions of factors that help or hinder their learning were gained. Implications for nursing include the importance of caregivers' involvement in care team discussions, the necessity of basing teaching approaches and materials in knowledge of best practices, and improved care coordination and discharge planning. Further nursing research, that can generalize findings and generate interventions is also needed to improve the care of this population.

Key words: technology-dependent, caregiver, parent, perceptions, discharge, teaching, education

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## Chapter 1

### Technology-dependent Children

#### Background of the Problem

The burgeoning biotechnological, pharmacological and knowledge advances of the past 30 to 40 years have saved or improved the lives of many children who previously would not have survived (Boroughs & Dougherty, 2009; Department of Health, 2004b). Health system factors, along with the desire to support the family unit, have led to increasing numbers of these children being cared for at home, often by their parents or guardians (Boosfeld & O'Toole, 2000; Johnson, Kastner & AAP Committee, 2005; Kirk & Glendinning, 2004; Lewis & Noyes, 2007; Ray & Ritchie, 1993). This shift in the locus of care-giving from hospital to home and from clinicians to family members poses a challenge for nurses who are responsible and accountable for appropriate and adequate discharge planning activities including teaching families how to care for their children at home (Scherf & Reid, 2005).

Discharge teaching is an important nursing function that requires an understanding of professional responsibility, content knowledge and teaching skill (Bastable, 2008; Woodring, 2000). In addition, nurses must be “aware of the uniqueness of individuals and ... use appropriate strategies and resources” (Steward-Gelinas & Romano, 2009, p. 117) to meet learning needs. However, there is a gap in knowledge related to caregivers' perceptions of nurse-led discharge teaching. The nature of this gap highlights the importance of developing knowledge that can facilitate nursing practice in this area. This chapter outlines both what is available in the literature and significant gaps in knowledge about what parents and guardians need in order to care for

technology-dependent infants at home. The current study aims to contribute knowledge related to caregiver perceptions. Caregivers' perceptions of nurse-led discharge education are an important part of nursing knowledge needed in this area in order to better understand if teaching interventions are effective and thus, whether or not nurses are meeting the health promotion needs of this population (Sneath, 2009). This knowledge may also help nurses improve current practice and identify areas for further research.

This chapter describes the scope and significance of the problem including technological and healthcare system factors that have contributed to the growth in numbers of technology-dependent children that are cared for at home. Support is provided for the importance of this study as a preliminary step in building knowledge related to the care of these children in the home setting. The purpose of the study, research questions, significance, and definitions of terms are then delineated.

Chapter 2 elaborates on the problem, discusses pertinent literature including research findings, and what is known about the factors outlined here. It provides strong support for the argument that an important step in further knowledge development for this population is to gain a better understanding of caregivers' perceptions of nurse-led discharge education interventions.

### **Significance of the Problem**

**Advances in medical care.** Advances in medical care have increased the chances of survival for persons experiencing catastrophic illness, trauma, and acquired or congenital conditions (Department of Health, 2004b; Fleming, 2004). This is also true of children surviving premature birth (Department of Health, 2004b). The advances in

pediatric care over the last 20 years have increased the number of infants with multiple and complex specialized health needs (Jackson Allen, 2009; Zaichkin, 2011) as a result of neurological, oncological, hematological, cardiac, respiratory, gastrointestinal, renal, musculoskeletal and multisystem complications (Fleming, 2004). Although overall rates of mortality have decreased, there has been a corresponding increase in the rate of disabilities experienced by infants who survive what were formerly fatal threats to health (Wang & Barnard, 2008). These disabilities, such as the inability to breathe or take in nutrition in the normal manner, result in both short and long term medical needs that require the use of technology to maintain survival. Technology has become an integral part of patient care in the hospital that is implemented, monitored and regulated by health professionals including nurses, physicians, and therapists. The ongoing advances in technology and other medical care have led to a growing number of technology-dependent children being cared for in the home setting (Seferian, Lackore, Rahman, Naessens, & Williams, 2006).

**Economic impact.** Interventions that have improved survival rates including advanced technology and equipment are expensive to research, develop, purchase, and use and this is a major factor in rising health care costs (Bodenheimer, 2005; Curtin, 2007). These costs have prompted decreasing lengths of stay in acute care settings and earlier discharges home (Hazlett, 1989; Woodring, 2000) where the use of technology to maintain physiologic functions must then be incorporated into the daily care needs of these discharged infants (Boroughs & Dougherty, 2009; Zaichkin, 2011). The literature suggests that there are positive economic outcomes related to the care of technology-dependent children in the home setting such as reduced healthcare costs (Berkemeyer &

Hutchins, 1986; Burr, Guyer, Todres, Abrams, & Chido, 1983). However, Newachek and Kim (2005) report that technology-dependent children utilize 61% of all healthcare resources required by children.

**Technology in the home setting.** Technology-dependent infants are being discharged home in larger numbers, earlier and with greater health needs than ever before (Zaichkin, 2011). The supposition is that their caregivers (e.g. parents, other family members, guardians) will receive the education and support services they need to provide ongoing care for these children (Department of Health, 2004b; Wang & Barnard, 2008) in spite of the fact that adequate support is not always available (Boroughs & Dougherty, 2009; Meltzer & Mindell, 2006).

There are many reasons that technology-dependent infants are increasingly discharged home with caregiver support. As stated previously, there are increasing numbers of such children and the cost of already expensive inpatient care continues to rise (Wang & Barnard, 2008). However, there is evidence that discharging technology-dependent infants to the home setting can be beneficial to family functioning and well-being (Fleming, 2004). The literature suggests that there are positive psychosocial benefits for both children and families (Berkemeyer & Hutchins, 1986; Burr et al. 1983).

**Family stressors.** Infants are entirely dependent on their caregivers for their nutrition, cleanliness, stimulation, and health care needs. Providing for the care needs of even a healthy infant is known to create stressors that can negatively affect family cohesion, coping, and health (Kuster, Badr, Chang, Wuerker, & Benjamin, 2004; Montagnino & Mauricio, 2004; Stephenson, 1999) and finances (Winkler, Ross, Piamjariyakul, Gajewski, & Smith, 2006). The birth of an infant with medical problems

is considered to be a major developmental crisis and support is important in helping parents successfully transition to parenthood roles (Miles, Carlson, & Funk, 1996). Caring for a technology-dependent infant in the home setting requires enhanced skills beyond those generally needed for child-rearing (Montagnino & Maurico, 2004; Wang & Barnard, 2004). It is thus essential that parents and other caregivers of technology-dependent infants are adequately prepared to provide care. That is, they have the specialized knowledge and skills required to provide this care. Nurses play a critically important role in equipping caregivers with the knowledge and technical skills needed to provide this care. In order to do this effectively, nurses must have a good grasp of the needs of these caregivers and how to tailor educational interventions to meet both individual and family needs.

**Discharge teaching.** Nurse led-discharge teaching is critical to the success of the transition in care from hospital to home (Woodring, 2000). Nurses are generally the health care professionals who lead or coordinate the discharge planning process, the education and development of lay caregivers, and often must do so under conditions of constricted resources (Woodring, 2000) such as decreased lengths of stay that compress the time that acute care nurses have to teach patients and families about their care (Blagojevic & Stephens, 2008; Woodring, 2000).

Since technology must now be integrated into care delivered by lay caregivers such as parents and guardians (Boroughs & Dougherty, 2009; Zaichkin, 2011), striving to ensure all are adequately prepared is an important role responsibility of nurses caring for this population. Understanding the demands being placed on the family who must care for a technology-dependent infant is an important part of the nurse's role in providing

care (Reeves, Timmons, & Dampier, 2006). As nurses have responsibilities to advocate for the type of care that will optimize health, adequate discharge teaching and preparation promotes the best interests of caregivers, technology-dependent children and families, thus meeting an important goal of the nursing profession (American Nurses Association [ANA], 2010). As little is known about whether the current educational interventions optimally meet the educational needs of caregivers, nurses have an obligation to technology-dependent children, their caregivers and families and society to discover the best and most cost-effective ways of meeting the health care needs of this population as well as ensuring optimal preparation of their caregivers.

**Prevalence.** The exact number of technology-depending infants living in the home setting is currently unknown. The Federal Interagency Forum on Child and Family Statistics (2009) provided some insight into the picture of children requiring complex home care. In 2008, there were 25 million children under the age of five in the United States and 9% (2.25 million) were identified as having special health care needs such as requiring prescription medication, more services than most children, or special therapies (Federal Interagency Forum on Child and Family Statistics, 2009). Additionally, of the 2.25 million children with special health care needs, 17.7% (398,000) required the use of or had a need for a specialized therapy. Detail regarding the exact nature of the specialized therapy is not provided in this report; therefore the current incidence of disabled technology-dependent children in the home setting is difficult to quantify. The only comprehensive data available for the United States was gleaned from a dated study (U.S. Congress, Office of Technology Assessment, 1987) which reported that up to 97,000 children were deemed to be technology-dependent in the home setting (Table 1).

Table 1

*Technology-Dependent Child Population Estimates, 1987*

Group	Definition	Estimated number of children
I	Dependent on mechanical ventilation for at least part of the day	680 to 2,000
II	Dependent on administration of intravenous medications or nutrition	620 to 8,975
III	Dependent on other respiratory or nutritional support (i.e. tracheostomy tube care, endotracheal suctioning, oxygen support, tube feedings)	1,000 to 6,000
IV	Dependent on other types of technology to compensate for body functions (i.e. cardiac or apnea monitoring, dialysis, urinary catheters, colostomy appliances)	7,800 to 80,000

*Note.* Adapted from “Technology-dependent Children: Hospital v. Home Care – A Technical Memorandum,” by U. S. Congress, Office of Technology Assessment, 1987, OTA-TM-H-38. Washington, DC: U. S. Government Printing Office.

Given the number of medical and technological advances that have occurred in the past 25 years, it is reasonable to suppose that these numbers have increased dramatically. One study showed that 26% of pediatric patients discharged from a large American tertiary

hospital required some form of medical device, a finding that illustrates the continued prevalence of technological dependence in this population (Feudtner, Villareale, Morray, Sharp, Hays, & Neff, 2005).

### **Purpose of the Study**

The purpose of this study was to:

1. Describe caregivers' perceptions of nurse-led discharge education designed to prepare them to care for their technology-dependent infants in the home setting.
2. Describe caregivers' perceptions of factors that facilitate or hinder the effectiveness of nurse-led discharge education designed to prepare them to care for their technology-dependent infant in the home setting.

This study resulted in insights that contribute to knowledge of the caregivers' experience of nurse-led discharge education and their perceptions of factors that help or hinder their learning. This knowledge will inform care that may improve nursing practice, provide stimulus for improved nursing education and identify opportunities for further research.

### **Research Questions**

The research questions this study proposed to answer are:

- 1) What are the perceptions of caregivers of technology-dependent infants of nurse-led discharge education that is designed to prepare them to care for their technology-dependent infant in the home setting?
- 2) What factors facilitate or hinder the effectiveness of nurse-led discharge education designed to prepare caregivers to care for their technology-dependent infant in the home setting?



This study uses a qualitative descriptive design to answer these questions by exploring caregivers' perceptions of nurse-led discharge education designed to prepare them to care for their technology-dependent infants in the home setting. Qualitative descriptive research is used to describe a phenomenon from the participants' perspectives. It provides the researcher with a "comprehensive summary of an event in the everyday terms of those events" (Sandelowski, 2000, p. 336). As a result, the phenomenon is contextually described and the meaning ascribed to the phenomenon by an individual can emerge. Interpretation and analysis of the subjects' narratives [perceptions] permit insights into their experiences (Gray, Grove, & Sutherland, 2016) and these insights contribute to our understanding of a phenomenon.

### **Importance of the Study**

The goals of the nursing profession are the protection, promotion and optimization of health, prevention of illness and injury, and alleviation of suffering (ANA, 2010). As a profession, nurses are privileged by society to meet individual, group, and societal needs. Nursing actions are also guided by The Code of Ethics for Nurses (ANA, 2015). This moral component of nursing action is directed towards achieving a "good" (Grace, 2001). The "good" intent of nursing actions ideally results in a "good" patient (i.e. individual, family, group, society) outcome. In this way, the profession's obligations to individuals, groups and society are met.

The nursing profession also has an obligation to develop knowledge that furthers its practice (ANA, 2015). This study contributes to knowledge development in the area of discharge interventions by facilitating a fuller understanding of caregivers' responses to discharge education interventions and their unmet needs. Insights from this study can

contribute to the development and ultimately, the evaluation of, strategies to improve discharge teaching for this population. The ultimate goal of the research is to benefit both technology-dependent infants and their caregivers and families.

### **Definition of Terms**

**Technology-dependent.** A child is “technology-dependent” if he/she needs both a medical device to compensate for the loss of a vital body function and substantial ongoing care to avoid death or disability (Health Care Financing Administration, 1988). Technology-dependence meets the Library of Congress Congressional Research Service’s (2006) federal definition of disability, “a physical or mental impairment that substantially limits one or more of the major life activities.”

**Caregiver.** Merriam-Webster Online (2013, Full Definition of Caregiver section) defines caregiver as “a person who provides direct care (as for children, elderly people, or the chronically ill).” For the purposes of this study, caregiving is the range of actions performed by the caregiver required to meet the health care needs of the technology-dependent infant in the home setting.

**Nurse-led intervention.** Burnes Bolton, Donaldson, Rutledge, Bennett, and Brown (2007) defined nursing interventions as “a composite of nursing actions including assessments, processes of care, and specific therapeutic actions” (p. 124). Naylor (2003) defined the purpose of nursing intervention research as the testing of “innovations in care that are shaped by nursing’s values and goals, guided by a strong theoretical basis, informed by recent advances in science, and designed to improve the quality of care and health of individuals, families, communities, and society” (p. 382). For the purpose of this study, discharge teaching is the intervention led by the nurse that is designed to have

a specific therapeutic action (i.e. preparing caregivers to perform technological skills at home). Naylor's definition ties the action of discharge teaching to the foundations of nursing's professional responsibilities, in this case, the achievement of a "good" for technology-dependent infants (i.e. receiving technological care from a trained caregiver in the home setting) and their caregivers (i.e. the ability to perform technological skills at home).

**Patient/family education.** Patient/family education typically involves the dissemination of information regarding a disease process, resources, and care plan post discharge and an evaluation of the patient's or families' understanding of the information (Bastable, 2008). Instead of this traditional aim of simply imparting information, Glanville (2000) emphasized the empowerment of patients [and families] to use their potentials, abilities, and resources to the fullest. Patient/family education has the potential to facilitate the transfer of power when the responsibility and accountability for caring for the technology-dependent infant shifts from the inpatient nursing staff to the caregivers in the home setting.

### **Assumptions**

The study was based on the perspective that all nurses who engage in discharge planning for their patients have a professional responsibility to provide effective discharge education in order to promote a "good" for individuals (i.e. infants, caregivers). In this instance, the "good" for the infant is the care he/she receives from their family caregiver and the "good" for the caregiver is the knowledge and skill to perform the needed technological care. It is assumed that knowledge, skill and teaching abilities do vary from nurse to nurse as they have been exposed to different patients, clinical situations and the practice of other clinicians. This exposure has

enabled them to acquire experience in the care of this patient population. Nurses are the most respected of all professions (Lilley, 2009) and it is assumed that this respect engenders caregivers' trust in their clinical practice and their role as patient educators.

In addition, it was assumed that caregivers had the ability to learn how to provide this care and the willingness to articulate their learning needs to the nurse. It was also assumed that most caregivers of technology-dependent infants were novices as most would have little to no experience with performing clinical and technical health care skills.

It was assumed that caregivers generally benefit from nurse discharge teaching but that a variety of factors and stressors can negatively impact effectiveness. Caregivers' learning needs may vary and this required individualization of the teaching plan of care. Previous experience in caring for infants, level of education, work experience, differing learning styles, and the teaching skills of the nurse were all factors that may have affected learning. The dynamics of the home setting such as the lack of spousal and family support, financial challenges, and the availability of home care services were additional stressors that may have interfered with learning. To fulfill nursing goals, nurses should strive to learn more about these factors and stressors and use what is already known to inform their practice related to discharge education. The caregivers' perspectives related to their experience of discharge education designed to prepare them to care for their technology-dependent infant in the home setting was gained via an interviewing process. The study used a qualitative descriptive approach as described in more detail in Chapter 3 to guide the interviewing process and subsequent data analysis.

### **Summary**

The care of technology-dependent infants in the home setting creates many challenges for caregivers and the nurses who must teach them to provide needed care.

Understanding caregivers' perceptions of nurse-led discharge education through qualitative study and analysis provided needed insights to assist in the development of the knowledge required to improve nursing care and discharge teaching through further research. A review of existing knowledge as well as gaps in knowledge related to the care of these infants is included in Chapter 2.

## Chapter 2

### Review of the Literature

Caregivers of technology-dependent infants face significant challenges when providing care in the home setting and there are many types of stressors which affect family functioning and the ability to provide care (Coyne, 1995; Kirk, Glendinning & Callery, 2005; Montagnino & Mauricio, 2004; Winkler et al., 2006). Nurses play an important role in preparing caregivers to provide this needed care to technology-dependent infants in the home setting (Barnes, 1992; Fiske, 2004; Woodring, 2000). As discussed in Chapter 1, nurses have an ethical obligation to understand the needs of patients and families (ANA, 2015). However, there is a gap in knowledge regarding caregivers' perceptions of nurse-led discharge education in the acute care setting and whether, or not, nursing discharge education meets the learning needs of these caregivers so that they can successfully provide needed care in the home setting.

Qualitative analysis of caregivers' perceptions of nurse-led discharge education adds to the existing body of knowledge by providing insights about the interwoven and complex issues faced by this population as they prepare for discharge. The following literature review demonstrates the gap in existing knowledge regarding nurse-led discharge teaching of caregivers of technology-dependent children designed to prepare them to provide care in the home environment and thus supports the need for this study.

The literature review is divided into five parts. The first section adds to the content presented in Chapter 1 regarding what is known about technology-dependent infants. The second section provides a brief overview of what is known about parental caregiving including some of the stressors families face when caring for a technology-

dependent infant at home. The third section provides a review and critique of research studies regarding what is known about caregivers' experiences of providing care in the home environment as well as what is known about the financial stressors experienced by caregivers of technology-dependent children. The fourth section provides a review and critique of research studies regarding caregivers' experiences of inpatient nursing care. The review of literature concludes with a discussion about discharge education. It is important to note that there may be some overlap between sections particularly with the review and critique of research studies presented in the third and fourth sections. Gaps in knowledge are identified which provide support for the primary aim of this study, namely, the need to know more about the caregivers' perceptions of the barriers and facilitators to effective nurse-led discharge education.

### **Technology-dependent Infants**

Technology-dependent children are a diverse group with correspondingly diverse technological support needs including: intravenous infusions of fluids, nutrition, and medications, apnea monitors, feeding tubes, elimination devices, peritoneal or hemodialysis, and breathing support including oxygen administration, tracheostomy and mechanical ventilation (U. S. Congress, Office of Technology Assessment, 1987). The diversity among these children is compounded when one considers not only the type of technology, but also the number of different technologies needed, the frequency and intensity of the care required, presence and number of additional health issues, and overall prognosis (Kirk & Glendinning, 2004). Each of these factors may cause additional difficulties for caregivers who are attempting to learn new skills as some technological care may be easier to learn than others, multiple technologies translate to an

increased time commitment in providing care, and co-morbidities may also require differing types of care. These children are often discharged to home in the care of their parents or caregivers either with or without home care services (Boroughs & Dougherty, 2009; Zaichkin, 2011). Even if home care services are available, family caregivers provide some needed care (Boroughs & Dougherty, 2009; Zaichkin, 2011). Thus, caregivers must be able to perform the technology-related clinical skills required to care for their child in the home setting. Nurses must be aware of these stressors and anticipate how they might affect the caregiver's ability to learn new skills (Lowenstein & Reeder, 2009) and thus provide care in the home environment.

### **Parental Caregiving**

Many parents have concerns regarding their abilities to care for their technology-dependent child in the home environment and are fearful of causing pain or harm (Coyne, 1995; Kirk et al., 2005; Montagnino & Mauricio, 2004; Winkler et al., 2006). Parents can also experience physical, emotional, and financial burdens (Winkler et al., 2006) that negatively affect family well-being and coping ability (Kuster et al., 2004; Montagnino & Mauricio, 2004; Stephenson, 1999). Specific burdens include social isolation (Kirk, et al., 2005; Winkler et al., 2006), depression (Kirk, et al., 2005; Kuster, et al., 2004) sleep deprivation, stress, and anger (Kirk, et al., 2005).

Collectively, the literature suggests that parents and other caregivers of technology-dependent infants experience many stressors post-discharge. It is unknown whether parents are, or feel, adequately prepared to care for their child at home. Encouraging and teaching parents and other caregivers to participate in care or independently care for their infant both within the hospital and post-discharge are



beneficent nursing actions because they are designed to achieve a good (Grace, 2001) for both the parent and the infant. By preparing caregivers adequately prior to discharge, nurses may help to relieve the stressors they experience post-discharge in the home setting.

### **The Experience of Caring for a Technology-dependent Child**

A review of the literature demonstrates that research regarding the care of technology-dependent children in the home setting primarily focuses on the caregivers' (i.e. primarily parents) overall experience caring for their children or the various effects on the family of this need to provide care at home. The majority of research studies found used a qualitative method to help understand parents' perceptions of caring for their technology-dependent children at home. However, some quantitative and mixed method studies were also found. The following discussion of the research is divided into two sections using this framework: qualitative methodology studies and quantitative/mixed methodology studies. A discussion of the research is included at the end of each section.

**Qualitative studies.** O'Brien (2001) conducted a descriptive study designed to examine the problems experienced by families of children with long-term dependence on technology in the home setting. Purposive sampling was used to recruit 15 families (11 mothers and four parent couples) with technology-dependent children aged three to 12 years from a variety of health care agencies, social service agencies, and parent support groups. One to five children (inclusive of the child who was dependent on technology) were present in each home. All parents were high school graduates and 51% had at least

an unspecified college degree. All parents and children were Caucasian except for one African-American child.

A one-time, unstructured interview was held with each mother or couple. Two primary themes emerged: living in a house of cards and dimensions of life. The perceptions of parents who felt they were living in a house of cards was based on frequent changes in the home and the unpredictable nature of those changes. The typical family responses included a need for vigilance regarding the child's condition, performance of technological care, and selection and monitoring of home care staff. In addition, families had to frequently advocate to meet the needs of the technology-dependent child, other children or the family unit. Reframing through humor, focusing on achievable outcomes, and maintaining hope was a primary coping strategy described by participants in the study. Dimensions of life, the second theme, represented the families' attempts to reconcile past and present experiences to make sense of their lives, managing daily life and maintaining a functioning family unit.

Kirk et al. (2005) used grounded theory to explore parents' experiences of caring for a technology-dependent child. Purposive sampling was used to recruit 23 mothers and 10 fathers from three specialty hospitals in England. Nine interviews included both parents whereas five were conducted with a sole mother or father. All but two of the parents were Caucasian but specific data were not presented. The technology-dependent children's ages were presented in ranges with 13 under five years of age and 11 between five and 18 years of age. Information about the parents' educational preparation was not provided.

The findings focused primarily on the parental role and the context in which parenting occurs. The context of parenting dealt with the medicalization of the home environment including the absence of privacy and disruptions that occurred due to the presence of home care staff. The dual role parents must assume, that of parent and caregiver, were identified as unpredictable and distressing due to the need to provide both usual parental duties plus clinical procedures that may be painful for the child. This dual role resulted in a resentment and desire to identify as a parent, not a nurse/caregiver. Parents reported feelings of social isolation, sleep deprivation, stress, anger, and depression. Another finding was how parents viewed the nurses who provided home care to their child. Despite being satisfied overall with nursing care, parents distinguished the difference between care provided by a nurse (i.e. a professional performing their job, routinized performance of procedures) vs. by a parent (i.e. not a job but their life, procedures have an added emotional significance). A potential source of conflict was identified whereby the nurses with specialized medical knowledge and skill may not recognize or value the parents' individualized experience of caring for their own children.

Carnevale, Alexander, Davis, Rennick, and Troini (2006) explored the experiences of 12 families (38 family members) using structured family and individual interviews and fieldwork observations lasting an average of two hours. The interviews were conducted in the families' homes. Participants were recruited through the Quebec Program for Home Ventilatory Assistance based at McGill University Health Center. Demographic data were collected, but not presented in the article.

Six themes were identified through an analysis of perceptions of the ventilator-assisted children, siblings, and parents. Theme one illustrates the parents need to

confront the stressful and overwhelming amount of responsibility they felt. Theme two described the families need for normalcy and use of common routines to attain stability. In the third theme, families described the conflicting societal values they experienced, specifically that they felt society devalued the life of their ventilator-assisted child. Captured by theme four was the families' feeling living in isolation. Theme five described the perspectives of the children (ventilator-assisted child and their siblings), some aspects of which were also visible in the other themes. Finally, theme six dealt with families questioning the moral order whereby life seemed to be unfair but nothing could be done about it.

Callans, Bleiler, Flanagan, and Carroll (2016) conducted a qualitative descriptive study to understand the experiences of family members of a child with a tracheostomy. Purposive sampling was used to recruit 18 participants (16 mothers and two fathers) with a child (infant through teenage years) who were interviewed in a focus group format. Detailed demographic data were not collected.

Through analysis of transcripts, four themes emerged: this is not the life I had planned: coming to accept a new reality; don't make the hospital your home, don't make your home a hospital; caregivers engage with providers that demonstrate competence, confidence, attentiveness, and patience; and participants value the opportunity to give back and help others. Out of theme one, this is not the life I had planned: coming to accept a new reality, feelings of guilt, anger, shock, disbelief, and disruption of the home emerged. Parents described the process of moving to take responsibility for their child and the unplanned challenges upon discharge including changes in family dynamics and routines and fears of going out and the risk of infection. In theme two, don't make the

hospital your home; don't make your home a hospital, parents described trying to maintain a sense of the normal despite the difficulties coordinating home care providers, equipment issues, and high stress levels. In theme three, caregivers engage with providers that demonstrate competence, confidence, attentiveness, and patience, parents described how confident nurses helped contribute to the development of confident families. An important component of this is teaching new skills slowly and in a detailed manner through verbal instruction and demonstration. In theme four, participants value the opportunity to give back and help others, parents described how they gained confidence over time and began to recognize their own expertise. This confidence helped them to know when to seek help, improved their ability to advocate for their child and gave them the opportunity an opportunity to shift into a new role by helping other parents with a technology-dependent child. In their discussion, Callans and colleagues made specific recommendations regarding discharge teaching including the use of web-based video instruction as well as providing ongoing support through family-to-family connections, early introduction to outpatient clinic nurses, and involvement in family support groups post-discharge.

***Discussion.*** The qualitative studies described above shed light on the complex issues that face parents and families of technology-dependent children. Although the results of each study differ, there are some common themes or issues that were identified including concerns about family functioning, managing life, trying to maintain a sense of normalcy despite the changes in the home environment, and feelings of anger and stress. Although the need to provide care was mentioned by parents in a few of the studies, the results of only one study (Callans et al., 2016), specifically described parents' perceptions

of learning to care for their child. However, the lack of this finding in the majority of studies must be considered within the context of the purpose of each researchers' study and the types of interview or focus group questions that were asked.

The age of the technology-dependent children in these studies varied greatly from birth to 18 years of age so it is difficult to say whether, or not, the parental or family experience may vary depending on the age of the child. However, the identification of such common issues or themes lends support that such issues may be experienced by parents and or families of technology-dependent children regardless of the age of the child.

In these studies, tactics to promote methodologic rigor including the use of purposive sampling and review of transcripts by multiple researchers were described. However, a full description of sample demographics was only given in one of the study reports and one provided only minimal demographic data. Of the two studies that presented such data, a majority of parents were well-educated and Caucasian. A lack of demographic data or access to only partial data limits the way in which the results can be viewed. It remains unknown whether the results accurately represent the experience of parents of a different socio-economic status, race, ethnicity, etc. As mothers are the primary caregivers identified in these studies, there is a gap in knowledge regarding the experience of fathers of technology-dependent children.

Two of the studies (Kirk et al., 2005; O'Brien, 2001) recruited participants from a variety of sources (i.e. multiple agencies, multiple hospitals) and thus, the reader may view the results as being somewhat representative of the experience of parents across institutions. Carnevale et al. (2006) recruited participants from one agency but it is

unknown whether they received care from one or many institutions. Callans et al. (2016) recruited participants from one large academic medical center and therefore, the results may only be viewed as representing the experience of parents who receive care at that specific hospital. Finally, the studies by Kirk et al. and Carnevale et al. were conducted in England and Canada respectively. As both countries have governmentally-sponsored and funded health systems, it is unknown whether these parents' experiences are similar to the experience of parents who received care in the United States where there are multiple funders including the government (e.g. Medicare, Veterans Affairs), various types of insurers and out-of-pocket expenses.

**Quantitative and mixed methods studies.** Stephenson (1999) conducted a descriptive correlational study to explore the stressors and coping abilities of families with healthy and technology-dependent infants. Participants were recruited from three large tertiary care centers in the Southern United States and a total of 172 families (85 in the technology group and 87 in the healthy family group) were enrolled. The family demographics (i.e. income, marital status, education, race/ethnicity) for the technology group were similar to the healthy family group and the vast majority of participants were Caucasian. However, neither the gender of the participants nor the age of the infants were specified for either group.

Statistical analysis of data gathered through three standardized family self-report instruments showed a significant positive correlation between family well-being and the demands/stressors related to life events in both groups. This finding is not surprising as all families have varying levels of demands and stressors and this researcher assumes that such demands would affect the family's sense of well-being. There was also a

statistically significant relationship between coping and perceptions of adequacy of resources and well-being in both groups. As with the first finding, all families have varying levels and access to resources and it is not surprising that the family's ability to cope is correlated with this measure. However, in between group comparisons, there was a statistically significant difference in pile up of demands and family well-being but not a significant difference in total coping scores. Again, it can be surmised that a sense of well-being is correlated with the number of demands being placed on the family. However, it is interesting to note that there was no between group differences in the correlation with coping scores. This lends support for the premise that families with technology-dependent children are, in general, coping well with the added demands that they face in caring for their child.

A retrospective pilot study conducted by Montagnino and Maurico (2004) described the impact of a child with a tracheostomy and gastrostomy on the family as perceived by the primary caregiver. A convenience sample of 50 participants was identified from a review of records at one large, pediatric tertiary hospital. Questionnaires were used to obtain mothers' perceptions; only 18 participants returned the questionnaires demonstrating a 36% response rate. The ages of the children ranged from two weeks to 14 years old.

The results of the analysis demonstrated that changes in the economic status of the family affected their ability to seek out resources and accept help to care for their child. Mothers also reported that they experienced anxiety learning new skills and handling emergencies, were fatigued, and felt socially isolated.



Caicedo (2014) conducted a longitudinal study of parents or guardians caring for technology-dependent children and other children aged two to 21 years of age with complex medical needs. A convenience sample of 84 participants were recruited from local pediatric primary and specialty practices, medical day care settings, and long-term/residential settings.

Participants were interviewed and surveyed initially and then monthly for 5 months. Biological mothers (75%), biological fathers (9%), grandmothers (5%), guardians (6%), and adoptive mothers (5%) participated in the study. Of note, 47% of study participants were Hispanic.

The majority of participants felt that there were negative effects on both their physical health (e.g. tired, weak, headaches) and their mental health (e.g. frustrated, anxious, angry, helpless/hopeless, worrying). They also reported having a lack of social life, difficulty doing household tasks, and tensions within the family including poor communication. There was also a perceived care burden as parents or guardians provided an average of 33 hours/week of direct care (range 1-168 hours) which often had a negative effect on the ability to work outside the home. There was also a financial impact as yearly out-of-pocket expenses related to the care needs of the child were between \$0 and \$5,719 (mean = \$350).

Toly, Musil, and Carl (2012) conducted a descriptive, correlational, longitudinal study designed to measure the effect of a chronic medical disorder on the family. A convenience sample of 103 mothers of technology-dependent children was recruited to participate from a variety of outpatient clinics at a large Midwestern hospital. Two interviews were conducted 12 months apart and 82 mothers completed both interviews.

Most mothers were Caucasian. The age of the children ranged from 6.75 months to 16.83 years of age at the time of the first interview.

Six instruments were used to measure depressive symptoms, family functioning, effect of chronic physical disorder on family, child's functional status, level of technological dependency, and demographics. Depressive symptoms were found to be the only predictor of family functioning at both time one and time two.

Toly, Musil, and Zauszniewski (2014) explored the feasibility, acceptability, and efficacy of a resourcefulness training intervention on the mental health outcomes of mothers with technology-dependent children. A convenience sample of 22 mothers was recruited from a pulmonary and gastroenterology clinic at large Midwestern hospital. Mothers were randomly assigned to an intervention group or a control group. Race/ethnicity, age, and family income data were collected but there was no comparison of this data between the intervention and control group reported in the literature. The majority of participants were Caucasian and fairly well-off financially.

The control group members were asked to journal about any significant events that occurred during the study period. The intervention group members were asked to journal about any significant events that occurred during the study period and received education on the resourcefulness training skills which included coaching on help-seeking behaviors (i.e. reaching out to family and friends, seeking help from professionals) and self-help activities (i.e. scheduling and organizing daily activities, positive self-talk). A laminated card with the resourcefulness training skills was provided to intervention group members after the education program.

Data were collected via an interview at baseline and then by mail survey at six weeks. An exit interview was also conducted at the end of the study period. The study response rate was 86% and showed that both groups found journaling to be a useful intervention to express thoughts and feelings and provided some relief from stress. The intervention group participants reported that the use of the resourcefulness training skills helped them work through daily challenges and reflect on stressful events. The researchers also reported that the intervention also had a medium effect on self-reported negative emotions and a small effect on depressive symptoms. However, the effect sizes were calculated at six weeks and this may have been too early to detect differences accurately.

**Discussion.** The quantitative and mixed methods studies also shed light on the complex issues that face parents and families of technology-dependent children. Although the purpose of each study differs, their collective results add to the body of knowledge related to the care of this population.

Although the purposes and results of these studies varied, there were results that lend support for findings identified through the qualitative methods discussed earlier. Effects on participants physical and mental health (Caicedo, 2014), depressive symptoms (Toly et al., 2014) and family demands and availability of resources or finances (Stephenson, 1999; Montagnino & Maurico, 2004; Caicedo, 2014) were issues that were identified through qualitative analysis. Participants in the study by Montagnino & Maurico also identified anxiety related to having to learn and perform new skills, a finding which is important in light of the findings of this current study and as discussed further in Chapter 5. No detailed information was provided regarding the types of skills

that were causing the anxiety however, although it is assumed that it was related to the provision of technological care.

Regarding the design of these studies, the majority used convenience sampling as the method to recruit participants. Convenience sampling is easy and economical as a researcher pursues potential participants who are easily available. However, participants recruited in this manner may not be representative of the population at large in regards to the variables of interest to the researcher (Polit & Beck, 2017). Stephenson (1999), Toly et al. (2012), Caicedo (2014), and Toly et al. (2014) recruited participants from multiple sites, whereas Montagnino and Maurico (2004) recruited participants from one large hospital. As noted earlier related to the qualitative studies reviewed, sample recruitment from different institutions lends support for the fact that the results may be more representative of the experience of parents of technology-dependent children rather than those recruited from one institution.

All instruments used to collect data in these studies were considered reliable and valid having been used numerous times in other studies and having had previously undergone testing to determine their psychometrics. For those studies that included a qualitative component, only Toly et al. (2014) stated that content analysis was used to identify themes from participant interviews; Toly et al. (2012) and Caicedo (2014) provided no explanation as to how interview data were analyzed.

Three of the studies collected data at multiple time periods. Caicedo (2014) interviewed and surveyed participants monthly for five months, Toly et al. (2012) collected data at two separate points and Toly et al. (2014) collected data at baseline and then at six weeks post-educational intervention. Such studies provide a more detailed

picture of the experience of participants because the phenomenon of interest may change over time or change in response to an intervention. In addition, collecting data at multiple points may enhance the interpretability of the results as data may be compared over time (Polit & Beck, 2017).

All but one of the studies' purposes were to help describe the experience of caring for a technology-dependent child and the effect this has on an individual or family. The study by Toly et al. (2014) is important because its purpose was to evaluate the effectiveness of an intervention designed to help caregivers cope more effectively with the challenges that they face in providing care in the home environment.

In comparing the participant demographics across studies, only mothers of technology-dependent children participated in in three of the studies (Montagnino and Maurico, 2004; Toly et al., 2012; Toly et al., 2014). Stephenson (1999) did not report the gender of family caregivers who participated in the study for either the healthy children group or technology-dependent child group. The participants in Caicedo's (2014) study included the most varied caregivers including mothers, fathers, grandmothers, and guardians. Although the results were presented in aggregate and not by caregiver role, this study is important because it includes the voice of fathers in the results. Again, the majority of participants were identified as Caucasian in studies that reported such demographics which is a limitation of these studies as the results may not be representative of the experience of all races/ethnicities in the population. However, 47% of participants in Caicedo's study identified as Hispanic which provides some insight into the experience of a minority population caring for a technology-dependent child. As the results of Caicedo's study were similar to the results of other studies (Stephenson, 1999;

Montagnino & Maurico, 2004), the case could be made that Hispanic participants' experiences caring for a technology-dependent child is similar to that of Caucasian participants.

**Financial stressors.** The financial burden of caring for a technology-dependent infant in the home setting is just one of many stressors caregivers must face (Stephenson, 1999; Montagnino & Maurico, 2004; Caicedo, 2014). It is estimated that that patients in the United States must pay out-of-pocket for 10% of the expenses of home care services after coverage by health insurance and either Medicare or Medicaid (Centers for Medicare and Medicaid Services, Office of the Actuary, 2007). Porterfield and DeRigne (2011) conducted a study to determine the out-of-pocket medical costs per \$1,000 of household income for families providing care at home for children with special health care needs (CSHCN). Data from the 2005-2006 National Survey of CSHCN ( $N = 31,808$ ) were used. After controlling for insurance type, it was determined that families incurred out-of-pocket medical costs between 2.25 and 3.9% of household income. Out-of-pocket costs were lower for families that had access to care coordination services. It is important to note that these findings are not specific to technology-dependent children but relate to the care of all children who meet the criteria for designation as a CSHCN as “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally” (Child and Adolescent Health Measurement Initiative, 2012).

**Discussion.** The stressors related to the financial impact of caring for a technology-dependent child in the home environment was not mentioned in detail in the

review of studies in the literature. When mentioned, the studies were conducted in the United States; financial stressors were not mentioned in the studies completed in Canada or the United Kingdom (Carnevale et al., 2006, Kirk et al., 2005, Reeves et al., 2006). Although the cost estimates included in this section are not specific to the care of technology-dependent children in the home setting, this researcher felt that the financial data are important findings for nurses and case managers to consider when planning for discharge as these costs may have an impact on other household finance decisions.

### **Caregiver's Experience with Inpatient Nursing Care**

The review of literature also uncovered studies that dealt with caregivers' experiences of inpatient nursing care of their technology-dependent children. Bruns and McCollum (2002) conducted a descriptive, mixed methods study to understand how clinicians and mothers ( $N = 196$ ) of infants who were cared for in a neonatal intensive care unit (NICU) in one of six hospitals rated the importance of parent-professional partnerships in the areas of caregiving, information exchange and relationships. Mothers ( $n = 55$ ) who had an infant cared for in a NICU for a minimum of four weeks completed a questionnaire which included Likert-type questions, open-ended questions, and a demographic form. Neonatologists ( $n = 18$ ) and nurses ( $n = 123$ ) also completed the survey. Statistical analysis of the quantitative data revealed that all groups highly rated the importance of caregiving, information exchange, and relationships. In addition, respondents were generally satisfied with the current practice in these three areas. The data also showed that mothers and professionals felt that neonatologists and nurses were implementing these practices. However, the mothers' scores for implementation were lower than their scores for how important the practices were to their experience which

demonstrates that there was room for improvement in how these practices were being implemented.

Reeves et al. (2006) explored the negotiation of care by parents of technology-dependent children in the hospital. A convenience sample of six parents was recruited to participate in a one-time, qualitative, semi-structured interview. Analysis of the transcribed interviews revealed the following themes: living with technology, expert parents, power and control, and negotiation of care.

Under the theme, living with technology, parents identified that they have extended roles, serving as both parent and care provider and this can dictate all aspects of their lives. In addition, parents reported attempting to attain a sense of normalcy in their parenting activities such as feeding their child. Parents felt that they were the “experts” in caring for their children and at times, this could create conflict with nurses in the hospital. Although parents wanted confident and competent nurses caring for their children, parents often felt that they knew more about their child than the nurse including caring for their child’s tracheostomy. At times, this led to a perception that the nurses were intimidated by the parents’ expertise. Regarding power and control, parents are in control of their child’s care at home but some of that control is relinquished when the child is an inpatient. This lack of control was not an issue when nurses cared for the child in a way that in which parents approved. However, parents also felt that they did not want to take control particularly when learning a new skill; they preferred that the nurses provided the technological care. The theme, negotiation of care, was illustrated when nurses and parents discussed the child’s care and made a mutual decision as to who was going to provide certain aspects of care. Some parents lacked confidence in the



nursing care and felt they could not leave the child's bedside. At times, nurses assumed that if the parent was present, they would perform the care and this was a potential source of conflict.

Avis and Reardon (2008) conducted a qualitative descriptive study and used a one-time interview to explore parents' views of the nursing care their children receive when in a hospital. Twelve parents participated in the study. Communication with staff was deemed as the most important aspect that influenced parents' perceptions of nursing care and effective communication supported positive nurse/parent relationships.

Giambra, Sabourin, Broome, and Buelow (2014) used grounded theory to explore how parents of technology-dependent children communicate with nurses on the inpatient unit. Purposive sampling was used to enroll 11 mothers of children aged four to 15 years into the study. Mothers participated in a one-time, semi-structured interview.

Antecedent inputs identified include a respect for their own and each other's expertise and positive communication behaviors such as questioning and listening, explaining and advocating, verifying understanding, and negotiating roles. A Theory of Shared Communication was proposed that incorporated these inputs identified as facilitating effective parent-nurse communication as well as a mutual understanding of the child's plan of care.

**Discussion.** The three qualitative and one mixed methods studies provide some insight into the experience that parents have during their child's hospitalization. Although their purposes differed, the results of each study highlighted the importance of clinician (i.e., nurse, doctor)-parent communication when a child is hospitalized. Nurses are the caregivers who have the most amount of contact with patients and their family

members by virtue of their role; therefore, it is particularly important for nurses to understand parent's perceptions regarding the importance of communication.

Two of the studies (Bruns & McCollum, 2002; Giambra, et al. 2014) focused on the perceptions of mothers whereas Reeves, et al. (2006) and Avis and Reardon (2008) recruited parents to participate in their study and did not specify the parents' gender. However, two of the quotes were specifically noted as being stated by a mother. None of the studies provided demographic data related to the sample and only one (Giambra, et al.) provided the age of the children. The lack of demographic data to describe the participants and children is a flaw in these studies as the reader is unable to consider the findings in comparison to the results of other studies where the sample characteristics are fully presented.

Two of the studies (Avis & Reardon, 2008; Reeves, et al., 2006) were conducted in the United Kingdom whereas the other two studies were conducted in the United States; as noted earlier, it is difficult to compare the experience of caregivers/parents from different countries due to differences in health systems. However, the fact that communication emerged as a common theme lends support for the premise that parents of hospitalized children may have similar experiences in both the USA and UK.

### **Discharge Teaching**

A review of the literature related to discharge teaching for caregivers of technology-dependent children revealed no research studies related to the effectiveness of teaching techniques specific to this population. However, the benefits of, and need for, discharge education for parents and other caregivers who will provide needed care in the home environment as they prepare for discharge was cited by a number of authors.

Nurse-delivered patient education has been shown to achieve many good outcomes for patients and families including improved care skills, coping, problem solving, knowledge acquisition, overall well-being, quality of life, stress level and avoidance of adverse aspects of care such as premature death (Redman, 1998).

Nursing educational interventions can be designed to increase comprehension, recall, and application of information (Kessels, 2003), competence (Bastable, 2008), confidence (Bastable, 2008; Wilkins, 2006), ability (Coyne, 1995; Glanville, 2000), and empowerment so that patients [caregivers] can achieve self-management (Bastable, 2008).

In addition to the benefits of discharge education, a number of authors provided outlines or tools specific to the care of the technology-dependent child in the home environment. Barnes (1992) provided an overview of the technical and decision-making skills required for parents who will be caring for a child with a tracheostomy. Nurses were identified as the primary educators and recommended the development of individualized teaching plans that required parents to improve their manual dexterity in order to successfully perform needed skills. Skill performance on their own child was recommended so that parents can build a sense of comfort and competency performing tracheostomy care skills prior to discharge.

Fiske (2004) provided a comprehensive overview of tracheostomies and tracheostomy care including indications, complications, anatomical and developmental changes, types and sizes of devices, and routine care. In addition, goals, objectives, and techniques for teaching home care were identified including the recommendation that

teaching begun prior to tracheostomy surgery, the use of dolls to teach technical skills, and a period of rooming in prior to discharge.

Gracey and Fiske (2004) developed a tracheostomy teaching guide that included topics such as the use of humidified oxygen, stoma care, suctioning, changing the tube and assessment of normal vs. abnormal noises, signs of illness or emergency needs. In addition, tips for organizing resources were also identified as an important topic for teaching.

Lewis and Noyes (2007) provided an overview of discharge planning for children with complex needs. Specific goals for discharge planning were presented and included the identification of services that may be needed to support the family and child, the importance of effective communication, the initiation of discharge planning early in the hospitalization period, and the need to provide the appropriate training for those who would be providing care and coordinating roles post-discharge. In addition to training, they also recommended that parents be fully informed about the implications of their provision of care to their child and that support systems must be in place to assist them as they assume the caregiver role.

**Discussion.** The literature reviewed in this section describes the importance of nurse-led discharge teaching in general, as well as some broad recommendations and specific tools to use when educating caregivers of technology-dependent children. The authors of these articles are all master's-prepared nurses. As such, these articles can be considered to be expert opinion or Level VII evidence as described by Melnyk and Fineout-Overholt (2010). Level VII is the lowest category on their hierarchy of evidence with Level I or evidence based on systematic reviews or meta-analyses of multiple

randomized controlled trials or evidence-based guidelines based on such reviews.

Although expert opinion is valuable evidence, it is evident that more research is needed in this area to determine the most effective discharge teaching strategies for this population including the individualization of teaching based on the caregiver's preferred learning style.

### **Summary**

The physical, psychological, and financial burdens related to caring for a technology-dependent infant in the home setting are well documented. Because nurses have a societal obligation to protect, promote and optimize health, prevent illness and injury, and alleviate suffering related to their populations of concern (ANA, 2010), they are also responsible for developing knowledge supportive of these goals and effective interventions. Nurses can fulfill these goals by supporting individuals as they transition to the role of parent and increasing their knowledge and skills required to care for their technology-dependent infant.

This chapter reviews information about technology-dependent infants and the stressors that caregivers and families face in the hospital and when providing care in the home environment. Nurses currently provide discharge education to caregivers of technology-dependent infants to prepare them to provide needed care at home. However, little is known regarding caregivers' perceptions of this discharge education and the factors that facilitate or hinder its effectiveness. In Chapter 3, details of the method used to study caregivers' perceptions of their preparation to care for their infant at home are provided along with the rationale for choosing this method.

## Chapter 3

### Design and Method

This chapter justifies the choice of descriptive qualitative method for the purposes of the study aims and questions. The process steps of this study, *Caregivers' Perceptions of Nurse-led Discharge Education Interventions: Knowledge Needed for Adequate Care of a Technology-dependent Infant in the Home Setting* are described in more detail. The study design, data collection and analysis processes are all elaborated as is the plan used to address rigor and trustworthiness in the findings. In addition, procedures to ensure the protection of human subjects and potential study limitations are provided.

#### The Qualitative Paradigm

An extensive literature review of lay caregivers' experience of caring for their technology-dependent infant in the home setting revealed that very little is known about caregiver's perceptions of nurse-led discharge education designed to prepare them to care for their infant. Caregiver's perceptions of factors that facilitate or hinder the effectiveness of the nurse-led discharge education are also poorly understood. Anecdotally, nursing leadership on the inpatient pediatric units at a large academic medical center located in the Northeast relate that, although caregivers are taught the knowledge and skills to care for their infant, many express deep concerns regarding their abilities to perform them in the home environment and/or are fearful of causing pain or harming their infant (names redacted to preserve confidentiality, personal communication, January 15, 2009). The nurse leaders' anecdotal impressions of caregivers' reactions to the need to provide care to a technology-dependent child in the home environment are supported by evidence from the literature as outlined in Chapter 2

(Coyne, 1995; Kirk et al., 2005; Montagnino & Mauricio, 2004; and Winkler et al., 2006). When little is known about a phenomenon such as caregivers' perceptions of nurse-led discharge education, qualitative research methods are considered a valuable initial step (Morse, 2003) in developing qualitative understandings of the phenomenon from the participant's perspective.

**Qualitative method.** This study used a qualitative descriptive design to explore caregivers' perceptions of nurse-led discharge education efforts designed to teach caregivers how to care for their technology-dependent infants in the home setting. Qualitative descriptive research is used to describe a phenomenon from the participants' perspectives. It provides the researcher with a "comprehensive summary of an event in the everyday terms of those events" (Sandelowski, 2000, p. 336). As a result, the phenomenon is contextually described and the meaning the individual ascribes to it can emerge. An understanding of the participants' subjective experience and the meaning they ascribe to it are important components of knowledge needed for the nurses to fulfil their roles (ANA, 2010). Findings from research aimed at understanding the person's perspective of nursing care provides nurses with knowledge needed to develop a program of research that leads to the design of effective nursing interventions (Ayres, 2007a; Sandelowski, 2008) and ultimately, good care.

All forms of qualitative research use description and interpretation, but a qualitative descriptive design provides a level of detail that allows for "low-inference" interpretation that will ease the process of gaining consensus on the meaning of the data (Sandelowski, 2000, 2009). Expert agreement on the meaning of the data serves as evidence that may be used to inform nurses of the current impact of their care and lead to the development of further nursing

research studies designed to test interventions to improve care. The ultimate goal of this study is to capture caregivers' experience of a nurse-led discharge intervention aimed at improving their ability to care for their technology dependent infant at home.

### **Study Rigor**

Rigor in qualitative research is defined as the fundamental trustworthiness of the investigation which parallel the concepts of validity and reliability in quantitative research (Lincoln & Guba, 1991). Lincoln and Guba (1991) described four criteria that supports the trustworthiness of a qualitative study:

- 1) **Credibility:** the confidence in the truth of the data and interpretation of data that is achieved through aspects of study design.
- 2) **Dependability:** the replicability of the data and conditions if the study was repeated with similar participants and context.
- 3) **Confirmability:** the objective congruence of two or more people's opinion of the data's accuracy, relevance or meaning
- 4) **Transferability:** the extent to which others can see the applicability of the study findings to other settings or groups.

Guba and Lincoln (1994) subsequently added authenticity as a fifth criterion related to trustworthiness. Authenticity is achieved through a faithful representation of the study participants' realities such that the reader can vicariously experience as aspect of the participants' lives.

Specific aspects of study design outlined by Lincoln and Guba (1991) and Guba and Lincoln (1994) were used by the researcher to achieve methodological rigor/trustworthiness related to the above criterion included:



## 1) Credibility:

- Reflexivity or self-reflection on personal biases, preferences, and preconceptions through frequent taking and review of field notes.
- Purposive sampling technique to ensure thick, information rich descriptions
- Audio recording and verbatim transcription of data, use of coding and peer review of data.
- Reviewing/debriefing of transcribed interviews with an academic team who had no role in providing care to participants
- Achieving saturation of data through an adequate number of participant interviews
- Providing a disclosure of researcher background.

## 2) Dependability:

- Carefully documenting all aspects of the conduction of the study.

## 3) Confirmability:

- Use of coding and review of data with an academic team who have no role in providing care to participants.

## 4) Transferability:

- Ensuring saturation of data and providing thick descriptions illustrated with verbatim participant quotes.

## 5) Authenticity:

- Reflexivity or self-reflection on personal biases, preferences, and preconceptions through frequent taking and review of field notes.
- Audio recording and verbatim transcription of data

- Providing thick descriptions illustrated with verbatim participant quotes

Study design features which enhance multiple criterion and thus, methodologic rigor/trustworthiness include researcher reflexivity, verbatim transcription of data, coding of data, review of data with others.

Member checks, or the sharing of the emerging interpretation of data to obtain participant feedback and potential agreement with the researcher's thinking, is another potential way to ensure methodological credibility (Lincoln & Guba, 1991). However, Morse (1994) and Sandelowski (1993) have critiqued this approach to ensuring qualitative study rigor. From their viewpoint, participants may change or influence their thinking about what had occurred after reviewing the researcher's analysis. Additionally, experiences that have occurred in between their interview and review may also affect the participants' thinking and recall of past events. Because the interviewer has synthesized multiple participant's responses into the analysis, a participant may be unable to see their individual viewpoint and disagree with the interpretation. Sandolowski (1993) cautions that some participants may be unwilling to review or potentially harmed with the review if the topic is emotionally charged. Some of the issues revealed in Chapter 2's literature review regarding caregivers' experience providing care in the home setting, along with researcher experiences during the recruitment process led to a decision not to use this strategy as a support for methodologic credibility. Some potential participants declined to be involved in the study after reviewing the recruitment materials and described their experience as "too upsetting" or "disturbing" to relive.

More detailed descriptions of the study design are included in the following sections to promote methodological transparency and thus the reader's understanding of its rigor/trustworthiness.

### **The Researcher's Role**

The credibility and authenticity of the study was enhanced through the researcher's reflexivity or self-reflection on possible risks for personal bias. Rossman and Rallis (2016) raise the issue of the relationship between the participants and the researcher(s). Attention must be paid to how the caregivers' description of their experience is shaped and potentially changed by the researcher and aspects of the study. For this reason, it is important that the researcher understands how aspects of his "personal biography" (i.e. prior disciplinary knowledge, professional and personal perspectives and reactions) might interfere with analysis and reporting of the data (Rossman and Rallis, 2016).

The study's credibility is further enhanced through a disclosure of the researcher's background. Although this researcher has been a nurse for 34 years, he has never worked in pediatrics or with new parents, nor has he ever fathered a child or cared for an infant for any length of time. This researcher has only provided nursing care to adult patients and has taught adult clinicians in both academic and practice settings. This inexperience with parenting and the needs of infants has potentially both positive and negative components. The lack of experience may help this researcher to avoid preconceptions about what it is like to be a caregiver of a technology-dependent infant. Alternately, this researcher may not have the ability to fully empathize with the caregivers' situations and thus appropriately probe further in the interviews as issues emerge.

The researcher has 34 years of nursing experience with 24 years of experience in nursing professional development designing, implementing, and evaluating educational interventions for all levels of nursing staff including staff nurses, assistive personnel, and nursing leadership. He is currently employed as the director of a patient education center at the study site. This center provides evidence-based health education material to patients, family members, and staff and assists in the development of materials as needed but the researcher has played no role in the development of existing nurse-led discharge education materials or interventions for the study participants. Through a review of the literature and dialogue with pediatric clinical nurse specialists and nurse directors at the study site, the researcher identified that there was little evidence describing caregivers' perceptions of nurse-led discharge education designed to prepare them to care for their technology-dependent infant in the home setting.

### **Participant Recruitment**

The recruitment site is a large academic medical center located in the northeast that provides a full range of pediatric health care services including intensive care. Caregivers of a technology-dependent infants who meet the study's inclusion criteria were recruited from two inpatient units, a Level IV, 18-bed newborn intensive care unit (NICU) and the 20-bed general pediatric unit. The NICU provides emergency medical and nursing services to full-term and premature infants. The patient population on general pediatrics includes infants and children aged one day through five years with medical surgical needs.

In data provided by the hospital's quality and safety staff, showed that in the calendar years 2011 and 2012, an average of 920 infants between the ages of one day and

three years of age were discharged from the two inpatient units (name redacted to preserve confidentiality, personal communication, May 22, 2013). It is difficult to quantify the number of infants discharged with technological care needs as discharge codes are based on clinical diagnosis, not specific care needs. However, during a 12-month period in 2008-2009, 53 infants were discharged with a tracheostomy, gastrostomy tube, or both (name redacted to preserve confidentiality, personal communication, June 15, 2009), a number that has remained somewhat constant in subsequent years.

Accounting for infants discharged with other forms of technology that meet the criteria described in Chapter 1, it was assumed prior to commencing the study that it would be possible to recruit the number of participants willing to be interviewed and able to answer the questions to adequately meet the requirements of thematic saturation as described later.

**Sample.** A commonly used technique to select participants in qualitative research that promotes methodological credibility is purposive sampling. Purposive sampling is the conscious decision by a researcher to select and include participants that will provide data needed for the study (Gray, Grove & Sutherland, 2016). This technique was used to recruit participants for this study in order to obtain “information-rich” cases (Patton, 2001; Sandelowski, 2000) about the phenomenon of interest (Gray, Grove & Sutherland, 2016).

**Sample selection criteria.** As caregivers report feeling unprepared to provide care regardless of demographics and other factors (Winkler, et al., 2006), limited selection criteria were used in order to ensure a variety of information-rich cases. Participants met the following inclusion criteria for this study:

1. Adult caregivers (i.e. greater than 21 years of age), biologic or adoptive parent or other family members of a technology-dependent infant less than three years old who had participated in nurse-led discharge education designed to prepare them to care for their infant in the home setting prior to discharge from the study site during the past year. The age requirement (i.e. adult) may limit additional factors that would influence the ability of the caregiver to perform the skills or influence their environment (i.e. teen parents may lack the maturity, intellectual capacity, and resources of an adult).
2. Caregivers were either the infant's primary provider of care or were accountable for providing care for substantial periods of time. Although the majority of past studies focus on parents' ability to provide needed care, other caregivers often participate as well and so it was considered important to include them in this study. Designation as a primary or frequent caregiver ensured that skills taught prior to discharge were those that needed to be performed in the home setting.
3. Caregivers may have been first time parents or have more than one child.
4. Caregivers needed to speak English proficiently. Although the study site has robust medical interpreter services, caregivers' ability to speak English was important for the researcher (who is not fluent in other languages) in collecting, analyzing and interpreting the data.

Potential participants who did not meet these criteria were excluded from the study. Other exclusion criteria included:

1. Caregivers who were health care providers (physician, nurse, respiratory therapist or speech language pathologist) or had provided technological care to either an infant or an adult in the past. These persons were excluded as they might be expected to have prior

experience handling the technological procedures such as suctioning, intravenous management, etc. and thus be knowledgeable independent of the nurse education. This criterion ensured that the infants' caregiver(s) had no, or limited knowledge and experience, with providing technological care.

Caregivers who met the inclusion criteria were offered the opportunity to participate regardless of race, ethnicity, culture, gender, sexual orientation, religion or geographic location.

**Sample size.** The exact sample size for qualitative studies is hard to calculate ahead of data analysis as the goal of sampling is to reach data redundancy (Lincoln & Guba, 1991) or theoretical saturation (Miles, Huberman, & Saldana, 2013) after which no new relevant information emerges from the data. Based on this goal, data collection will continue until redundancy and saturation occurs. This researcher aimed to interview caregivers until theoretical saturation occurred.

**Recruitment procedure.** A pediatric nurse leader identified potential participants whose child was a current inpatient or recent discharge in order to purposively recruit participants who had information relevant to the study. Potential participants were asked if they might be interested in participating in a one-time interview to discuss their perceptions of their discharge education. If the caregiver(s) expressed interest in participation, the unit nurse leaders provided a packet of information that contained a letter of introduction, consent form, and demographic form (Appendix A) and obtained permission for the researcher to contact the participant(s) by telephone.

The unit nurse leaders had completed the Collaborative Institutional Training Initiative (CITI) training prior to participating in this study. Their only role in the study was to identify

potential participants and make initial contact to determine their appropriateness and interest in participation.

### **Data Sources**

The goal of qualitative descriptive studies is to “capture each participant’s unique and context-specific viewpoint and story embedded in its cultural and historical milieu” (Kearney, 2007, p. 299). To meet this goal, data were collected during one semi-structured interview, a brief demographic questionnaire completed by the participants, and researcher observations and memos.

**Interviews.** A semi-structured, audio-recorded interview consisting of open-ended questions is commonly used in qualitative descriptive research (Ayres, 2007c; Sandelowski, 2000, 2009; Sullivan-Bolyai, Knafl, Tamborlane, & Grey, 2004) with questions organized temporally (i.e. past to future), topically (i.e. general to specific) and logically (Ayres, 2007c). Although this researcher had identified concepts of interest (i.e. caregivers’ perceptions; perceived barriers and facilitators to learning) and research questions to guide this work, some flexibility on the part of the researcher’s guiding interview questions was required to allow for the emergent nature of qualitative studies. Credibility of the study was enhanced as the interview guide (Appendix B) was reviewed and approved by an academic team who had no direct role in designing or providing care to the study participants. The interview guide consisted of a list of broad, topical questions designed to capture participants’ narrative answers of their contextual experience of nurse-led discharge education. They were organized temporally and designed to gather both general and specific answers. Examples of broader questions included “How did the nurses teach you to care for your baby?” and “How prepared did



you feel to care for your baby at home?” Probing questions such as “Which method did you like best and why?” and “What was your biggest learning need or worry?” were used to deepen and clarify my understanding of participant responses. As needed, reflective statements and questions were utilized such as “It sounds as if you are saying...” to allow participants the opportunity to correct previously answered questions. The researcher planned for the interviews to last between 60 and 90 minutes. Insights gained from earlier interviews were used to inform questioning of subsequent participants.

Interviews were conducted at a private and convenient site identified by the participant. This included their home or the researcher’s private office at the study site. Participants were asked to schedule a time when they did not need to provide care to their infant (e.g. child care was available).

**Demographic form.** Participants completed a short questionnaire to capture demographic characteristics and information related to the infant’s technological care needs (Appendix A). Demographic information related to age, gender, marital/partner status, relationship to the infant, race, and ethnicity was collected to provide a more detailed picture of the study participants. In addition, caregivers identified a list of care needs that contributed to the infant’s designation as technologically-dependent at the time of discharge. It was estimated that the questionnaire would take less than five minutes to complete.

**Researcher observations and memos.** The credibility, dependability and authenticity of the study was enhanced through researcher observation, memos and debriefing of findings with the dissertation committee. Observation is considered a fundamental aspect of all qualitative inquiry that promotes a contextual understanding, allows the researcher to see patterns of

behaviors, and provides direct personal experience and knowledge about the study participants (Rossman and Rallis, 2016). After each interview, the researcher kept field notes to describe what was observed during the interview (i.e. participant reactions, emotions, tone of voice, etc.) including the researcher's observations about participants' reactions and other contextual information. They also included the researcher's reactions to events, insights, questions about meaning, and possible design modifications (Rossman and Rallis, 2016), an iterative process which influenced subsequent interview questions. These memos captured the researcher's thoughts on the study method and design and thematic memos recorded the researcher's identification of possible emerging themes from the sources of data (interviews, observations, etc.) (Rossman & Rallis, 2016). These handwritten memos added to the audit trail and enriched the data. Reviewing these field notes, potential codes, and emerging themes with the academic team enhanced reflexivity (Rossman & Rallis, 2016) and helped to support authenticity and reduce any potential reactivity and bias related to the findings.

The use of memos and notes during data analysis further promoted reflexivity by challenging the researcher to continuously evaluate his skill in performing qualitative interviews. The goal of collecting these various documents and artifacts was to provide the researcher with the ability to write "thick descriptions" (Geertz, 1973). Thick descriptions aided the researcher's analysis and interpretation of the data as they describe the actions, words, events, time, place, and physical surrounds of the study participants in detail.

### **Data Analysis**

**Audiotape transcription.** The interviews were audio recorded and transcribed verbatim as recommended by Gray, Grove, and Sutherland (2016). This approach further enhances the study's methodologic credibility. A transcriptionist, funded by the researcher, transcribed the

recordings. Once transcribed, the researcher concurrently listened to the recordings and compared to the written transcripts to make corrections and notations regarding voice tone, inflection and pauses as these features added to the richness of the data and influenced the analysis (Morse & Field, 1995). Such notations also ensured the accuracy of the data. The names of individuals (i.e. other caregivers, nurses who provided the education) were removed from the transcribed interview to protect their identity.

Qualitative analysis of data requires immersion in and systematic organization of the data into themes and patterns so that the researcher can interpret deeper meanings and convey to others the findings in a coherent manner (Rossman and Rallis, 2016). As stated earlier, the basis of analysis is a thick description of participant actions and words. Thick descriptions promote methodologic rigor by contributing to the study's transferability. To facilitate the analysis of data, transcription of audiotapes occurred shortly after completion which allowed the researcher to add notes describing participant behavior, voice tone, inflection and pauses as these features added to the richness of the data and were important to the analysis (Morse & Field, 1995). Each interview was transcribed and analyzed prior to conducting the next interview. Analysis of each transcript began as soon as it was transcribed.

**Content analysis.** The qualitative content analysis approach to qualitative inquiry was used to analyze the data from this study as it is an appropriate method to describe a phenomenon when existing theories and research in the literature is limited (Hsieh & Shannon, 2005). Schreier (2012) described qualitative content analysis as a process to “systematically describe the meaning of your material” (p. 3) in which the researcher only analyzes data that is relevant to the research questions of the study.

Morse and Field (1995) and Hsieh and Shannon (2005) described the process of analyzing the data using content analysis as identifying codes for key words or topics from the interview content that are subsequently grouped into categories based on their similarities/dissimilarities and linkages/relationships. Morse and Field (1995) suggested that there are typically 10-15 categories identified per study using this method of analysis. Relationships between categories are then described based on their concurrence, antecedents, or consequences (Morse & Field, 1995). The researcher used the following step-by-step process suggested by Hsieh and Shannon (2005) to analyze interview content:

1. Each interview was read to obtain a sense of the whole.
2. Key words were identified in the transcript.
3. Notes were made regarding impressions/thoughts about the key words.
4. An initial coding scheme was developed from these thoughts/impressions.
5. Codes were sorted into broader categories based on linkages/relationships.

Interviews were read multiple times to ensure that key words and codes were identified in an iterative fashion. Through the re-reading of earlier transcribed interviews and comparison with the more recently transcribed interview, this researcher finalized the key words and codes such that categories and themes could be identified.

This is a descriptive and exploratory study with a goal of providing data requiring “low inference interpretation” (Sandelowski, 2000) and therefore, confirmability. Peer review with nursing experts who provide care to people who are transferred to home with technology will be conducted to assure coding scheme enhances methodologic credibility, dependability, and confirmability.

Finally, credibility of this study was enhanced through the process of negative case analysis (Lincoln & Guba, 1991). As the researcher began to identify potential codes, categories, and themes, he began to look for examples that challenged his thinking and required a re-interpretation of existing data. In this way, the interpretation represents the viewpoints of all participants. Examples of negative cases are presented in Chapter 4.

### **Protection of Human Subjects**

This research study proposal was submitted to the respective hospital institutional review board (IRB) to ensure the protection of human subjects. Approval was achieved prior to initiating the recruitment of participants including the identification of potential participants. A copy of the Notification of IRB Approval/Activation is included in Appendix C.

**Informed consent.** The researcher utilized a script to review the purpose of the study, requirements for participation, risks, and benefits as noted in the consent form with potential participants. The researcher confirmed the participant's eligibility to participate, gained verbal and/or written informed consent, and set up a convenient time and location for the interview.

If not already obtained at the time of initial contact, written informed consent was obtained prior to the start of all interviews. The researcher reviewed: the purpose and nature of the study, the voluntary nature of participation and ability to withdraw from the study at any time for any reason without repercussion to them or their infant, the inclusion and exclusion criteria for participation, potential benefits and risks, the use of study results including publication and dissemination, and the steps and methods to protect the anonymity of identities and information. Participants were given the opportunity to ask any questions related to any aspects of the study. The researcher

assessed the caregivers' understanding by asking them to review what they believe their agreement to participation entailed. The caregiver(s) were given a copy of the signed consent form for their records. The informed consent process supports the ethical principle of respect for persons as caregivers may freely choose to participate or not participate without coercion.

**Risks and benefits.** Participants were informed of the minimal risks to them inherent in the study including a possible risk of the burden of answering interview questions and the potential for stress or other emotional responses due to their recounting past events related to their infant's hospitalization, the discharge teaching experience, and provision of technological care in the home environment. Participants were reminded that their participation was voluntary and of their right to stop the interview, decline to answer any questions, and withdraw from the study at any time. The researcher also informed participants that they should contact their primary care provider for a referral to a counselor if they felt the need to process the experience of the interview. No emergent needs arose, but the plan was to refer participants to a local hospital emergency department and to inform the study site's Human Studies Committee of the IRB if any issues had occurred.

There were no direct benefits to participants related to their ability to provide care for their infant as they were recounting past events. Participants received a \$25.00 (twenty-five dollar) gift card for their participation and reimbursement for their parking fees if the interview occurred at the study site funded by the researcher. Participants were informed that their participation will inform future nursing research about the care needs of caregivers of technology-dependent infants. Future studies can lead to the development of interventions

designed to improve care in this population. Participants may have derived some personal satisfaction or benefit from this knowledge.

**Security of data.** Participants were tracked using an enrollment form and assigned an identifying numeric code to promote privacy and confidentiality. The list of codes and consent forms were kept separately from the other portions of the research files (i.e. transcripts, notes, etc.). All files were kept in a locked file cabinet in the researcher's locked office as a security measure. Only the researcher had direct access to these files.

Prior to the start of each interview, the researcher asked the participants to avoid identifying anyone by name (i.e. the infant, their spouse, other lay caregivers, health care providers, themselves) to promote confidentiality. All names used by the participants during the interviews were removed in the written transcripts of the recordings.

Participants were informed that any evidence of actual or suspected child abuse or neglect would be reported to the state Department of Health and Human Services as the researcher is a nurse and therefore, is legally bound to report this behavior.

### **Summary**

This chapter described the research method used to conduct this study as well as the specifics regarding methodological rigor, sample recruitment and size, protection of human participants, and analysis of data. The themes identified from participant interviews and an analysis of these themes is presented in Chapter 4.

## **Chapter 4**

### **Findings**

The purpose of this descriptive exploratory study, as described previously was to learn more about the needs of caregivers for technology dependent infants as they prepare to take the infant home. Specifically, the study aimed to:

1. Describe caregivers' perceptions of nurse-led discharge education designed to prepare them to care for their technology-dependent infants in the home setting.
2. Describe caregivers' perceptions of factors that facilitate or hinder the effectiveness of nurse-led discharge education designed to prepare them to care for their technology-dependent infant in the home setting.

Chapter 3 outlined the method used, criteria used for selection of participants and recruitment strategies as well as the process for data collection and identification of themes. Chapter 4 begins with a review of recruitment and consent procedures, a description of the interview settings and describes reasons for variation in the data collection processes described in Chapter 3. The findings of the study are also presented and are organized as follows: the sample characteristics for both the caregivers and their infants are given; the roles of the clinicians who participated in the teaching process are identified and the teaching methods used described. The researcher's analytic process is briefly reviewed. For example, how the codes were identified, clustered into categories, and developed into themes are discussed. Finally, each theme is presented, described, and supported by direct quotes from participants.



## **Data Preparation**

Sources of data used in the analytic process included the transcribed interview, the audio recordings, demographic information, the researcher's field notes and anecdotal information provided by nursing leaders for the areas in which the infants originally received care. Interviews averaged 50 minutes in length and ranged in length from 26 minutes to 1 hour 50 minutes. All interviews were digitally recorded and transcribed verbatim. Field notes were taken during the interviews and during the iterative process of data collection and analysis. At the completion of each interview, time was taken to listen to the recording and to note, for example, emotions, pauses, and to consider different ways to word questions. This added to the field notes and after the first interview served to inform ensuing interviews. All data were coded and de-identified to facilitate confidentiality.

## **Data Gathering, Analytic Process and Descriptive Statistics**

Following a brief review of the recruitment process, a description of the sample's demographics is provided. Additionally, the interview setting and factors relevant to the teaching these participants received, which were ostensibly aimed at preparing them to care for their child at home, is detailed. Finally, the themes that emerged from the analysis are described using participant quotes to illustrate important aspects.

**Recruitment and consent procedures.** Potential study participants were identified on the inpatient units by a pediatric nurse leader and provided with a recruitment packet that included an introductory letter, consent form, and demographic form. A total of 20 recruitment packets were distributed to potential participants. The packets contained a letter of introduction, demographic data form, and a copy of the

consent form so that potential participants could review the materials prior to speaking with the researcher. Thirteen caregivers who met inclusion criteria agreed to participate in the study. Prior to each interview, the researcher called each potential participant, verbally reviewed the consent, and allowed time for questions and clarification. Verbal consent was obtained via a telephone call, the demographic data form was completed and an interview was scheduled. At the time of the interview, the researcher reviewed the purpose of the study and forms and obtained written informed consent from each participant prior to the start of the interview.

Two caregivers voluntarily withdrew from the study after completing the verbal consent process via a telephone conversation but prior to the interview. At the time of the first phone call, both participants requested that the researcher telephone at a different time to schedule the interview due to their busy schedules. During a subsequent call, one caregiver stated that she did not have the time to participate in the interview whereas the second caregiver failed to respond to two attempts by the researcher to schedule an interview and it was later discovered that the second caregiver's infant died.

**Study sample.** Caregivers of a technology-dependent infant who met the study's inclusion criteria were recruited at a large academic medical center in the Northeast section of the U.S.A. The caregivers' infants were cared for and discharged from two inpatient units, a Level IV, 18-bed NICU and a 20-bed general pediatric unit after they had been transferred from the pediatric intensive care unit. All caregivers had performed needed technological care for their infant in their home setting after discharge.

**Sample demographics.** Nine caregivers of technology-dependent infants were interviewed by the researcher. Saturation was obtained by the eighth interview as no new

themes or potential themes emerged from the data. Descriptive statistics were used to analyze the data collected on the Demographic Form (Appendix A). Table 2 contains a summary of caregiver demographic data.

Table 2

*Caregiver Demographics*

Variable	Level	Number	%
Age in years	20-29	2	22.2
	30-39	5	55.6
	40-49	2	22.2
Gender	Male	1	11.1
	Female	8	88.9
Partner status	Single	1	11.1
	Married	7	77.8
	Partnered	1	11.1
Relationship to infant	Parent	9	100.0
	Guardian	--	
	Grandparent	--	
	Aunt/Uncle	--	
	Sibling	--	
	Other	--	
Race	American Indian/Alaska Native	--	
	Asian	--	

	Black or African American	--	
	Native Hawaiian/Other Pacific Islander	--	
	White	7	77.8
	Other	2	22.2
Ethnicity	Hispanic or Latino	1	11.1
	Not Hispanic or Latino	8	88.9
Education	<High school diploma	--	
	High school diploma/GED	1	11.1
	Some college	1	11.1
	Associate's degree	3	33.3
	Bachelor's degree	2	22.2
	Master's degree	2	22.2
	Doctoral degree	--	
Income	< \$25,000	2	22.2
	\$25-50,000	1	11.1
	\$50-75,000	--	
	\$75-100,000	1	11.1
	>\$100,000	4	44.4

*Note. Total number of survey participants, N=9*

*\*-- No survey participants responded for this level.*

The caregivers' ages ranged from 29 to 48 years with a mean of 35.9 years.

Eighty nine percent ( $n = 8$ ) were female and 100% ( $n = 9$ ) were the biological parents of

their infants. Seventy eight percent ( $n = 7$ ) of the caregivers were married, 11% ( $n = 1$ ) was partnered, and 11% ( $n = 1$ ) were single. Regarding race, 77.8% ( $n = 7$ ) identified as white, 11.1% ( $n = 1$ ) identified as mixed race, and 11.1 % ( $n = 1$ ) identified as “other” but did not provide specific information. Eighty nine percent ( $n = 8$ ) identified their ethnicity as not Hispanic or Latino whereas 11% ( $n = 1$ ) identified as Hispanic or Latino. All caregivers were high school graduates (diploma/GED). Forty-four percent ( $n = 4$ ) had a bachelor’s or master’s degree, 33.3% ( $n = 3$ ) had an associate’s degree, and 22.2 % ( $n = 2$ ) had some college or high school diploma/GED as their highest level of education. One caregiver (11%) did not provide information regarding annual income. Of the eight who responded, 56% ( $n = 5$ ) had an annual income greater than \$75,000, whereas 33% ( $n = 3$ ) had an annual income of less than \$50,000. Caregivers had an average of two children (range one to four). Forty-four percent ( $n = 4$ ) of caregivers had only one child whereas 56 % ( $n = 5$ ) had between two and four children. Two caregivers (22%) had a technology-dependent child who is a twin. The average age of all children was 3 years (range 5 months to 8 years) whereas the average age of the children who were technology-dependent was 18.1 months (range 5 months to 36 months).

Table 3 provides a summary of the demographic characteristics of the technology-dependent infants. The infants’ mean age was 18 months with a range of five months to three years. The majority (67.7%) was male ( $n = 6$ ) and 33.3 % was female ( $n = 3$ ). The infants race and ethnicity demographic data matched that of the caregivers.

Table 3

*Infant Demographics*

Variable	Level	Number	%
Age	0-12 months	1	11.1
	13-18 months	6	66.7
	19-24 months	--	
	25-36 months	1	11.1
	>36 months (3 years)	1	11.1
Gender	Male	6	66.7
	Female	3	33.3
Race	American Indian/Alaska Native	--	
	Asian	--	
	Black or African American	--	
	Native Hawaiian/other Pacific	--	
	Islander	--	
	White	7	77.8
	Other	2	22.2
Ethnicity	Hispanic or Latino	1	11.1
	Not Hispanic or Latino	8	88.9

*Note. Total number of survey participants, N = 9*

*\*-- No survey participants responded for this level.*

Table 4 provides a summary of the technology required by infants in the home setting. A feeding tube and a tracheostomy for breathing support were required by 66.7% ( $n = 6$ ) of the infants. Oxygen therapy was required by 55.5% ( $n = 5$ ) of the infants and

33.3% ( $n = 3$ ) required an apnea monitor. One infant (11.1%) required an intravenous infusion and the support of a mechanical ventilator upon discharge from the hospital.

The infants' mean number of technological care needs was 2.4.

Table 4

*Technology Care Needs*

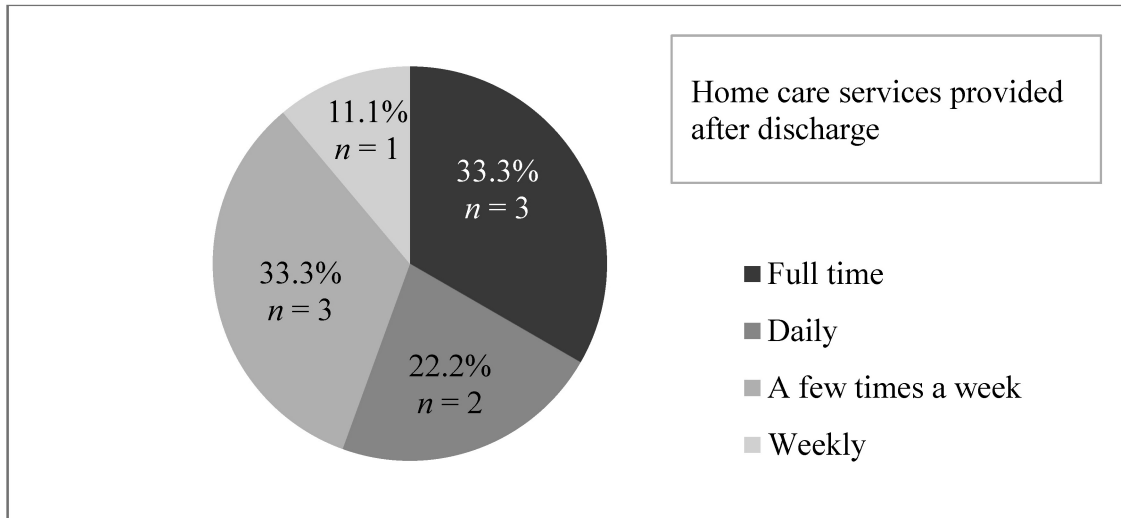
Variable	Level	Number	%
Technology Type	Feeding tube	6	66.7
	Breathing support: tracheostomy	6	66.7
	Breathing support: oxygen	5	55.5
	Apnea monitor	3	33.3
	Intravenous infusion	1	11.1
	Breathing support: ventilator	1	11.1
	Elimination devices: catheter/ostomy	0	0.0
	Peritoneal dialysis/hemodialysis	0	0.0

*Note.* Total number of survey participants,  $N = 9$   
 Mean number of technology care needs, 2.4.

The frequency that the caregivers received home care services performed by a registered nurse after discharge is shown in Figure 1. Three caregivers (33.3%) reported that they had full-time home nursing care, 22.2% ( $n = 2$ ) reported that they had daily support, 33.3% ( $n = 3$ ) reported receiving services a few times a week, and one (11.1%) caregiver reported receiving a weekly home care visit.

Figure 1

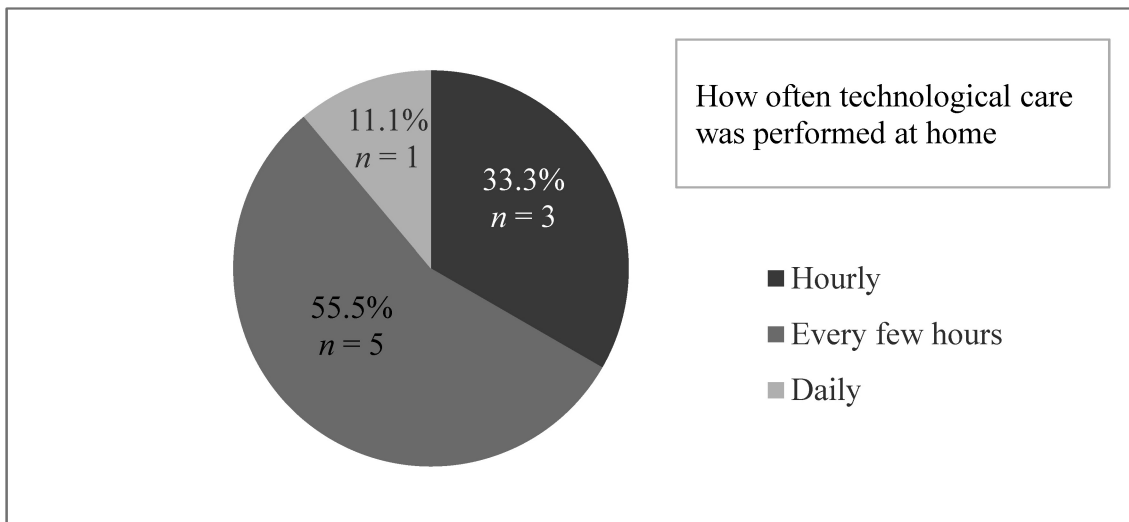
*Frequency of Home Care Services after Discharge*



Despite the frequency of home care support from a registered nurse, caregivers actively provided the needed technological care to their infant at home. Figure 2 captures the frequency with which caregivers reported performing a task related to the technology required by their infant.

Figure 2

*Frequency of Technology Care Performance at Home*





It is apparent from Figure 1 and Figure 2 that caregivers were performing a significant amount of needed care for their infants in the home setting despite having various levels of home care support.

*Participant reports of clinicians involved in teaching.* Although the questions used in the interviews are about nurse involvement in teaching designed to prepare the caregivers to care for their technology-dependent infant at home, the caregivers often related that others were involved in the teaching as well. This teaching occurred either informally during the health care team's clinical rounds at the bedside (i.e. plan of care, possible care trajectories) or more formally in sessions related to the performance of technological care (i.e. suctioning, tracheostomy changes, etc.).

Table 5

*Clinicians and Others Involved in Teaching*

Variable	Type	Number	%
Clinicians	Registered Nurse	9	100.0
	Physician	3	33.3
	Respiratory Therapist	1	11.1
	Vendor	3	33.3

*Note.* Total number of survey participants,  $N=9$

Table 5 provides a summary of the roles involved in teaching the caregivers. All caregivers ( $n = 9$ ) related that nurses were involved in teaching, whereas physicians (e.g. medical team members or surgeon) were mentioned by three caregivers (33.3%) and a respiratory therapist was mentioned by one caregiver (11.1%). Three caregivers (33.3%) also mentioned that home care vendors were involved in teaching related to the

equipment to be used in the home setting. The vendors' teaching occurred either prior to discharge or at home post-discharge.

### **Setting**

Each caregiver was to be interviewed once and caregivers were given the option of choosing a private and convenient site for the study interview. The initial interview plan was to schedule a time when the caregiver did not have to provide care to their infant. For four of the participants, interviews were conducted in the caregivers' home. In three of these cases, a home care nurse or family member provided any needed care to the infants during the interview to allow the caregiver focused time to participate in the study. However, a home care nurse briefly interrupted one interview to ask the caregiver a question which was quickly answered and did not significantly disrupt the interview. In the fourth case, the caregiver's home care nurse had cancelled and therefore, needed to attend to the infant's needs for suctioning one time during the interview. In addition, the caregiver's other two children were present in an adjoining room but were entertaining themselves by watching a cartoon videotape. Again, there were no significant interruptions to the interview. Three of the participant interviews took place in the researcher's office at the hospital; one of these caregivers had brought her infant into the hospital for an outpatient appointment and the infant was present during the interview. The infant was napping at the time and required no care during the interview. Two caregiver interviews were conducted on the general pediatric unit as their infants had been readmitted to the hospital for ongoing health issues; the infants were present during the interview. In both cases, the caregivers had to interrupt the interview to suction their infant once or twice, but this did not significantly disrupt the flow of the interview. All

caregivers who were interviewed were quite experienced providing technological care to their infants. When an interruption in the interview occurred as noted above, this researcher was impressed with how seamlessly the caregivers attended to the infants' needs and returned to the interview without any visible distraction or loss of attention to the researcher.

**Researcher interview experiences.** In general, the interviews proceeded smoothly and participants were willing to share their recollections of their hospital experience of care and of learning to care for their infant. A small number of participants did state something like "I'm not sure if I should say..." or "I'm not sure this will help your study..." prior to answering a question. Such responses were typically stated prior to relating a less than positive experience that occurred with a member or members of the care team. The researcher explained that it was important to share both good and less than optimal experiences to ensure the data accurately captured their experiences. In addition, the researcher reminded the participants that their comments would not be presented in such a way that they could be identified. After this exchange, participants shared their experiences freely. The researcher also addressed these concerns up front during the written consent process with participants who were subsequently interviewed to allay any fears they may have had. As a longstanding employee of the hospital and as an experienced nurse educator, it was difficult, at times, to hear a participant relate a negative experience of care or an interaction with a nurse or nurses that was less than supportive. In such cases, the researcher empathically responded with a statement such as "that must have been difficult for you" or "tell me more about what happened" to support the participant's continued sharing of their experience.

Participants' behavior during the interviews was quite varied. Some eagerly shared their stories in detail regardless of the topic (i.e. whether it was a general question about how the infant was diagnosed with their health problem or more specifically about individual nurse actions during teaching sessions) whereas, in other cases, the researcher had to prompt the participant with a follow up probing question or comment such as those noted above.

## **Findings**

**Teaching methods.** The caregivers discussed multiple teaching methodologies in answer to the questions “How did the nurses teach you to care for your baby?” and “What methods were used?” Table 6 provides a summary of teaching methodologies identified by the caregivers. Observation of nurses (or others) performing routine or technological care and verbal discussions or teaching sessions were mentioned by all caregivers. In addition, all caregivers related that much of the teaching of the technological care was done “hands on” whereby the nurse (or others) coached the caregiver through the performance of a specific skill (i.e. suctioning, tracheostomy care, setting up tube feedings) on their infant. Three caregivers (33.3%) mentioned that the nurse used a doll in their teaching sessions so that they could perform a skill on the doll either before providing the care to their infant or to reinforce teaching by allowing time to practice a skill. Videos were used as a teaching methodology for two caregivers (22.2%) and paperwork or other written materials such as a discharge summary were mentioned by five caregivers (55.6%). The caregivers' perceptions of the teaching methodologies and nurses' (and others') teaching skill are discussed later in this chapter under the presentation of themes.

Table 6

*Teaching Methodologies*

Variable	Level	Number	%
Method	Observation	9	100.0
	Verbal	9	100.0
	Hands on	9	100.0
	Doll	3	33.3
	Video	2	22.2
	Paperwork	5	55.6

*Note.* Total number of survey participants,  $N=9$

**Thematic analysis.** The process of content analysis as described by Morse and Field (1995) and Hsieh and Shannon (2005) was used to analyze the interview data. As such, each transcribed interview was read multiple times to obtain a sense of the whole and to identify key words and topics. As the number of completed interviews increased, these key words and topics were subsequently grouped into categories based on their similarities/dissimilarities and linkages/relationships. Relationships between categories, if present, were identified and a theme was identified to capture the essence of the caregivers' perceptions of the experience of learning to care for their technology-dependent infant in the home setting.

Through analysis of the interview transcripts and other data, it became evident that the nurse-led teaching/learning process designed to facilitate caregivers' ability to care for their technology-dependent infant in the home setting is complex and influenced by many factors. Caregivers described their infants' overall trajectory of care including admission and, at times, readmission(s) to the hospital as well as transitions between care

settings including discharge to home. They also described their interactions with nurses and other members of the care team as well as the process by which they were taught to care for their infant. Many challenges to both the provision of care to the infant and the caregivers' learning experience were also identified in both the hospital and home setting. Although it is a complex experience, this researcher identified an overarching theme which captures the experience of caregivers learning to care for their technology-dependent infant in the home setting through analysis of data: *caregiver learning and self-advocacy is enhanced by positive nurse/caregiver relationships and team cohesion, especially during anxiety-producing transitions in care.*

Morse and Field (1995) suggested that there are typically three to five themes and 10 to 15 categories identified per study using this method of content analysis. In addition to the overarching theme, the findings of this study are congruent with these estimates as five major themes and 14 related categories were identified:

1. The nurse/caregiver relationship enhances learning.
2. The complexity of care presents challenges to the learning process.
3. Team performance affects caregivers' level of anxiety/uncertainty.
4. Caregivers' level of expertise improves self-advocacy.
5. Transitions in care settings contribute to caregiver anxiety.

Specific words or terms used by caregivers are identified as codes. Table 7 provides a summary of major themes, categories and codes identified during data analysis.

Table 7

*Major Themes, Categories, and Codes*

Theme	Category	Code
Nurse/caregiver relationship enhances learning	Feeling known	Knew us
		Know me
	Quality of teaching	Right there
		Hands on
		Enough time
Complexity of care presents challenges to the learning process	Uncertainty in care	Not sure
	trajectory	Didn't know
	Patient acuity and care setting	ICU
	Length of stay	Longer
		Relationship
Team performance affects caregiver's level of anxiety/uncertainty	Caregiver inclusion in team	Our nurse
		Our team
	Team conflict	Uncomfortable
		Different
	Team communication	Communication
Caregiver's level of expertise improves self-advocacy	Family caregiver as expert	My kid/child
		I knew
	Skill performance	Practice

		Safe
		Comfortable
Transitions between care settings contribute to caregiver anxiety	Support at home	Home care nurse
		Family
		Friends
		Support group
	Equipment and supplies	Equipment
		Overwhelming
	Skill performance at home	Ready
		Prepared
	Nursing skill level	Different
		Experience

**Illustration of themes.** In this section, the five major themes and associated categories identified through the analysis of transcript data are illustrated with quotes from the caregivers. When appropriate, participant quotes are provided for the categories within a major theme. Although there was some similarity in words used by caregivers to describe their experience, the identified major themes and categories emerged from the data even when caregivers used different words or terms. Although the major themes are presented separately for discussion purposes, there are some areas of overlap between the major themes and/or categories within a major theme and these are noted in the text. As noted in Chapter 3, a quote that presents a negative case (Lincoln & Guba, 1991) may also be provided to illustrate when a caregiver or caregivers had an experience that was



markedly different than the experiences of other participants. Inclusion of negative cases, where these were identified, provides a more inclusive illustration of the caregiver experience and enhances the credibility of the study. Individual caregivers are designated as Caregiver A, Caregiver B, Caregiver C, etc. Quotes from all nine caregivers are used to illustrate various of the identified major themes and categories.

*Nurse/caregiver relationship enhances learning.* This major theme was identified through an analysis of the caregivers' perceptions of their experiences with the provision of care (i.e. clinical, psychosocial support, teaching, etc.) by nurses. Caregivers began to relate their impressions of care, either in general or specific to nurses, when initially asked to provide some context as to what led to their infants' need for technological support. Caregivers' perceptions were also obtained through a question such as "what do you think the nurse or nurses did that was most beneficial to meeting your learning needs?" Almost all caregivers identified a nurse or team of nurses that had an impact on their overall care experience or specifically, their ability to learn to care for their infant's technological needs. This major theme is comprised of two categories: (a) feeling known and (b) quality of teaching.

*Feeling known.* This category represents the caregivers' perceptions of feeling known by the nurse or nurses involved in their care. Some caregivers related that a nurse or nurses "knew me" and/or "knew my child." In such instances, the caregiver often referred to "our nurse," one of "our nurses," or "our team." The nurse's or nurses' ability to establish a therapeutic relationship led to the caregiver's perception of feeling known and created a safe and trusting environment in which to ask questions, either in clinical rounds with the team or during teaching sessions. The nurse's assessment of the

caregiver's ability to learn and learning preferences also contributed to the sense of feeling known. Caregiver A related that:

I think it was their persistence. So, I didn't know what I didn't know....And the nurses got to know me, so they knew that I would want to know more, and they were really good about answering all the questions....the nurses are really good about understanding. They get to know the parents as much as they get to know the kid, the baby, and I think that they are good at tailoring their teaching method to the parent...as a parent, you watch this and you say this person is crucially skilled, and then getting to know me, as a parent, and there's a personal and social aspect of it that can't be denied [and] that develops a level of trust.

As previously stated, almost all caregivers identified a nurse or team of nurses that had an impact on their overall care experience or specifically, their ability to learn to care for their infant's technological needs. Despite these positive experiences of feeling known, some caregivers also described an interaction with a nurse that was different than the norm. A quote from Caregiver B illustrates such an interaction which is presented as an negative case for this category. In this quote, the caregiver describes an instance when a nurse who was assigned to care for her infant was not a regular part of "our team."

Patient care assignments are driven by many factors. For example, assignments may consider the number of nurses assigned to a shift, patient acuity, the experience level of the nurse, and a nurse's knowledge of a patient he/she has cared for previously. In balancing these factors, and more, it may have not have been feasible to assign a member of Caregiver B's team of nurses to care for her infant. This resulted in the assigned nurse's lack of knowledge regarding the caregiver's level of comfort and skill related to suctioning her infant. The nurse expected that the caregiver independently suction her infant. Caregiver B stated that she got a,

Very mixed message and the nurse who said it wasn't on our team....And the other [nurse], I think was more of like trying to be cautious and not really

knowing us and the situation...Like I said, she didn't even watch us do it. She'd never seen us do it. And neither one of us, we never suctioned without a nurse there. We didn't just go in and suction. We just didn't do that. Because I wouldn't want to do that because what if something went wrong? We just didn't do that. I don't think she saw that or I'm not really sure what that issue really was, but our nurse was like yes, she said she wasn't too happy with that. She said, but are you guys comfortable with this? And we said yes, we are. We're absolutely. You're standing right there. You're teaching how to do it.

Caregiver B's description of "her" nurse's reaction to the situation in which she confirms that a nurse's presence during suctioning was supportive and still required from her perspective to facilitate learning illustrates the importance of feeling known/knowing the caregiver as important factor in planning the teaching experience.

*Quality of teaching.* In addition to the importance of feeling known by the nurse, this category represents the caregivers' perceptions of the nurses' approaches to teaching that were effective in facilitating their learning. Most often, caregivers described the importance of observing nurses caring for their infant and nurses describing what they were doing during the provision of care as the start of the learning process. When described in a positive way, quality of teaching meant that caregivers' readiness to learn was considered as well as their ability to set the pace for their involvement in the learning process and in the provision of care to their infant. In addition, caregivers mentioned the importance of being coached by the nurse while performing skills, as well as having nurses who gradually increased the caregiver's involvement in care and facilitated the ability to perform skills repeatedly over time. These nurse strategies led to positive learning experiences. Nurses who were calm, reassuring, specific, methodical, and "right there" during teaching sessions were also viewed positively and were viewed as having high quality teaching abilities. A few caregivers related that they had preferred learning

styles and nurses who considered this in planning teaching sessions were also viewed positively. Caregiver C stated that the nurse,

...would explain what we needed to do and then show us how to do that and...coach us through while we were performing the tasks ourselves....The guidance all the steps of the way. We also have some written materials that went along with the G-tube placement....Usually when I'm learning new things I like to be able to read about it and then have somebody explain it to me....And then to [have a] gradual release of responsibility....It was helpful because I didn't have to assume that responsibility in the hospital until I was comfortable. The nurses are really great about gauging how much you're ready for I think. Just in terms of your ability to process where you are in your emotional state....I think they were very thorough in terms of just that coaching model....So, I think that being there for questions and that gradual release of responsibility to the person whose learning is the way to go....The way that they taught at least worked for me.

A quote from Caregiver D illustrates a negative case for this category. Caregiver D's infant had been admitted for insertion of a gastrostomy tube and the infant's total length of stay was three days. Although Caregiver D relates that she had positive interactions with the nursing staff overall, she felt pressured to perform a skill (i.e. attaching an extension to a gastrostomy tube) that was causing her infant to have pain due to the stitches at the insertion site. Caregiver D describes one nurse's abrupt approach.

[The nurses] were very helpful and patient....There was one [nurse] who was not. She told me it was like brushing her child's teeth. You just have to do it....Don't try and tell me that this is anything like brushing a child's teeth when my son just had surgery and had a hole cut into his stomach and it's not, you can't even compare it....I think a big part of it had to do with the fact that they took the stitches out, and about a day later he was so much better during the, getting the extensions on and off. But before that, you know, they just kept coming in and they're like, well you just need to do it. It has to be done. And I'm like, yeah, I know that. And I said, I have yet to see a single nurse in this hospital get that extension on and off independently, without somebody holding him down.

Although the attachment of an extension may be an easy task for most nurses to perform, Caregiver D related that many nurses had difficulty doing it independently but expected her to be able to do so. The nurse in this interaction minimized Caregiver D's impression

of the complexity of the task and her concerns about causing her infant pain. The nurse's quality of teaching lacked many of the positive attributes listed as illustrative of this category. Despite the short length of stay, Caregiver D learned to perform the skill adequately in preparation for discharge to home. Length of stay is discussed more fully as a category in the next theme.

In summary, nurses were perceived by participants to play a key role in facilitating the learning process for them as they prepared to provide care for their technology-dependent infants at home. A therapeutic relationship that facilitates learning and the overall experience of care appears to exist when caregivers feel known by a nurse or a team of nurses and when the nurse is "right there" during teaching sessions. In addition, caregivers feel supported within this relationship by nurses who pay attention to caregiver factors such as readiness to learn and preferred learning style. Nurse teaching that is perceived by caregivers to be of high quality is individualized to the learner, proceeds at a reasonable pace, provides ample opportunity for repetition, and is caring and supportive. Despite almost all caregivers relating a positive impression of nurses and their teaching abilities, a few did describe instances where an interaction or teaching session was not positive. The implications of this major theme for practice and nurse education, are discussed in Chapter 5.

***Complexity of care presents challenges to the learning process.*** All interviews with caregivers were started with a general question such as "what were you told about your baby's condition?" or "tell me a little bit about your baby's condition and the reason he has a tracheostomy?" Caregivers then described the events leading up to a diagnosis and subsequent interventions in exquisite detail including timelines, set-backs,

procedures, admissions, readmissions and their emotional state during this time. From analyses of their responses to these questions, the second major theme emerged and relates to the complexity of clinical care required to meet the needs of the technology-dependent infant. The clinical course for each infant varied depending on the timing of diagnosis and resulting care required. Many of the infants required multiple elective or unplanned admissions and time in both intensive care and general care units. The changing clinical course, severity of illness, and physical environment often led to challenges to the learning process. This major theme is comprised of three categories: (a) uncertainty in care trajectory, (b) patient acuity and care setting, and (c) length of stay.

*Uncertainty in care trajectory.* In this category, many caregivers described the ever-changing clinical needs of their infants and their resulting feelings of uncertainty about what to expect. At times, even the clinicians were uncertain about the infant's clinical course. This uncertainty often made it difficult for the nurses to teach the caregivers. In this quote, Caregiver B describes what occurred during their infant's stay in the intensive care unit and the infant's unanticipated need for a tracheostomy.

He was premature and for about three months he could not breathe on his own. He was on a ventilator for three weeks and then CPAP for two months. When they tried to take him off he just couldn't do it without coding or having deep bradycardias. They did a bronchoscopy as a rule out...and no one was really sure what the issue was with him...we did the bronchoscopy and [doctor] came out and said he needs a trach....So, we really didn't get a lot of information at the time....They didn't throw out the word trach, about him might needing something. They really, I think everyone was kind of taken off by that. So, we had no preparation for it...my husband and I didn't even know what a trach was....So, we had no clue what was coming down the road.

This quote illustrates the uncertainty that occurred when trying to diagnose an underlying cause for the infant's condition as well as the rapidity of clinical decision-making that can occur in response to changes in the infant's condition. Caregiver B did relate that

knowing a tracheostomy was a potential option and receiving some information about what to expect post-surgery would have been valuable. However, she also recognized that the clinical team may have not provided information related to tracheostomies because they were unsure of the infant's need as well as the limited amount of time that lapsed between the decision to perform a trach and readmission to the intensive care unit (ICU). After the operation, Caregiver B did relate that "the [unit] did a good job in just kind of getting us through day-by-day and explaining, taking it easy, not bombarding us with a ton of information right off the bat" which is consistent with some of the elements of quality teaching outlined in the first theme that was presented.

*Patient acuity and care setting.* Many caregivers described situations in which there was limited teaching that occurred in the ICU due to the acuity of the infant's condition. Caregivers seemed to understand the nurses' priorities were geared more towards meeting the infant's care needs rather than the teaching of caregivers. Patient acuity and clinical needs in the ICU clearly impact the nurses' time spent on formal teaching sessions as illustrated by this quote from Caregiver E.

In the [ICU] there wasn't a lot of teaching....I found the nurses there, they were wonderful in caring for him, they weren't as focused on [teaching], especially those first three, four days. He had a lot of bradycardiac episodes and he required a lot of care, I think, the first three days at least. And then he had trouble weaning off of the narcotics. So, I think he was pretty intense and he kept them very busy. So, I think it was hard for them. They did their best I think and trying to answer whatever questions I had and would ask them.

During her interview, Caregiver E stressed that the ICU nurses were highly involved in fielding questions at the bedside and involved her and her husband in discussions on clinical rounds with the health care team. Such interactions do allow for caregivers to learn about their infant's care even if it is not a formal teaching session per se. Some

caregivers reported that the ICU nurses did not see teaching as a primary function as the priority was on providing needed clinical care. To illustrate this, Caregiver E states:

We asked a lot of questions. It was mostly to do with him and his care and what he would need. I had a lot of questions about the medications even before he woke up. They had warned me that he could have difficulty withdrawing from them, so I wanted to know how are you going to wean him? What if he has trouble even when you wean him? What's the process for that? When we go to the other floor will they be able to handle weaning him? I think a lot of my questions probably stemmed from my fear of worrying about him. I felt like when I was in the [ICU], I wasn't asking a ton of questions about the trach care so much. I think I got the message kind of from them that it was like, we're supposed to start your teaching but we're not really great at teaching here [as it is not our primary focus]. The nurses up on the floor, they're better at teaching the trach care.

The participants perceived that the complexity of care required in the ICU setting can affect their learning process. This includes the acute clinical needs of the patient which are better met by expert nurses as well as the caregivers' report that ICU nurses did not view teaching as a priority in their setting.

*Length of stay.* The infants' lengths of stay varied between three days and five months. For infants with longer lengths of stay, caregivers often described how time was an important factor in learning how to perform the technological skills that would be needed to care for their infant in the home setting. In one instance, an infant had been admitted for insertion of a gastrostomy tube and stayed in the hospital for a total of three days. The following quote is from Caregiver D and it illustrates the difficulties caring for her infant post-discharge. The shortened length of stay limited her ability to learn how to care for her infant effectively in the home setting.

I was supposed to be venting and I didn't know how to vent...I definitely could have been taught a little better how to vent a G-tube, because I really didn't know what I was doing. I tried to do it how the nurse showed me in the hospital. I only saw it once with the whole plunger pulled back thing...I didn't vent [at home] because I wasn't comfortable doing it...I think it should have been a longer hospital stay...and [had] more opportunities to do the feedings in the hospital, which I think we could have had...where they come in and you see it, they show



you, and they walk you through it, a few feedings, and then you do some on your own in the hospital.

The ability to perform a skill repeatedly was identified by many caregivers as necessary to their ability to learn effectively. In addition, caregivers related that the process of observation, practice and progressing to independent performance was also an effective teaching strategy. This held true regardless of the complexity of the task to be performed. Caregiver D reports that she only observed venting once in the hospital and therefore, did not perform the skill at home because she did not feel comfortable. In addition, she had limited experience feeding her infant via the G-tube while in the hospital. After her infant's discharge, Caregiver D had difficulty ensuring adequate hydration for her infant due to a number of issues related to G-tube feedings including her inability to manage the G-tube. Subsequently, her infant was readmitted to the hospital for hydration; in addition, this also allowed nurses to address some gaps in Caregiver D's learning.

In summary, the clinical care needs of technology-dependent infants are varied, every-changing, and complex. Nurses must teach and caregivers must learn to provide care within this difficult environment. The uncertainty and changing trajectory of care, patient acuity, care setting, and length of stay can all impede an effective teaching/learning process by challenging caregivers and nurses alike.

***Team performance affects caregiver anxiety/uncertainty.*** Although the purpose of the study is to determine caregivers' perceptions of nurse-led discharge education, caregivers often shared information related to other disciplines or roles including case managers, surgeons, residents, fellows, and respiratory therapists. This occurred in response to both general questions or probed such as "tell me more about that

experience” or more specific questions or probed such as “what did the nurse do that was most beneficial to meeting your learning needs?” Caregivers shared many thoughts and experiences related to their interactions with all members of the care team. Important aspects of the clinical team’s performance or functioning and impact on caregivers’ level of anxiety or uncertainty are illustrated in this major theme which is comprised of three categories: (a) caregiver inclusion in the team, (b) team conflict, and (c) team communication.

*Caregiver inclusion in team.* There is a connection between this category and the category of “feeling known” as described in the first major theme that was presented. Participants had a sense of belonging to the team and this contributed to their feeling known by the nursing staff and other care team members. Some caregivers referred to “our team” when describing the nurses who cared for them, while others described it as all nurses who involved them in their infants’ care. When a caregiver felt that they were included as a team member, that led to a better understanding of the care trajectory and a feeling of respect from the clinicians. Most often, caregivers felt that they were part of the care team through participation in clinical rounds during which the plan of care for their infant was discussed. The nurse’s encouragement or expectation that the caregiver attend rounds was an important factor in caregiver participation. Involvement in rounds allowed the caregiver to be better informed, to ask questions, and to share their own impressions of their infant and the plan of care. In this quote, Caregiver G relates her experience as part of the team in the study setting in comparison to her experience in another hospital setting where the clinicians did not involve her to the same extent in discussions related to her infant’s care.

[The nurses] let us take control when they thought it was appropriate. And they let us not take control when it was appropriate....they're very open with their education and they're teaching you and sharing it with you. They don't hide anything. There's no whispering to the doctor on the side. Everything is out in the open. The doctors, the attendings, I was amazed by how the attending came right in and sat down and said I'm Dr. So and So. This is what's going on. This is what we're doing and why. Great. And everything was like that. Every little thing [the team] did....Come here. Do rounds with us. There was not one round that I didn't go to. I was involved in every round and I was able to talk and ask questions and say you know what? I don't understand that. Explain that again why? And no one was getting frustrated.

Caregiver G's involvement in rounds appears to have been welcomed by the clinicians and she felt included in the team. She was satisfied with the clinician's communication during teaching sessions, individual conversations, as well as during rounds. Caregiver G's comments are similar to that of other caregivers who were involved in clinical rounds. However, not all caregivers mentioned their involvement or participation in clinical rounds. As previously stated, caregiver involvement in the team overlaps or is connected to the category of "feeling known" in the first theme presented. Caregivers who did not mention participating in rounds tended to not use terms such as "our nurse," "our team," or similar terms when describing the clinicians. Rather they would use "the nurse," "a nurse," or "the doctor" which seems to imply a lack of a close relationship or membership in the team.

*Team conflict.* There were a number of instances described by the caregivers in which conflict between team members regarding some aspect of clinical care led to caregivers having feelings of anxiousness or uncertainty. Examples of such conflicts include disagreement about the course of treatment, readiness for discharge, technique when performing a skill, or approach to teaching. In this quote, Caregiver E described an interchange between physicians, respiratory therapists, and nurses regarding

their expectations for the number and timing of tracheostomy changes required prior to discharge.

So, it's not just even the nurses who are doing the teaching...at one point in time our respiratory therapists were refusing to do the trach changes because they...felt six was too much to do in a week. And they didn't believe it should be done. It was actually an argument that occurred. The [Ears, Nose and Throat] staff, the respiratory therapists, the nurses, they were all bickering. Literally bickering over whether or not we can do another trach change today, this evening, or not. Or can we do one tomorrow? And I was kind of uncomfortable too and awkward having that argument with respiratory therapy...Then they started getting me worried about getting his trach irritated. His pain. Would it cause swelling?

Subsequently, the physicians explained their rationale for the planned number of changes which helped to allay Caregiver E's anxiety around the dispute. The physicians have joint appointments at a nearby specialty hospital and six changes a week is their standard of care. These physicians were trying to influence the standard of care at the study site but it had not been communicated in a programmatic manner. Caregiver E went on to state that "you have the nurses who were kind of in between. In the middle between the doc, the respiratory therapists, and the doctors. So, that made things a little awkward too. So, if they can get [the new standard of care] worked out and communicate amongst each other...yes, consistency and communication. Because if you change something, [the nurses] need to know about it. [The team has] to find a way to communicate it effectively to them." The importance of team communication will be taken up again in the next section describing which the third category for this major theme.

A number of caregivers mentioned that there were changes in clinical procedures or differences in the technique nurses used to perform a procedure. In this quote, Caregiver C describes how nurses use of different techniques to check the placement of a gastrostomy feeding tube led to a sense of uncertainty and doubt in the caregiver's ability to perform the skill.

I guess I wasn't sure. Did I hear the right noise? Did I hear it in the right spot? A lot of the times during checking that placement...some nurses were really good at coaching you and other nurses were like we don't do that anymore...you might have had your day nurse was OK showing you [how to check placement by instilling air and listening with a stethoscope] where the night nurse was no, we don't do that anymore....[It] wasn't a piece that they taught parents anymore and that they practice themselves in the hospital....They just assumed once they had been x-rayed that first time...that it was in the right place and that that was that.

There appeared to be a lack of clarity regarding the accepted technique or need to check placement of the gastrostomy tube prior to feeding. Caregiver C related that some nurses continued to instill air to check gastrostomy tube placement despite having knowledge of the change in procedure because "Why not? It doesn't hurt them." This rationale made sense to her and she continued to check placement in this manner.

*Team communication.* The importance of clear communication was mentioned a number of times by caregivers during the interviews. Inconsistent communication around how to perform a clinical procedure such as in the previous category or a lack of understanding team member roles and how to access needed information can lead to caregivers feeling overwhelmed and confused. In this quote, Caregiver F described her uncertainty regarding team communication and how this led to difficulty asking for medication for her daughter.

This process with the reconstruction and everything, there's 40 different people involved and I don't know who to ask and I don't know...the difference between a resident and a fellow and the doctor, the hierarchy of who to ask and you start with the nurse and then the nurse has to go ask....So that process is so huge that that is overwhelming. It's very complex. It's very overwhelming. It's very, I don't know the word for it. Frustrating. Like I feel dumb not knowing the person that's coming in the door to talk to me what question to ask. And then have them say, oh, no, I'm the GI doctor. I don't do that. Or, no, I'm only the surgeon. I'm here to check her neck. So it is frustrating but intimidating. It's very intimidating not knowing and then you kind of scale back a little bit and you talk to the nurse and if the nurse doesn't know the answer either, then she's got to go through the whole entire process, too.

Caregiver E recognized the nurse's role in facilitating team communication but also identified that, at times, the nurse is also unclear about who is directing care related to the infant's medications. She related that this lack of clarity regarding when and how often a rescue dose of medication could be given led to her infant exhibiting symptoms of withdrawal and caused her significant anxiety and frustration. A senior physician clarified the plan and communicated with the nurses to ensure that they were also clear on the medication orders and subsequently, Caregiver E felt better able understand the plan.

*Caregiver level of expertise improves self-advocacy.* All caregivers were novices when learning to perform the skills required to care for their infant who was technologically-dependent but their experience meeting the basic care needs of a healthy child varied as noted in the analysis of demographic data presented in the beginning of this chapter. Forty-four percent ( $n = 4$ ) of caregivers had only one child whereas 56 % ( $n = 5$ ) had between two and four children.

Many of the caregivers related that they knew what was normal for their child's behavior, whether it was related to their technological care needs or not. As an example, one caregiver knew that something was wrong with her infant's breathing pattern because it was different from other times when the infant had a cold or was ill. This major theme illustrates that, as caregivers gained skill in recognizing their infants' behavioral or clinical cues or in performing technological care, their ability to advocate for their own or their infants' needs increased. Their ability to advocate for themselves also improved when they were better able to evaluate their own performance of a technological skill and to identify their own learning needs. In other words, they became aware of their own

limitations in their abilities to care for their infant at home. This major theme is comprised of two categories: (a) family caregiver as expert and (b) skill performance.

*Family caregiver as expert.* A number of caregivers related instances where they were often recognized by the nursing and medical staff as knowing their child. They were invited to participate in rounds and to share their thoughts and recommendations regarding their infant's care or course of treatment. In some instances, an individual or group of nurses or physicians failed to recognize that the caregiver was an expert who knew their child better than the clinical team. In this quote, Caregiver G relates an instance when a nurse was suctioning her infant in a way that was different than the norm and this caused the infant distress. As her infant had a number of readmissions, she had become quite skilled in performing the technological care at home. Because of her knowledge and skill in performing the suctioning and how her infant normally reacted, she was able to advocate for a change in nursing assignments to ensure the skill was performed in the standard way.

We had an issue with a nurse. We had been taught one way and it had worked [at home]. And then when a nurse came in and did it a different way and obviously causing stress to him... He was coughing. He was choking. He was crying. He was uncomfortable and every time this nurse suctioned him, that would occur. It was like oh, my gosh. Stop. Just stop. He's uncomfortable. When she was confronted, you know, she gave it back. I mean she basically said I've been doing this for so long....And I immediately said I don't want you, I don't want you as my nurse anymore....I appreciate that this is how you've done it, but it doesn't work for him. And if you can't adjust, like [every other nurse] has, then...I don't want you caring for him.

She went on to describe how nurses at the study site usually reacted and engaged her in conversations about her son's care, thus demonstrating the nurses' acknowledgement of her expertise providing care.

If I noticed [a nurse performing a skill differently] I would say, ‘Now why are you doing it that way?’ I would say ‘is that better than how I do it?’ And I’d say ‘we usually do it like this at home.’ And [the nurse would say] ‘OK. Great. Is that better for [your son]? Yes, he seems to react better if [we do it your way].’

Subsequently to such interactions, the nurses integrated the caregiver’s feedback and modified their own techniques within the parameters of safe practice to reflect their input. This illustrates the nurse’s recognition of the expertise of the caregiver in knowing what is best for their infant.

*Skill performance.* This category represents the caregiver’s ability to identify learning needs and to perform the necessary technological skills successfully. As a caregiver’s involvement in care or skill in performing a clinical task increased, the caregiver was often more comfortable advocating for their own or their infant’s needs. The following quote illustrates how Caregiver E was able to advocate for increased home care services while still in the hospital due to her assessment of her own abilities to care for her infant at home.

I don't know if I felt like I needed a hospital, but I felt like I needed more support with trach care and more practice under someone else's supervision [and] I had actually told them. [The doctors and case manager] at first told me it was going to take several weeks to get home care set up....I said unless you can guarantee me 100% that he's safe to go home with me, and only me, and no nursing care, I won't sign anything, any discharge papers...[and] suddenly, within a matter of another week, we had nursing care set up. They were actually looking into him going to a rehab hospital...because I had said I'm not going home....unless you can guarantee me he is 100% safe with me caring for him by myself. So, we almost went to a rehab but we were able to get the nursing care in place rather quickly. They pushed it through.

*Negative case.* The following quote illustrates an negative case for the two categories in this major theme. Despite Caregiver D’s expertise in knowing her infant and self-assessment regarding her abilities to perform needed care, she did not feel able to advocate for herself and her infant for additional discharge teaching. She knew



that the primary problem with her ability to perform gastrostomy tube care was the presence of stitches holding the tube in place and causing the infant pain. However, the nurses' assessment was that the caregiver was just not dealing with her infant's behavior appropriately.

I think I saw one feeding before we went home. I wasn't comfortable leaving. I probably should have pushed to stay longer. But I didn't....And I felt like [the nurses] were more trying to make it like, you know, you need to deal with his behaviors, over the fact that there was a reason why he wasn't letting us do that. I knew that, because I'm his mom and I know him better than they do, and I've seen that kid go through hell and back and continue to smile. So I knew there was something wrong.

Caregiver D knew how her infant normally behaved and recognized that his behavior (e.g. struggling, attempting to move away, pulling, pushing her away) was in response to pain caused by the stitches holding the gastrostomy tube in place. Despite her discomfort and lack of ability performing the skill, she was unable to advocate for herself and her infant (i.e. a longer length of stay, more practice performing the skills) and was discharged to home. Once the infant's stitches were removed, Caregiver D was better able to perform the needed skills at home successfully. This illustrates that even when a caregiver has a skill set, it does not necessarily mean they are always willing or able to perform the task. Their personal barriers to providing care cannot be overlooked and must be considered when doing attempting to transfer caregiving responsibilities from professional staff to family or other intimate caregiving providers.

*Transitions between care settings contribute to caregiver anxiety.* Transitions between care settings created many different issues for all nine caregivers. The types of transitions include transferring from intensive to general care, readmission to the hospital from home, discharge to home, and transferring between two hospitals.

Such transitions contributed to caregivers' anxieties in a variety of ways. Caregivers worried about the different nurse staffing levels in general v. intensive care as well as the differing skill levels of the general care, intensive care and home care nursing staff. The availability and type of support in the home setting also contributed to caregiver anxiety as supports were not in place or unavailable. The availability, types and use of supplies and equipment post-discharge also contributed to their anxieties because initial delivery of needed supplies was delayed, the supplies and/or equipment differed from that used in the hospital, or there was limited instruction in the care and maintenance of home equipment. Worries about their ability to perform the needed skills in the home setting post-discharge also contributed to caregivers' anxiety levels. This major theme illustrates how transitions in care settings contributed to caregiver anxiety and it is comprised of four categories: (a) nursing skill level, (b) support at home, (c) equipment and supplies, and (d) skill performance at home.

*Nursing skill level.* Caregivers' impressions of the skill level of nurses varied across settings. Some had very positive experiences with nurses during the provision of care or in teaching sessions in the intensive care unit, general care unit, or in the home. Other caregivers described a specific situation that was less than positive. One area of concern that caregivers expressed was over infants who spent time in the intensive care unit and then transitioned to the general care unit. In this situation, in addition to concerns about a potential difference in skill level, Caregiver E mentioned the different staffing levels on the two care units. Her anxiety stemmed not only from the different nurse to patient ratio but also from her own discomfort and lack of confidence caring for her infant. Her experience supports the issue with the level of teaching that occurred in

various settings as mentioned in the discussion of the second major theme presented previously.

I was very nervous to leave the [intensive care unit] and go to the floor. They were like don't you want to be out of there? I was like no, because I felt like I knew going to the floor the patient/nurse ratio would be different. And leaving the [intensive care unit], I definitely didn't feel confident taking care of his trach and taking care of him. So I was nervous because I knew that the nurse who would be caring for him would have other patients and wouldn't be-- right there like in the [intensive care unit]. I was definitely feeling insecure and unprepared to take care of the trach myself.

*Support at home.* The level of support or lack of support from family, friends, and home care staff influenced caregiver anxiety levels post-discharge. All caregivers had home nursing care support but the number of hours and frequency of visits varied as noted in Figure 1. The level of support from family and friends also varied. Caregiver F described the anxiety she felt due to the lack of support she had post-discharge, specifically when she was alone with her infant.

[They told me] you're going to get 60 hours [of home nursing care], I was like that's great. And then I got home and went, oh, my god, I can't go to the bathroom and leave her in the room by herself and there's no one there. And because I'm a single mom, there's no one there....I didn't realize she was going to be tethered in the living room and that continuous care meant every single minute. I wasn't aware of that until the first week when they left me home with her....if I get up to go to the bathroom at home and the monitor goes off, and I'm in the middle of going to the bathroom, then oh, my god, what do you do? And that's, it's almost like living in fear that I can't do anything.

Caregiver F also compared the support she had after the birth of her daughter and how her support system eroded over time as her daughter began to experience health issues. Her current lack of support continued to frustrate her and causes anxiety about managing to care for her infant, and herself, in the home setting.

...I asked my mother who is very close to [my daughter] and [she said], I can't handle it. Your grandmother died of this. I can't go near that. So please don't ask me to be your backup. I can't do it. And that was the first time that...I started

learning that I lost a lot of [support] along the way because a lot of people are scared of her. When I first had her, we had like 40 visitors a day and people were everywhere...and now....You lose support....I've actually asked people to baby sit her and they've said no so I haven't been able to go grocery shopping. So then I've had to call for people to...bring me groceries because if you're not going to baby sit her and I can't get out, someone's got to bring me groceries.

A quote from Caregiver B is provided to illustrate a negative case for this category. In addition to her husband and home care nurses, she had family and friends who were willing to assist with her infant's care and/or provide a period of respite for her. Two of her friends were advanced practice nurses who were available to answer questions and this support significantly decreased her anxiety levels when she had questions about her infant's care.

We did it as a team. My husband was as hands on as I was....he and I are the only ones that have ever done his trach changes and his trach care, unless he was gone and I needed a nurse that day....That was a huge plus for our family....we also had a great support system. We had great nurses for my son who had the trach. And for my other son who didn't have a trach, we had help....we had six women that came in and were at my house if we did not have nurses around my house and my husband wasn't home to help me out. One of them would always be there on their own accord. So, that really made life easier for us.

Two caregivers specifically mentioned that a support group made up of other caregivers with technology-dependent infants would have been very helpful. The support group could either meet in person or virtually through a discussion board or social media platform where a caregiver could post a question and create a dialogue. Caregiver F stated:

Is there a parent group that if I can't get a hold of somebody here that I can call or join or be on Facebook to [get tips on how to clean the suction catheters]...It drives me insane. The tubes are there for like a week. And the inside of that tube isn't clean but yet I'm suctioning her and it's supposed to be a clean suction. So I didn't know who to ask....Nobody told me how to clean it....It's an issue and it would be great if there was...a Facebook page about kids [who have had the same surgery] to chat with moms that, single moms that are home and how are they handling it?

*Equipment and supplies.* A common issue described by the caregivers related to the equipment and supplies needed to provide care to their infants at home. Many caregivers were frustrated and anxious about the type and/or availability of equipment and supplies once they were at home. A prime source of the caregivers' anxiety was that the equipment used at home differed from that used in the hospital. Anxiety was allayed for some caregivers because they received training by the equipment vendor prior to discharge while others received their first teaching session in their home. A quote from Caregiver H illustrates that despite feeling confident performing tracheostomy care, it was difficult to manage the equipment due to the lack of information related to its maintenance over time.

...I [change the trach] fair amount and having instructions all written out, there's easy things to reference, you have links to view videos if you want to, they offer to record us so we can watch ourselves doing it...but one of the hardest things to do at home is take care of the equipment because...the equipment that you have at home is different, significantly different, from what's [in the hospital]...[and] all of the equipment requires some form of maintenance. Replacement parts, cleaning filters, things like that. And no one really had a written schedule for all of them. We've pieced it together and ordered it ourselves...the manufacturer's pamphlets, directions, instructions, don't go over the maintenance of it very well....that was all a lot more overwhelming than cleaning, caring for the trach, learning what to do in an emergency, all of that was a fine pace for me.

*Skill performance at home.* In response to the question "What was it like to have to perform [a skill] on your baby at home for the first time?" Caregivers related that they had varying levels of success and anxiety depending on the skill. Some caregivers performed the skill with another family member and found this helpful. Some caregivers described being prepared by having a system or a plan in place to ensure the needed supplies were in reach. And in some cases, despite being confident in their ability to perform a skill, providing care did not go as smoothly as planned. The following quote

from Caregiver I describes a situation in which she changed her infant's tracheostomy for the first time in the home setting.

My mind went blank because once she turned purple, it's hard to see your own, my own daughter turning purple and no medical person around. When she did that in [the hospital], there was always someone around that knew more than I did and wouldn't stay shocked like I did. I couldn't think of where the key to the oxygen was. I couldn't think of like the suction. I was just like where is the suction? Even though...everything was in my sight. I was just kind of like scattering through the table. Like oh, my god. Where is it? Where is it? Even though everything was in my sight. It was just, I forgot what to do. What do I do first? What do I do second?

### **Summary**

This chapter reviewed the study's recruitment and consent procedures as well as the interview process and settings. The presentation of demographic data, the roles of the clinicians involved in teaching and the methods of instruction used to teach caregivers were also presented. Finally, the overarching theme, major themes, categories, and key words identified through qualitative content analysis of the interview transcripts were presented and illustrated with verbatim quotes from caregivers. Chapter 5 includes a discussion of how the identified overarching theme and major themes answer the study's research questions. The researcher's insights as they relate to information presented in the literature are also presented. Finally, the strengths and limitations of the study as well as implications for nursing practice, education, policy and research are reviewed.

## Chapter 5

### Discussion, Strengths, Limitations and Implications

Chapter 1 outlines the scope and significance of the problem that is the basis for this study, *Caregivers' Perceptions of Nurse-led Discharge Education Interventions: Knowledge Needed for Adequate Care of a Technology-dependent Infant in the Home Setting*. Support is provided for the importance of this study due to a gap in knowledge related to caregivers' perceptions of nurse-led discharge teaching interventions designed to prepare caregivers to care for their technology-dependent infants in the home setting. This gap highlights the importance of developing nursing knowledge that can facilitate practice in this area. Chapter 1 also includes a definition of terms, the purpose of the study, and the research questions.

Chapter 2 includes a review of the literature related to the stressors families face when caring for a technologically-dependent infant in the home setting and current approaches to discharge teaching for this population. The review of literature supported the premise that there is a gap in knowledge related to whether, or not, current discharge teaching practices meet the learning needs of caregivers of technology-dependent infants prior to discharge.

Chapter 3 outlines the method used to conduct the study. Support is provided for the study's qualitative descriptive design, study features that support methodological rigor/trustworthiness, recruitment procedures including participant inclusion/exclusion criteria, sources of data (e.g. interview transcripts, researcher memos, etc.), the use of

content analysis approach to analyze data, the process for protection of human subjects, participant risks and benefits, and tactics used to ensure the security of data.

In Chapter 4, study findings that emerged from analyzing the interview data and researcher memos and observations, are presented. Nine caregivers of technology-dependent infants who met inclusion criteria participated in a one-time interview conducted by the researcher. Concurrent analyses of the verbatim interview transcripts, along with demographic data, and researcher notes and memos resulted in the identification of one overarching theme and five major themes with associated categories and key word codes.

This chapter reviews the resulting themes and categories described in Chapter 4 and discusses how the overarching theme and major themes answer the study's research questions. The overarching theme and major themes are discussed in the context of what was known and not known about the phenomenon of *caregivers' perceptions of nurse-led discharge education interventions*. The researcher's insights as they relate to information presented in the literature are also presented. Finally, the strengths and limitations of the study as well as implications for health policy and nursing education, practice and research are reviewed.

## **Discussion**

As noted previously in Chapter 4, there is some understandably overlap and interconnectedness between the overarching theme and major themes. The interconnectedness and/or overlap between the overarching theme and major themes are because they represent the dynamic interplay of many factors that influence the



caregivers' experiences. However, for the purposes of discussion and in relation to prior research they are discussed separately, as pertinent.

**Research questions.** The overarching theme and major themes that emerged from the data answered the study's research questions related to this cohort of caregivers.

As a reminder, the research questions were:

- 1) What are the perceptions of caregivers of technology-dependent infants of nurse-led discharge education that is designed to prepare them to care for their technology-dependent infant in the home setting?
- 2) What factors facilitate or hinder the effectiveness of nurse-led discharge education designed to prepare caregivers to care for their technology-dependent infant in the home setting?

Through the process of data collection and analysis, many positive and not so positive factors that affected the learning experiences of these caregivers of technology-dependent infants, both during hospitalization and post-discharge, emerged. Some of their experiences are mirrored in prior research literature as discussed in Chapter 2 and thus, in turn support the findings of these studies. However, new insights also emerged that were not been previously described, or not well described. The findings, taken in their entirety, illustrate the caregivers' perceptions of the attention, care and education that they received prior to their infant's discharge. Specifically, their perceptions of the overall experience of learning to care for their infant in the home setting were uncovered. The overall theme that captured elements of the five major themes is articulated as *"caregiver learning and self-advocacy is enhanced by positive nurse/caregiver relationships and team cohesion, especially during anxiety-producing transitions in*

*care*". The five major themes are: *the nurse/caregiver relationship enhances learning; the complexity of care presents challenges to the learning process; team performance affects caregivers' level of anxiety/uncertainty; caregivers' level of expertise improves self-advocacy; and transitions in care settings contribute to caregiver anxiety*. The following two sections describe how the findings answer the study's research questions.

***Caregiver perceptions of nurse-led discharge education interventions.*** At some point during their interviews, most caregivers spoke highly of a specific nurse or nurses in general using statements such as "our nurse was always right there" and "we had great nurses" to illustrate their experiences during teaching sessions or delivering clinical care. Such statements provide a generic, yet representative, perception of the caregivers' experience of learning to care for their technology-dependent infant. However, when looking at the entirety of the data and the complex interplay of many factors described by the caregivers, this researcher identified an overarching theme which captures the experience of caregivers learning to care for their technology-dependent infants in the home setting: *caregiver learning and self-advocacy is enhanced by positive nurse/caregiver relationships and team cohesion, especially during anxiety-producing transitions in care*. This overarching theme answers the study's first research question because it encompasses the similar and disparate ways that caregivers answered the interview questions and captures their overall perceptions of the experience of nurse discharge education. However, the overarching theme does not explicitly capture how the complexity of the infant's care needs presents challenges to the learning process. The four major themes which are explicitly embedded within the overarching theme focus on the caregivers and care team: nurse/caregiver relationships, team performance, caregiver

expertise, and caregiver response to transitions. The fifth major theme focuses on how the complexity of care required by the infant continuously influenced the overall caregiver experience as well as the actions and experience of the nurses and other clinicians. As such, complexity of care is implicitly captured in the overarching theme and represents an aspect of the caregivers' perceptions of their experience.

The overarching theme represents the overall perceptions of caregivers who participated in this research study. The factors that affected the caregivers' ability to learn to care for their infant are also embedded within this overarching theme. More detail related to the themes as well as findings from the literature that lend support to this study's findings are provided in the next section.

***Factors that facilitate or hinder learning.*** The quotes that were used to illustrate each theme capture the caregivers' perceptions of factors that facilitate or hinder the effectiveness of nurse-led discharge education designed to prepare them to care for their technology-dependent infants in the home setting. In some cases, the findings of this research study are supported by the results of other studies described in the review of literature in Chapter 2 and, at times, extend nursing knowledge about caregivers of technology-dependent infants.

The first major theme, the nurse/caregiver relationship enhances learning, illustrates a facilitating factor for the effectiveness of discharge education. The study by Reeves, et al. (2006) demonstrated that nurses who provided care to a technology-dependent child in a manner that was similar to care provided by a parent helped the parent retain a sense of control and maintain a balance of power in the nurse/caregiver

relationship. In this study, nurses who assessed the care preferences of parents as well as the manner in which they performed care facilitated the parents' sense of feeling known and helped establish a trusting relationship with the nurse or nurses. In addition, nurses who knew the parents' preferences allowed them to negotiate care and to perform skills until the parents felt comfortable to provide this care. The importance of relationship-building and information exchange was identified by the parents, neonatologists, and nurses in the study by Bruns and McCollum (2002). Although the concept of feeling known was not explicitly named in their study, the process of information exchange is one way to understand another's perspectives and preferences and to build a relationship or a sense of being known.

The quality of nurse teaching was identified in Chapter 4 as having either a facilitating or hindering effect on caregiver learning. Caregivers in this study identified many nursing actions that facilitated their learning including verbally explaining things while providing care, assessing caregivers' readiness to learn, allowing caregivers to set the pace of learning, gradually involving caregivers in providing care, and using repetition of skill performance to improve the caregivers' ability. Nurses who were calm, reassuring, specific, and methodical were viewed as excellent teachers. Alternatively, caregivers negatively described nurses who pressured them into performing skills or had unrealistic expectations of their ability to perform skills. As noted above, parents who participated in the study by Reeves, et al. (2006) alluded to a gradual, phasing in of their involvement in performing new skills which is similar to feedback received from caregivers in this study regarding the nurses' assessment of their readiness to learn and the caregivers' ability to set their own pace of learning. The participants in the study by

Callans, et al. (2016) described the effectiveness of nurses who provided detailed descriptions and demonstrations during teaching sessions as well as the importance of teaching at a pace that matched the participants' learning needs. In addition, Callans, et al. concluded that confident nurses helped contribute to the development of confident families.

As stated previously, the second major theme, the complexity of care presents challenges to the learning process, describes how the infants' care needs influenced the overall caregiver experience as well as the actions and ability of the nurses to teach in an effective manner. The infants' trajectory of care was uncertain at times for both caregivers and clinicians. At times, the infants' care needs required the nurses to make clinical care the priority rather than meeting the caregivers' learning needs. Longer lengths of stay provided ample opportunity for nurses to teach in ways that were preferred by caregivers (e.g., caregiver controls the pace, gradual phasing in of skills, etc.) and ultimately, caregivers felt more prepared to care for their infants in the home setting. The negative case that was provided to illustrate this major theme demonstrated that shorter lengths of stay (i.e., two days), provided little time to teach and led to the caregiver feeling unprepared for discharge as well as the need to readmit the infant post-discharge. The complexity of care needs effect on caregivers' learning was not mentioned in the literature and thus, this study provides new knowledge regarding the caregivers' experience.

The third major theme, team performance affects caregivers' level of anxiety/uncertainty, represents how aspects of team performance affected caregivers' levels of anxiety/uncertainty and subsequently, their ability to learn. During the

interviews, caregivers mentioned the different clinicians involved in the care team including nurses, various levels of physicians, respiratory therapists, and home care equipment vendors. As such, “team” can be defined as simply as a nurse/caregiver dyad or involving multiple people in multiple roles. In some cases, caregivers felt included in the care team through their involvement in rounds, having input into their infants’ overall care plan, or influencing the way in which nurses cared for their infant. Alternately, some caregivers viewed the team as being made up solely by the clinicians and did not feel as if they were part of the team which meant they felt ill-informed or misinformed and had not input into their infants’ plan of care. Inclusion in the team facilitated effective communication. Effective team communication (i.e. involvement in rounds, sharing of information, clarity of information, etc.) was identified by participants in this study as facilitating a positive care and learning experience. Communication was also identified as a key factor in the effectiveness of care and caregiver understanding of the plan of care as perceived by participants in the studies by Bruns and McCollum (2002), Avis and Reardon (2008), and Giambra, et al. (2014). This study’s findings as well as the findings of prior studies demonstrate the importance of the nurse’s role in facilitating team communication and potentially, decreasing the caregivers’ anxiety levels.

The presence of team conflict often led to a lack of trust between a caregiver and a clinician or clinicians. At times, conflict within the team (e.g., between two or more clinicians, between caregiver and clinician) required the nurse to act as a broker or go-between to ensure caregivers remained informed, to advocate for the caregiver and infant, or to help facilitate a trusting relationship between the caregiver and other clinicians. Although not specifically addressing the concept of team, a positive clinician/parent

relationship and information exchange were described as priorities in the study by Bruns and McCollum (2002) and these could be thought of as positive team behaviors as noted in this study. Both Kirk, et al. (2005) and Reeves, et al. (2006) reported that conflict between parents and nurses could negatively impact their relationship within the team. In both studies, the nurses' failure to recognize the parents' knowledge or expertise were potential sources of conflict. This failure could be interpreted by caregivers as being excluded from the team.

In this study, one cause of team conflict was the variation in teaching methods and skill as well as expectations of caregivers across nurses or across disciplines. This inconsistency and lack of a standardized approach to teaching within each unit and between units as well as a resistance by nurses to using teaching materials developed at a neighboring hospital was identified prior to the start of this study (names redacted to preserve confidentiality, personal communication, 2009).

The link between increased caregiver expertise in skill performance and their ability to advocate for themselves or their infant was captured in the fourth major theme. Increased caregiver expertise is due, at least in part, to the nurses' teaching interventions and the quality of the nurses' teaching. Expertise can be viewed as not only the ability to perform the skill but also the level of confidence one has in one's ability to perform. As illustrated in the negative case presented in Chapter 4, the caregiver lacked confidence in her ability to perform and felt she needed more teaching and practice, but was unable to advocate for a longer length of stay for her infant. The participants in O'Brien's (2001) study described their ability to perform skills and to advocate for their child within the context of unpredictable change post-discharge using coping mechanisms such as

reframing thinking, focusing on achievable outcomes, and maintaining hope. Callans, et al. (2016) also described how parents recognized their increasing expertise and confidence over time and this facilitated their ability to advocate for their child. However, nurses' failure to recognize the expertise of parents or parents' knowledge of their child was described by Kirk, et al. (2005) and Reeves, et al. (2006) as sources of conflict that may affect parental advocacy efforts.

The fifth major theme, transitions between care settings contribute to caregivers' anxieties encompassed caregivers' worries about nurse staffing, nurse skill in performing technology care, the level (or lack of) support available post-discharge, and their own ability to independently care for their child at home. In addition, transition to home often required the caregiver to use equipment that was different than that used in the hospital setting, as well as the need to ensure adequate supplies, and the knowledge regarding ongoing maintenance of the equipment. The challenges of coordinating home care staff (i.e. selection, monitoring) was mentioned as a challenge or worry by participants in the studies by O'Brien (2001), Kirk, et al. (2005), and Callans, et al. (2016). Participants in Kirk, et al. and Reeves, et al. (2006) also lacked confidence or satisfaction in the skill level of some home care staff, a sentiment mirrored by participants in this study. One of the themes identified in the study by Carnevale, et al. (2006) illustrated that some families of technology-dependent children lacked adequate home support leading to a sense of isolation. A few caregivers in this study felt that they were bearing the burden of caring for their infant alone and described their need for better support from home care staff, family or friends. The results of this study as well as those found in the literature



support the need for improvements in care coordination with home care agencies and equipment vendors during discharge planning.

Once discharged to home, it is apparent from the data presented in Figure 1 and Figure 2 that caregivers were performing a significant amount of needed care for their infants in the home setting dependent on the individual needs of their infants and despite having various levels of home care support. This essentially illustrates the burden caregivers face when providing technological care to an infant in the home setting. The results of this study add a new dimension to the knowledge related to the experience of caregivers of technology-dependent infants found in the literature, specifically, their overall perceptions and the factors that facilitate and/or hinder the effectiveness nurse-led discharge education designed to prepare them to care for their technology-dependent infant in the home setting. The implications of these findings for health policy and nursing education, practice, and research are presented in a subsequent section.

### **Strengths and Limitations**

The findings of this study should be interpreted within the context of its strengths and limitations. The strengths of the study include the many study design features used to support methodological rigor/trustworthiness as outlined in Chapter 3 (e.g. purposive sampling, verbatim transcription, researcher reflexivity, review by academic team, etc.). A feature of all qualitative studies is to obtain the participants' rich descriptions of the phenomenon of interest. In this study, the information-rich transcripts facilitated the researcher's ability to identify detailed and representative themes and categories. The involvement of an experienced academic team who supervised this novice researcher

allowed for valuable guidance, not only in the conduct of research, but also in the consideration of others' viewpoints and validation of identified codes, categories and themes as well as the choice of caregiver quotes used as illustrations. As this researcher was the only one conducting the semi-structured caregiver interviews, there was a relative consistency in interview techniques.

Regarding the study's limitations, although qualitative studies are grounded in the real-life experiences of the participants, their self-reported stories are their subjective experience and such perceptions may only be part of the picture. This issue will be discussed further in the section on implications for nursing research. In addition, the caregivers' responses may have been influenced by an unintentional desire to please the researcher or say what they thought the researcher wanted to hear despite the researcher's attempts to ensure an unbiased interview experience.

The study only represents the experience of caregivers of technology-dependent infants being cared for at one, large academic medical center in the Northeast section of the United States. Despite the design features used to enhance methodological rigor/trustworthiness, it is unknown if another researcher would arrive at the same conclusions given a similar sample and setting. The small sample size ( $N = 9$ ) is not representative of the population and there was little demographic variation in the caregivers as eight of the nine participants were female and the majority were Caucasian, well-educated and financially well off. It is unknown if caregivers who differ from this sample of participants would have answered the interview questions differently and if themes and categories developed from the data would have been similar to those identified in this study. However, although the number of participants was small and

lacked diversity, the study findings supports the findings of previous studies and adds to the body of knowledge about this patient population.

Another potential consideration to this researcher's study is that the study by Callans, et al. (2016) was conducted at the same institution. Participants were recruited from the same patient care units but it is unknown if any of the participants participated in both studies. However, two of the themes identified by Callans, et al. have some similarity to the findings of this study. In both cases, participants described the important role nurses have in supporting and teaching caregivers of technology-dependent children. Participants in both studies also identified similar qualities of effective teaching: detailed verbal instruction, demonstration of skills, content presented at a reasonable pace, etc. In addition, participants in both studies wanted the care team to include their input into the plan of care and to be recognized for their expertise and knowledge of their child and their child's care.

Although not described in the literature, a process of re-education of nurses in the care of children with a tracheostomy occurred and a standardized approach to discharge education was launched in April of 2013 (name redacted to preserve confidentiality, personal communication, May 1, 2017). Two participants for this researcher's study were interviewed during the roll out of these two process-improvement initiatives and three participants were interviewed between three and four months post-implementation. A few of these participants alluded to the changes in nursing practice (i.e. standardization of tracheostomy care) and educational materials but it is evident from their interviews that these changes had not fully been integrated into practice by all nurses.

### **Implications for Policy, Education, Practice, and Research**

The findings from this study suggest both what are good practices, and policies and needed changes to adequately meet the complex needs of these caregivers and their families. Implications are discussed in the following order: health policy, nursing education, practice, and research.

**Health policy implications.** The lack of a standardized approach to discharge teaching for caregivers of technology-dependent infants was noted by participants in this study. Although individualized teaching plans are necessary to meet the individualized needs of caregivers and their infants, such care plans must be based on evidence-based best practices. Such best practices can be identified through research and testing of various interventions as well as expert opinions. Mitchell et al. (2013) developed a clinical consensus statement on the care of pediatric and adult patients with a tracheostomy tube designed to reduce variations in practice. The authors conducted a literature review and subsequently achieved consensus on 77 statements including tracheostomy tube changes, management of emergencies, and specific patient and caregiver education needs including the dissemination of required information and teaching of specific skills for family members prior to discharge. A literature review was unsuccessful in identifying similar consensus statements that address other learning needs of caregivers of technology-dependent infants such as gastrostomy tube care. The development, dissemination and adoption of such statements is recommended to ensure clinicians integrate these best practices to ensure caregivers are being prepared to safely care for their infants at home using the best evidence available.

Although not related to the findings of this research study, this researcher has a suggested change that could have implications for health policy. As noted in the review of literature, the only comprehensive data regarding the prevalence of technology-dependent children is the data collected by the now defunct U. S. Congress, Office of Technology Assessment (1987). Subsequently, technology-dependent children were identified as children with special health care needs (CSHCN), a group that includes children with multiple types of health issues (e.g., learning disabilities, depression, developmental delays, cerebral palsy) and functional difficulties (e.g., breathing or respiratory problems, swallowing difficulties, seeing or hearing) (Child and Adolescent Health Measurement Initiative, 2012). Approximately 14.6 million children aged 0-17 years met the criteria for designation as a CSNCN per the National Survey of CSHCN conducted in 2011/12 (Child and Adolescent Health Measurement Initiative, 2012). However, it is unknown how many of these children are technology-dependent and more specifically, how many are infants that are technology-dependent. As the definition of CSHCN is quite broad, the levels of care needs required by the children would most likely vary; a more specific categorization that includes technology-dependence is recommended. This information would lead not only to a better understanding of the prevalence and potential scope of the health issues of this population, but may also be used to guide decisions about resource allocation, potential changes in care delivery, and opportunities for future research.

**Nursing education implications.** Regarding the implications for nursing education, it is critical that nursing students as well as practicing nurses understand the experience caregivers and families of technology-dependent children have after discharge

including the many challenges they face at home. Such knowledge would assist nurses with assessing the caregiver, infant and family, anticipating needs, identification of potential interventions and developing individualized plans of care including addressing educational needs.

Some caregivers in this study perceived a lack in nursing skill in the performance of technological care related to a tracheostomy. In addition, a caregiver reported that the nurses had stated they were not comfortable themselves performing such care. This finding suggests that there is a need to educate nursing students and nurses to ensure their competence in performing all aspects of technological care. Meeting this educational need becomes even more important if a nurse has little opportunity to perform the skill. As stated in Chapter 3, approximately 900 patients were discharged from this study's site and of these, an average of 53 infants were discharged with a tracheostomy, gastrostomy tube, or both. The opportunity to provide technological care to this patient population in any given year would be based on the nurse-patient staffing ratio, the competence of the nurse to provide such care which may influence patient assignments, and the average lengths of stay for these patients. Based on the perceptions of some of the caregivers regarding the nurses' skill level and the admission of at least one nurse that she does not perform trach care frequently, coupled with the low number of patients, it appears that nurses do not frequently have to perform such care. In such cases, tracheostomy care and other aspects of care related to technology should be periodically reviewed with the nursing staff to ensure their competence. Unit-based clinical nurse specialists are well positioned to influence and improve the care of technology-dependent children through bedside consultation regarding clinical care, education and mentoring of staff nurses, and

facilitating the use of evidence in the development of clinical policies and procedures that guide care.

A nurse's ability to perform a skill does not necessarily mean that the nurse possesses the skills necessary to teach caregivers to perform the skill. This is evidenced by the caregivers in this study describing the varying teaching techniques used by nurses as well as the effectiveness of various approaches to education. In addition, it is key that nurses understand the process of learning. Alexander, Schallert, and Reynolds (2009) suggested the following definition of learning:

“the multidimensional process that results in a relatively enduring change in a person or persons, and consequently how that person or persons will perceive the world and reciprocally respond to its affordances physically, psychologically, and socially. The process of learning has at its foundation the systemic, dynamic, and interactive relation between the nature of the learner and the object of the learning as ecologically situated in a given time and place as well as over time” (p. 186).

This definition describes the interaction of the learner with both the content to be learned and the environmental context for learning as well as the process by which learning occurs. It also captures the notion that learning is both a process and an outcome. The environmental context in this study clearly influenced the caregivers' ability to learn new skills. The caregivers' relationship with the nurses and other team members, presence or absence of team conflict, the effectiveness of communication, the complexity of care required by the infants, care setting and the nurses' teaching skill are all important environmental factors identified in this study that influence the process as well as the outcome of learning.

As individuals age chronologically and developmentally, their learning experiences and changes in knowledge affect subsequent learning and knowledge

development (Alexander, et al., 2009). In general, the older one is, the more “experience” one has. Although the caregivers in this study are adults (i.e. over the age of 21), they are novices in the content area. Based on their experiences, most adult learners have general knowledge of how they best learn and how to attend to the content they are going to learn and many caregivers identified their preferred learning style and the pace at which they preferred to learn. Thus, nurses must consider both the content to be taught and the method of delivery when planning educational strategies for caregivers. Caregivers’ perceptions of what they need should also be included in the learning plan.

Nurses must be knowledgeable of best practices for patient/family education to be competent in assessing learning needs, developing a teaching plan, delivering the education, and evaluating its effectiveness. This has implications for the curriculums in schools of nursing which are meant to lay the foundation for entry into practice as well as ongoing education for practicing nurses.

**Nursing practice implications.** There are many implications for nursing practice that can be gleaned from the themes and categories identified in this study. As stated previously, nurses need increased knowledge, understanding and appreciation of the experiences of caregivers and families of technology-dependent infants in order to plan and deliver quality care. In addition, nurses must have the knowledge and skill to provide evidence-based care for children who need technology as well as the skill to teach caregivers to prepare them to safely care for their child at home. Nurses must work to establish relationships with caregivers that are based on mutual trust and a recognition for the expertise of the caregiver as it relates to knowing their child, their child’s reaction to care, and the best way to perform a skill when needed. Nurses must



also advocate for caregivers in multiple ways including ensuring that caregivers are included in the care team to ensure they are knowledgeable about the plan of care and have input into the plan. All clinicians must work to avoid and resolve conflicts in the care setting regarding the infants' course of treatment and plans of care including teaching plans. The team should include caregivers during care rounds to include their perspectives, facilitate decision-making, and clarity of communication to avoid confusion and conflict.

It is evident from the findings in this study that there are opportunities to improve care coordination and discharge planning for caregivers of technology-dependent infants in order to facilitate a smooth transition to the home environment. Nurses can and should take a lead role in identifying caregiver learning needs upon an infant's admission and developing educational plans that address these needs. Such teaching care plans should not only include the perspectives of other disciplines but also should guide all disciplines teaching of caregivers. With individualized teaching care plans, the uniqueness of each caregiver could be considered and potential barriers to learning could be addressed. Nurses must also consider the infants' lengths of stay and find ways to provide adequate teaching for their caregivers. The use of dolls or other simulation equipment may be used to provide opportunity to repeat skills so that the caregiver can gain confidence and competence within a compressed period of time.

The knowledge gained through this study and previous studies, will help nurses anticipate and prepare for the challenges caregivers face at home. This would include ensuring caregivers are taught to use the equipment that will be used at home while they are still in the hospital, ensuring that caregivers have adequate supplies to provide care

and assisting with the identification and scheduling of home care staff to cover the initial discharge period in the home environment. In this way, caregivers can focus on providing care and not experience the stress and anxiety that comes with having to learn new equipment, order supplies, and select home care staff. In addition, nurses should ensure that caregivers have access to needed supports in their community after discharge. This could include establishing a caregiver support group or referring caregivers to an existing group, a need identified by at least two of the caregivers in this study.

**Nursing research implications.** As stated in Chapter 3, qualitative research is particularly valuable when little is known about a phenomenon. Because of the gap in nursing knowledge related to the perceptions of nurse-led discharge education by caregivers of technology-dependent infants, a qualitative descriptive method was chosen by this researcher for this study. The findings of this study provide insight into the caregivers' overall perceptions as well as the factors that facilitate or hinder the effectiveness of nursing discharge education. These findings also support the need for continued research into the caregivers' experience of learning to provide technological care.

As noted in Chapter 2, the participants in studies that included demographic data were primarily Caucasian and female. This holds true for this researcher's study as well. Consequently, the findings of this study (or previous research) may not describe the experience of non-Caucasians or males, in this case, fathers of technology-dependent children. In addition, the inclusion criteria for this study required participants to be able to speak and understand English. Only a few of the studies reported in the literature described participant inclusion criteria, but for those that did, the ability to speak and

understand English was required. Again, this study as well as previous studies' findings may not be representative of the experience of non-English speakers. Finally, the focus of this study was on the experience of caregivers of technology-dependent infant under age three whereas the caregivers in the studies described in Chapter 2 had children with a wide variety of ages within a single study. In some cases, there were similar results across the studies despite the differences in the age of the child, but it is unknown whether the perceptions and experience of caregivers vary based on the age of their child.

Because sample size for qualitative studies is dependent on when the analysis of data results in saturation and no new themes emerge, many such studies have small sample sizes. Saturation was achieved in this study after eight interviews and confirmed by interviewing a ninth participant. As noted in the review of literature and analysis of research studies in Chapter 2, some studies had small sample sizes (e.g.,  $N = 11$ ) whereas others included up to 172 families. Participants were recruited from a single source and data were collected through a single interview or focus group in a majority of the studies. Although a few of the studies did collect data at multiple points over time, the need for longitudinal studies of this population with larger and more diverse samples is evident. Such studies would be valuable for nurse researchers to be able to assess the caregivers' comfort and confidence in skill performance over time. In addition, more intervention studies are needed that would test the effectiveness of different nurse-led discharge teaching interventions that vary in regards to teaching method (i.e. video, demonstration, simulation, etc.) and types of resources (i.e. written material, links to online resources, enrollment in a caregiver support group) provided.

## Conclusion

The nursing profession has an ethical obligation to develop knowledge that furthers its practice (ANA, 2015) and this in turn facilitates the goals of the nursing profession: the protection, promotion and optimization of health, prevention of illness and injury, and alleviation of suffering (ANA, 2010). This study contributes to nursing knowledge by providing insight into caregivers' perceptions of nurse-led discharge education designed to prepare them to care for their technology-dependent infants in the home setting. The findings presented include an overarching theme, *caregiver learning and self-advocacy is enhanced by positive nurse/caregiver relationships and team cohesion, especially during anxiety-producing transitions in care*. This overarching theme encompasses five major themes: *the nurse/caregiver relationship enhances learning; the complexity of care presents challenges to the learning process, team performance affects caregivers' level of anxiety/uncertainty; caregivers' level of expertise improves self-advocacy; transitions in care settings contribute to caregiver anxiety*.

The overarching theme and five major themes suggest that, although caregivers of technology-dependent infants generally have a positive perception of nurse-led discharge education, there are opportunities for nurses to improve the care of this population. Further research is needed in this area to enhance our understanding of caregivers' experiences and the most effective nurse-led discharge teaching methods so that they are prepared to provide safe and highly skilled care to their technology-dependent infants in the home setting.

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Protocol: Caregivers' perceptions of nurse-led discharge education interventions

Subject # \_\_\_\_\_

**Demographic Form**

Please complete this form by checking the appropriate box or filling in information in the space provided. Completing this form is voluntary and you may choose not to answer any question(s).

**Information about you, the caregiver:**

Age: \_\_\_\_\_ years

Gender:  Male  Female

Partner status:  Single  Married  Partnered  Other: \_\_\_\_\_

**Your relationship to your infant:**

Parent  Gaurdian  Grandparent  Aunt/Uncle  Sibling

Other: \_\_\_\_\_

**Race:**

American Indian/Alaska Native  Asian  Black or African American

Native Hawaiian/Other Pacific Islander  White  Other: \_\_\_\_\_

**Ethnicity:**

Hispanic or Latino  Not Hispanic or Latino

**Education:**

< High school diploma  High school diploma/GED  Some college

Associate degree  Bachelors degree  Masters degree

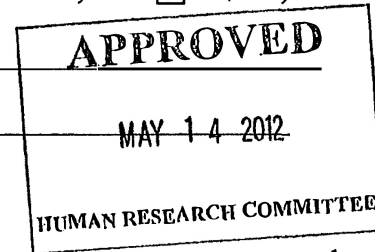
Doctoral degree

**Your household income level:**

< \$25,000  \$25-50,000  \$50-75,000  \$75-100,000  > \$100,000

How many children do you have? \_\_\_\_\_

What are their ages? \_\_\_\_\_



Protocol: Caregivers' perceptions of nurse-led discharge education interventions

Subject # \_\_\_\_\_

**Information about your infant:**

Age at time of discharge from [redacted]: \_\_\_\_\_ years \_\_\_\_\_ months

Age now: \_\_\_\_\_ years \_\_\_\_\_ months

Gender:  Male  Female

**Race:**

American Indian/Alaska Native  Asian  Black or African American

Native Hawaiian/Other Pacific Islander  White  Other: \_\_\_\_\_

**Ethnicity:**

Hispanic or Latino  Not Hispanic or Latino

Length of admission at [redacted]: \_\_\_\_\_ years \_\_\_\_\_ months

**Information about your infant's technology care needs:**

**What type(s) of technology did your infant require at home:**

- Intravenous infusion:  fluids,  nutrition, and/or  medications
- Apnea monitor
- Feeding tube
- Elimination devices (catheter, ostomy)
- Peritoneal or hemodialysis
- Breathing support: oxygen administration
- Breathing support: tracheostomy
- Breathing support: mechanical ventilation
- Other: \_\_\_\_\_

**Which of the following technologies did you learn to manage at home:**

- Intravenous infusion:  fluids,  nutrition, and/or  medications
- Apnea monitor
- Feeding tube
- Elimination devices (catheter, ostomy)
- Peritoneal or hemodialysis
- Breathing support: oxygen administration
- Breathing support: tracheostomy
- Breathing support: mechanical ventilation
- Other: \_\_\_\_\_

<b>APPROVED</b>
MAY 14 2012
HUMAN RESEARCH COMMITTEE

Protocol: Caregivers' perceptions of nurse-led discharge education interventions

Subject # \_\_\_\_\_

**Did you have home care services after your infant was discharged from [REDACTED]?**

Yes     No

**If yes, how often?**

- Full time
- More than once a day
- Daily
- A few times a week
- Weekly
- Less than weekly

**How long did you have home care services?** \_\_\_\_\_ months

**How often did you perform the needed technological care at home:**

- Hourly
- Every few hours
- Daily
- A few times a week
- Weekly
- Other: \_\_\_\_\_

**How long did your infant require technological care?** \_\_\_\_\_ months

**APPROVED**  
  
MAY 14 2012  
  
HUMAN RESEARCH COMMITTEE

### Interview Guide

Thank you for agreeing to participate in this research study. I am interested in learning about how caregivers of infants who are discharged to home with some sort of technology care needs are taught to care for their baby while in the hospital and in preparation for discharge.

I am conducting this study as part of the requirements for my PhD in nursing at Boston College. Your answers to the interview questions will be held in the strictest of confidence and every effort will be made to maintain confidentiality and your anonymity. You do not have to answer any questions you don't want to answer and if you feel the need to end the interview at any time, that is also fine. I anticipate that the interview will take approximately an hour.

I am audio-taping the interview so that I can listen to it afterwards to make sure I fully capture our conversation. Would it be ok with you if I tape it? Do you have any questions before we begin?

Questions:

1) What were you told about your baby's condition and the need for your baby to have a (tracheostomy, gastrostomy, both)?

2) I'd like to discuss how you were taught to care for your baby while you were in the hospital. At what point during your baby's hospitalization did the nurses begin to teach you to care for your baby?

Probe: What were you told about how to care for your baby?

3) How did the nurses teach you to care for your baby? What methods were used?

Probe: Which method did you like best and why?

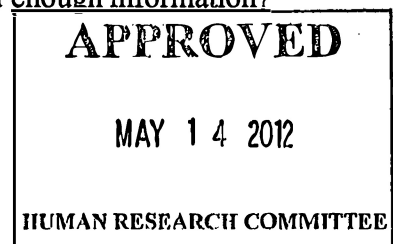
Probes: What did the nurse do that was most beneficial to meeting your learning needs? Why do you think this was beneficial?

Probes: What were the easiest things to learn? What was the most difficult? What made them easy or difficult?

Probes: Were you given too much information at any one time? Was it hard to absorb?

Probe: Were there any areas where you did not think you received enough information?

4) How prepared did you feel to care for your baby at home?



Probes: What was your biggest learning need or worry? Were you able to meet your learning need or resolve the worry? What helped you to resolve this learning need or worry?

Probes: Which skill or skills were you most concerned about performing? Why?

5) Did anyone else besides you learn to care for your baby when you get home?

Probe: What do you think their biggest concern or worry was about performing these skills at home?

Transition: I'd like to discuss your experience with caring for your baby at home once you were discharged from the hospital.

1) How long was your baby hospitalized before going home for the first time?

Probe: Were you ready to leave the hospital when you did?

Probe: How prepared did you feel to care for your baby once you got home?

2) Did you feel supported in caring for your child even after you left the hospital?

Probe: Who provided this support?

3) Were you concerned about providing your baby's care once you got home? What did you do about it?

Probe: What was it like to have to perform (individualize skills based on response) on your baby at home for the first time?

Probes: Were you comfortable? If not, how long did it take for you to become more comfortable doing (individualize skills based on response)?

Probe: What was the most stressful event for you once our baby was at home?

Probe: Did your baby need to be readmitted at any time? If so, what happened?

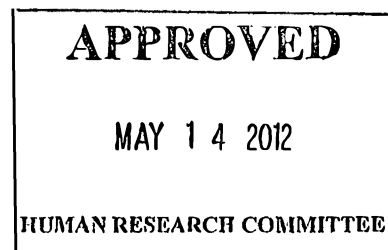
4) What could the nurses have done differently to prepare you to care for your baby at home?

Probes: Is there anything about the educational materials and/or teaching that you would like to see improved? How would you improve them?

Closing transition:

1) Is there anything else you would like to share with me regarding the nurses' efforts to educate you about how to care for your baby at home?

Thank you for your time and participation.





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## Application: Notification of IRB Approval/Activation

**Protocol #: 2012-P-000765/1;**

Date: 05/14/2012

To: Brian French  
Nursing  
 VBK 6

From:   
 Research Management  
 116 Huntington Ave Suite 1002

Title of Protocol: Caregivers' perceptions of nurse-led discharge education interventions: Knowledge needed for adequate care of technology-dependent infants in the home setting  
 Version Date: 04/05/2012  
 Sponsor/Funding Support: None  
 IRB Review Type: Expedited  
 Minimal Risk: 45 CFR46.110 and 21 CFR56.110  
 Expedited Category/ies: (7) Research on individual or group characteristics or behavior, or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or QA methodologies.  
 IRB Approval Date: 05/14/2012  
 Approval Effective Date: 05/14/2012  
 IRB Expiration Date: 05/14/2013

This Project has been reviewed and approved by the IRB. During the review of this Project, the IRB specifically considered (i) the risks and anticipated benefits, if any, to subjects; (ii) the selection of subjects; (iii) the procedures for securing and documenting informed consent; (iv) the safety of subjects; and (v) the privacy of subjects and confidentiality of the data.

**NOTES: The following documents are noted and approved with initial approval.**



- 1) Protocol Summary, Version Date 04/02/2012
- 2) Informed Consent (1), Version Date, 05/11/2012
- 3) Contact letters (2)
- 4) Phone Script (1)
- 5) Interview Guide Questionnaire
- 6) Demographics Questionnaire

As Principal Investigator you are responsible for the following:


1. Submission in writing of any and all changes to this project (e.g., protocol, recruitment materials, consent form, study completion, etc.) to the IRB for review and approval prior to initiation of the change(s),

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- except where necessary to eliminate apparent immediate hazards to the subject(s). Changes made to eliminate apparent immediate hazards to subjects must be reported to the IRB.
2. Submission in writing of any and all adverse event(s) that occur during the course of this project in accordance with the IRB's policy on adverse event reporting.
  3. Submission in writing of any and all unanticipated problems involving risks to subjects or others.
  4. Use of only IRB approved copies of the consent form(s), questionnaire(s), letter(s), advertisement(s), etc. in your research. Do not use expired consent forms.
  5. Informing all physicians listed on the project of changes, adverse events, and unanticipated problems.

The IRB can and will terminate projects that are not in compliance with these requirements. Direct questions, correspondence and forms (e.g., continuing reviews, amendments, adverse events, safety reports) to , (617) 424-4116.

