

DEVELOPMENT OF THE THEORY OF SHARED COMMUNICATION: THE PROCESS OF  
COMMUNICATION BETWEEN PARENTS OF HOSPITALIZED TECHNOLOGY DEPENDENT  
CHILDREN AND THEIR NURSES

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Barbara Klug Giambra

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AND THEIR NURSES

Technology dependent children such as those who require a feeding tube, tracheotomy or ventilator are a special group of chronically ill children who require complex care on a daily basis. When these children are hospitalized, the accompanying parent and the nurse caring for the child on the inpatient unit must communicate together about the care of the child. Care for the technology dependent child is optimized when parents and nurses both understand the plan of care for the child. To discover the process of parent-nurse communication that results in mutual understanding of the child's plan of care, a grounded theory study to explore the perspectives of the parents of previously hospitalized technology dependent children was undertaken. The Theory of Shared Communication emerged from the data and illuminates the parent-nurse communication process. The antecedents of the process are respect for own and others expertise. The communication process consists of six communication behaviors; ask, listen, explain, advocate, verify understanding and negotiate roles. The behaviors are nested within each other and all are not necessarily required for the non-linear process to result in the relational outcome of mutual understanding of the child's plan of care. An integrative review of the literature regarding the process of communication between parents of hospitalized chronically ill children and their nurses shed light on the components of the process, but no study was found that explicated the entire communication process. A subsequent grounded theory study added the perspectives of the nurses to the original theory. No new components of the process were uncovered, but the nurse's narratives added significantly to our understanding

of the communication process. Additionally, parents of currently hospitalized technology dependent children confirmed the propositions of the Theory of Shared Communication.

Marion E. Broome, PhD, RN, FAAN, Chair

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Table 1: Demographic data (n=11 participants)

Category	N	%
Female	11	100
Mother	9	82
Grandmother	1	9
Adoptive Mother	1	9
African American	2	18
White	9	82
Parent's Age		
31-40 years	3	27
41-50 years	4	36
51-60 years	2	18
Did not respond	2	18
Parent's Education		
GED	2	18
Some college or technical school	3	27
College graduate	3	27
Post college graduate	1	9
Did not respond	2	18
Child's Age		
4-7 years	3	27

8-10 years	4	36
11-15	4	36
Child's Technology Needs		
(may require more than 1)		
Feeding tube	8	72
Tracheotomy	4	36
Ventilator	1	9
Insulin pump	2	18

Table 2: Interview Schedule

1. Tell me the story about your child who is technology dependent.
2. Tell me about communicating with the nurses when your child is hospitalized.
3. Tell me about a time when you and the nurses were able to communicate something about your child that was important to both of you.
4. Tell me about a time when you and the nurses really understood each other.
5. Tell me about how you know when you and the nurses have the same understanding in mind as you are talking about your child's care.
6. Tell me about a time when you and the nurses just couldn't understand each other.
7. What do you expect great communication with the nurses to include or look like?
8. What do you need nurses to communicate with you when you and your child are in the hospital?
9. Can you summarize in one word or phrase your communication with the nurses?
10. Is there anything else you'd like to tell me?

Table 3: Description of Evidence Quality Levels

Quality Level	Definition
1a* or 1b*	Systematic Review, meta-analysis or meta-synthesis of multiple studies
2a or 2b	Best study design for domain of the clinical question (e.g. Randomized controlled trial, Qualitative study)
3a or 3b	Fair study design for domain of the clinical question (e.g. Prospective cohort study)
4a or 4b	Weak study design for domain of the clinical question (e.g. Descriptive study)
5	Other: General review, expert opinion, case report, consensus report or guideline

\*a = good quality study, b = lesser quality study

Table 4: List of Studies included in Integrative Review

Citation Country Evidence level	Study design, Methodology	Sample, Population Setting	Purpose/objective	Findings/Themes
Avis & Reardon (2008) United Kingdom [2a]	Qualitative Interviews	n = 12  Parents of children with special healthcare needs discharged from hospital	Explore parent perceptions of child's nursing care while hospitalized	1) Communication with staff (most important), 2) Nurse-parent relationships, 3) Prior experiences of hospital care, 4) Perceptions of nurses and nursing
Ford and Turner (2001) Australia	Qualitative Phenomenology Interviews	n = 4  Pediatric nurses who care for hospitalized children with special needs and their families	Explore experiences of pediatric nurses caring for hospitalized children with special needs and their families	1) Special relationships 2) Multiple dimensions of who is expert - nurses described needing to learn from the parents how best to care for their child 3) Development of trust between nurses and families - parents develop trust in the nurse when they are able to see the nurse providing optimal care for their child 4) Feelings of frustration and guilt
Giambra, Sabourin, Broome & Buelow (2014) Midwest, United States [2a]	Qualitative Grounded Theory Interviews	n = 11  Parents of technology dependent children hospitalized in the last year in a children's hospital	Discover parent perception of parent-nurse communication process	Shared Communication Process components: respect for own and others expertise, ask, listen, explain, advocate, verify understanding negotiate roles relational outcome is the degree of mutual understanding between the parent and nurse regarding child's plan of care
Margolan, Fraser & Lenton (2004)	Cross-sectional Survey and Interviews	n = 15  Parents of children who	To discover parent perceptions of services they received including	Parents described being fully involved in process of discharge planning. Parents felt roles were

United Kingdom [4b]		were ventilator dependent	discharge from the hospital.	not negotiated with nurses, and their emotional needs were not taken into account when trying to learn procedures.
Shields, Hunter, & Hall (2004) United Kingdom [4a]	Descriptive Parent and Staff Perceptions Questionnaire	n = 85 Parents of hospitalized children (34% with a chronic condition) And n = 73 staff (64% nurses)	To examine the attitudes and perceptions of parental needs among parents and staff.	Family and staff both ranked the 1) need to trust as most important, 2) need for information (parents) and need to be trusted (staff) second most important and the need to be trusted (parents) and needs related to the ill child and other family members third (staff), respectively. Parents of chronically ill children more likely to say their need to be able to ask how to explain the illness, participate in nursing care, learn and be informed, and feel important in contributing to child's well-being was fulfilled than parents of acutely ill children.
Shields, Young, & McCann (2008) Australia [4a]	Descriptive Need of Parents Questionnaire	n = 130 Parents of currently hospitalized children (33% with chronic condition) and n = 79 staff (69% nurses)	To compare the perceived needs of parents with those of staff caring for them	Parents and staff agreed on high importance of 1) nurses recognizing and understanding parent's feelings, 2) parents should get exact information about child's condition, and 3) parents should be told everything being done to or for child and why. Staff placed more importance on parent's communication needs than parents.

Table 5: Exemplar nurse interview questions

I asked the nurse these questions today ...
I noticed the nurse did this today...
I felt as though I had to stand up for my child about this today...
Today, the plan of care for my child is...

Table 6: Exemplar parent journal prompts

I asked the nurse these questions today ...
I noticed the nurse did this today...
I felt as though I had to stand up for my child about this today...
Today, the plan of care for my child is...

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Figure 1 Model of the Theory of Shared Communication

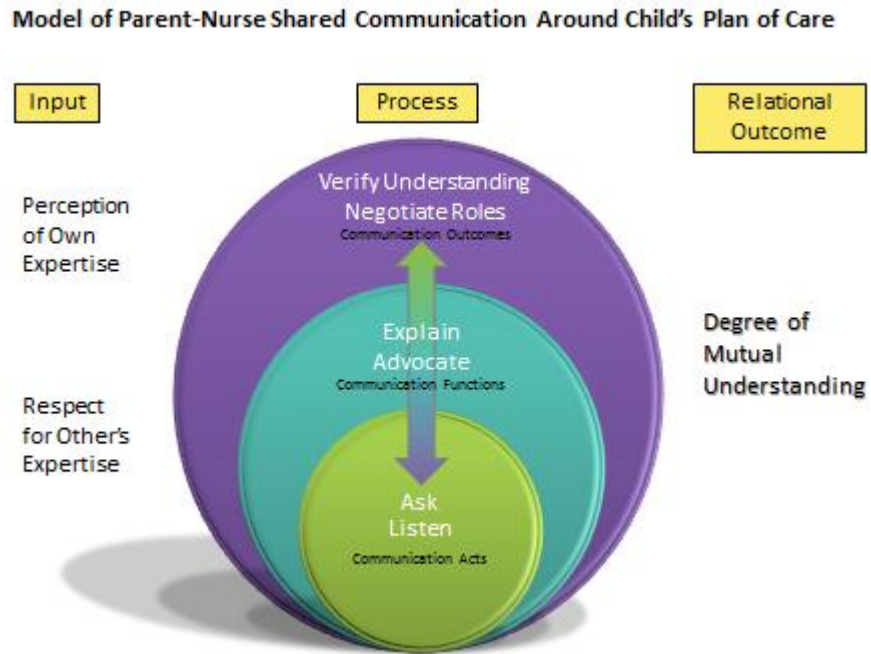
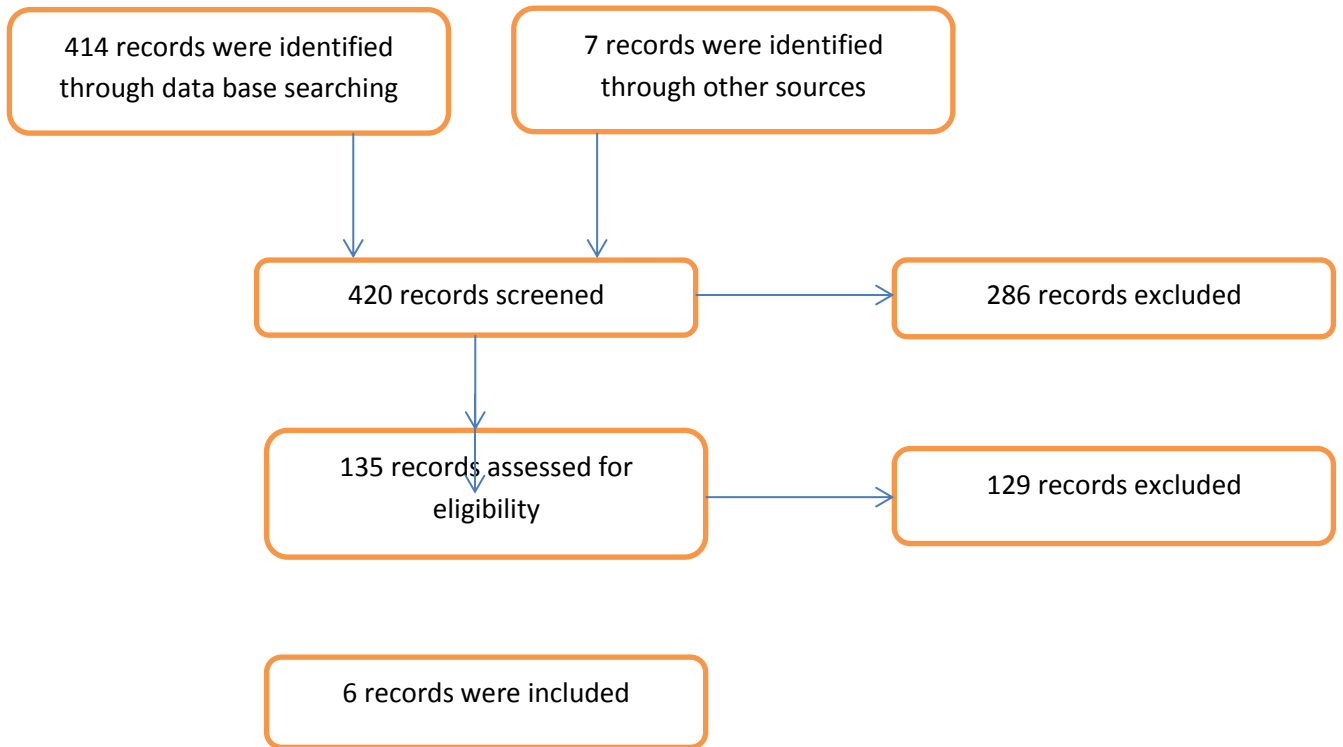




Figure 2: Literature search flow diagram



## **Chapter One: Foundation**

Barbara K. Giambra

### **Section One: Introduction and overview of program of research**

This chapter will describe the scope and significance of the problem and describe the concept of Shared Communication. The author's interest in the topic of parent-nurse communication was sparked by parent stories and clinical observations of communication between parents of technology-dependent children and their nurses which led to less than optimal outcomes. The author worked with technology dependent children and their parents as a bedside nurse and then as a nurse practitioner in several areas of the States over the last 25 years. Over the last 15 years, the author worked at a 587 bed, Midwestern, free-standing, children's hospital that provides quaternary care to children from around the region and the world. Parents with whom the author worked expressed dissatisfaction with the communication process when poor communication with the nurses negatively impacted the outcome of care for their child. Nurses frequently voiced concerns over the efficacy of their communication with parents when they felt the parents did not understand the subject of the dialogue. When nurses and parents communicated well and believed they both understood each other, care for the child by both parents and nurses appeared to be enhanced.

In order to better understand this phenomenon, the author attempted to analyze the concept of mutual understanding; that is, the point at which the nurses and parents both understand the plan of care for the child. Although related concepts of communication between nurses and families of technology dependent children in a home care or ambulatory setting and communication between physicians and parents of hospitalized children were well described (Brinkman, et al., 2007; Dickinson, Harrington, Noble, & Newman, 2004; Kirk, 2001; Laidlaw, et al., 2007; Lutenbacher, Karp, Ajero, Howe, & Williams, 2005; Smythe & Spence,

2006), the concept of mutual understanding between inpatient nurses and the parents of either technology dependent or chronically ill hospitalized children was not found in the literature.

Technology dependent children are a special group of chronically ill children who require complex care on a daily basis. Parents of technology dependent children know their chronically ill child best. They understand not only the care of the child, as demonstrated in the care they provide each day, but also the unique responses of their child to the care. This information is important to the nursing care of the child, particularly when the child is hospitalized.

The lack of literature regarding the concept of mutual understanding of the plan of care for the child, as well as the communication process in which parents and nurses engage to achieve that understanding led to the design of a qualitative study. The purpose of that study was to determine the process of parent-nurse communication from the perspective of the parents of technology dependent children who have been hospitalized. This grounded theory study resulted in the Theory of Shared Communication which will be described in detail in Chapter Two (Giambra, Sabourin, Broome, & Buelow, 2014). This grounded theory study was followed by an integrative review of the literature about the communication process between the parents of hospitalized chronically ill children and their nurses and is explained in Chapter Three (Giambra, Broome & Stiffler, under review). Enhancing understanding of the process of communication between parents of technology dependent children and their nurses on the inpatient unit culminated in a second qualitative study to add the nurses' voice to the original theory and confirm the theory's propositions. This final study is detailed in Chapter Four. Understanding the communication process between parents of hospitalized technology dependent children and their nurses will inform nursing practice to improve communication, nursing care, and outcomes for the child.

## **Section Two: Background**

### **Prevalence of chronically ill children.**

More than 10 million children, or approximately 14-15% of all children less than 20 years of age in the United States have special health care needs (U.S. Department of Health and Human Services, 2008; Newacheck and Kim, 2005; VanDyck, Kogan, McPherson, Weissman, & Newacheck, 2004). The United States Maternal Child Health Bureau defines children with special healthcare needs (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" (McPherson et al., 1998). These children have not only primary but also acute and chronic healthcare needs (Neff, 2008) and may have more than one concurrent chronic illness. Children with chronic illnesses experience more frequent trips to the doctor's office and emergency room than their healthy playmates (Owens, et al., 2008). Not surprisingly, children with chronic illnesses are also frequently hospitalized and account for 55-60% of all hospital discharges (Wise, 2004).

### **Prevalence of technology dependent children.**

Children who are technology dependent are a subset of chronically ill children with special healthcare needs. The United States Office of Technology Assessment defines technology dependent children as those who require "a medical device to compensate for the loss of a vital bodily function and substantial and ongoing nursing care to avert death or further disability" (1987, p.3). The care needs of these children exist on a continuum of constant assessment and numerous nursing care needs to less frequent assessment and intermittent nursing care. The needs of technology dependent children vary and may range from high tech (i.e.; use of a mechanical ventilator) to low tech (i.e.; a gastrostomy) needs (Wang & Barnard, 2004). While there are currently no estimates of the number of technology dependent children

in the United States due to the lack of specific items about technology dependence included on national surveys, it appears that their numbers are growing as medical technology evolves. Many of these children rely upon more than one type of technology (Kirk, 2008). Just a few decades ago, children who were reliant upon complex medical technology were frequently institutionalized in order to receive the ongoing nursing care they needed. In the 21<sup>st</sup> century, most technology dependent children are cared for by their parents or guardians at home (Toly, 2012; Neff, 2008; Bowie, 2004). This trend to discharge technology dependent children home to be cared for by their family has led to a unique set of issues including involvement of the family in the care of the child.

Healthcare professionals should engage with their clients in patient-centered care and strive to include the patient in shared decision-making to optimize their care (IOM, 2001). Children with special healthcare needs and those with technology dependence in particular may not be independent decision makers when it comes to their healthcare. Generally, their parents or guardians make healthcare decisions for them. For that reason, the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau emphasizes the importance of family-centered care (n.d.).

#### **Family-Centered Care.**

The Institute for Patient- and Family- Centered Care (IPFCC) espouses the following four core components of patient- and family-centered care: respect and dignity, information sharing, participation and collaboration (IPFCC, 2013). Each of these core components are intended to aid healthcare professionals to empower the family to participate in the care of and medical decision making about their child. Family-centered care in the hospital setting is defined as care “planned by the health staff around the whole family, not just the individual child” (Shields, Pratt, Davis, & Hunter, 2009). To adhere to the above mentioned core components, healthcare

professionals need to listen to and respect the family's perspective, communicate with patients and their families clear, unbiased, and timely information, and collaborate with and encourage the family to engage in shared planning and decision making about their child's care (IPFCC, 2013). In order to discover the goals of the technology dependent child and their family, nurses must communicate with them. When admitted to the hospital, nurses must talk with the child and family to determine not only their goals for that admission, but also for each day and shift. Care should also be taken to discover any needs anticipated for the patient and family after discharge as the requirements for technology dependent children at home can be extensive.

#### **Impact on the family.**

Parents experience many distressing emotions such as shock, sadness and guilt when their child is first diagnosed with a chronic illness (Schmidt, Bernaix, Chiappetta, Carroll, & Beland, 2012). Parents may also feel overwhelmed by the volume of information they receive at the time of their child's diagnosis, which can increase their anxiety (Hummelinck & Pollock, 2006).

Once the shock of the initial diagnosis wears off, parents experience a variety of stressors including psychosocial, such as changes in family dynamics, as well as physical, and financial stressors. Several authors have described the psychosocial stressors parents of technology dependent children face including lack of privacy, managing the home in addition to their child's complex needs, performing the dual roles of nursing and parenting, managing to find time to parent their other children, advocating for their child to receive education and other opportunities, feeling as though they may be hurting their children when performing care, and worrying that they may not have enough knowledge or expertise to meet all of their children's needs (Hewitt-Taylor, 2008; Kirk, Glendinning, & Callery, 2005; MacDonald & Gibson, 2010; Margolan, Fraser, & Lenton, 2004). Related to the above stressors, changes in family dynamics

such as sibling behavioral issues, marital disharmony and general family dysfunction have been reported (Wang & Barnard, 2004). In addition to the emotional toll, parents face significant physical demands when caring for their technology dependent child, especially as the child grows in stature (Wang & Barnard, 2004; MacDonald & Gibson, 2010). Financial concerns can overwhelm parents of technology dependent children as many are uninsured, have family incomes less than 200% of the federal poverty guidelines (poor and near-poor) and often have to cut back on work hours or quit working altogether to care for their child (Looman, 2009, Margolan, Fraser, & Lenton, 2004). These stressors may be compounded by the usual parenting issues all parents face.

#### **Parents as experts.**

Along with parenting, parents of technology dependent children also spend a tremendous amount of time and energy caring for their child at home. Responsibilities of parents as caregivers for their children may include administering medications and enteral feedings, calculating nutritional intake and subsequent insulin needs, suctioning, tracheotomy changes, and skin care in addition to problem solving the technology upon which their child depends (Sullivan – Bolyai, Knafl, Sadler & Gilliss, 2004). These parents become experts regarding their child's care (Kirk, Glendenning & Callery, 2005, Shields, Young, & McCann, 2008). The parent's holistic expert knowledge includes not only their child's growth and development needs and achievements but also the unique medical care required for the child on a daily basis (Buford, 2005). Perception of parental expertise by the nurse may influence communication between parents and nurses (Giambra, Sabourin, Broome, & Buelow, 2014). Many authors have found parents of chronically ill children want their relationships with nurses to include better communication (Avis & Reardon, 2008; Buford, 2005; Carter, Cummings, & Cooper, 2007; Fisher & Broome, 2012; Hummelinck & Pollock, 2006).

### **Nurses and communication.**

Nurses are the most consistent person with whom parents communicate when their child is hospitalized (DeLucia, Ott, & Palmieri, 2009). The frequency of those interactions speaks to the need for RNs, in particular, to be able to communicate effectively with the parents in order to meet the needs of the parents as well as those of the children for whom they are caring.

According to a study by Avis and Reardon (2008), communication between parents and nurses, from the perspective of parents of chronically ill children, was not as direct as the parents would have liked and role negotiation was poorly accomplished. Additionally, parents in this study felt the nurses did not support their emotional needs, therefore the parent-nurse relationship suffered from a lack of trust (Avis & Reardon, 2008). Thorne and Robinson (1988a) also found trust among families of chronically ill patients and their healthcare professionals to be a significant issue. According to the authors, family members begin with naïve trust in the professional, and then became disillusioned with the abilities or priorities of the professional and move into a period of disenchantment. Finally, families come to the realization that they need to have a relationship with the professional in order to better care for their loved one, and eventually enter into a guarded alliance with the professional (Thorne & Robinson, 1988a).

Communication between families and healthcare professionals is integral to prevention of medical errors. Documentation of near miss medical errors, those that are discovered before resultant harm to the patient, shows that family knowledge of the patient is crucial for optimal care (Campbell, 2004; Greenhouse, Kuzminsky, Martin & Merryman, 2006). The Joint Commission launched its "Speak Up" Initiative (2007) in an effort to help families become aware of their rights and ultimately receive better, more satisfying care. The Joint Commission advocates for patients and their families to be informed about the care they should anticipate,



expect that their opinion will be heard, and receive treatment with respect and courtesy, among other things. The patient and family are encouraged to follow the 'Speak Up' recommendations specifically to prevent errors in care. Communication between the family and healthcare professionals may ultimately improve the safety of the care given to the child and the parent's satisfaction with the child's experience in the hospital.

Parents are known to be more satisfied when they are able to communicate about their hospitalized child's care. Maisels and Kring (2005) demonstrated significant increases ( $p < .005$ ) in parent satisfaction with all aspects of their child's care when their questions were answered and lab results were explained. Ammentorp, Mainz, and Saybroe, (2005), found parents placed a high priority on communication with both physicians and nurses. Nurses who are more knowledgeable about the care needed for their patient are more likely to be confident in their ability to provide that care and patient outcomes are improved (Gillespie, Chaboyer, Wallis, & Werder, 2011). Improved outcomes lead to increased parent and nurse satisfaction. Improving communication by specifically including parents during rounds on their child was found to be linked to more timely discharge at one children's hospital (Muething, Kotagal, Schoettker, Gonzalez del Rey, & DeWitt, 2007) and increased professional satisfaction. Additionally, Looman, (2009) found families of children with special healthcare needs in Minnesota whose healthcare professionals communicated well with other service professionals were significantly less likely to report financial problems (Odds Ratio = 0.484). As evidenced by these studies, optimal family communication with professionals, including nurses, can have significant implications for the family and their child.

Given the importance of communication as outlined above, it seems reasonable to assume that nurses are taught to communicate well with their patients and their families. Despite the imperative nature of the need for nurses to have good communication skills,

training is not standardized among educational institutions. Although most nurses receive education regarding active listening and reflective communication prior to beginning their careers, parents still continue to be dissatisfied with their communication with nurses. Specifically, parents want to be listened to and have their expertise valued (Buford, 2005; Sydnor-Greenberg, & Dokken, 2000). They want to be given information about their child's diagnosis, prognosis and day to day management (Hummelinck & Pollock, 2006) and have the unique needs of the individual family recognized (Avis & Reardon, 2008).

As medical technology advances, patient acuity increases and the amount of time nurses are able to spend at the bedside caring for the patient and families' needs has become more limited. One study showed nurses on a pediatric inpatient unit had a mean time per interaction with their patients of 4 minutes, 24 seconds including rounds, monitoring and patient care (Shin & White-Traut, 2005). Less time with the family may translate into less time to practice and hone communication skills. One randomized controlled trial of a communication skills training program with nurses showed improved communication skills even among those nurses who considered themselves skilled to begin with, indicating the importance of maintaining these skills (Doyle, Copeland, Bush, Stein, & Thompson, 2011).

### **Section Three: Studies of the process of communication between parents of hospitalized technology dependent children and their nurses**

Shared communication, that is, communication that flows between parents and professionals and is understood by both parents and professionals, has been found to be a key factor in the provision of optimal care (Carter, Cummings, & Cooper, 2007; Sydnor-Greenberg & Dokken, 2000). Optimal care for a technology dependent child depends on shared communication between parents and nurses to create a mutual understanding of the plan of care for the child.

Guided by doctoral studies in nursing, research methods and communication, a qualitative study was designed to discover the process of communication leading to mutual understanding of the child's plan of care from the perspective of parents of hospitalized technology dependent children. The grounded theory study culminated in the emergence of the Theory of Shared Communication (Giambra, et al., 2014) illuminating the process of parent-nurse communication leading to mutual understanding of the child's care plan. The theory was grounded in the perspective of the parents and provides the foundation for subsequent studies.

Literature regarding the process of communication in the study population as described previously was lacking. Therefore, a study of the existent literature regarding communication between parents of hospitalized pediatric chronically ill patients and their nurses on the inpatient unit was undertaken. Multiple study designs were found that addressed and added to the understanding of parent-nurse communication. None of the studies, however, described the entire process of that communication.

In order for true shared communication to exist, it must be created and perceived by both parents and nurses. The perception of the nurses regarding the process of communicating with parents of technology dependent children was neither included in the first study nor found in the literature. Based on the results of the integrative review, the entirety of the communication process between parents and nurses was still unknown. In order to explicate the process, a third study was designed. The overall goal of this study was to apply and extend as well as discover the value and relevance of the Theory of Shared Communication to nursing practice. The study attempted to answer the following questions:

- 1) Can the propositions of the theory, validity of its concepts, the linkages of presumed relationships between concepts and attainment of the outcome be confirmed?

- 2) How are the nurses' perceptions of the process of communication with parents of hospitalized technology dependent children similar or dissimilar to the parents' perceptions of the process?

Parents of technology dependent children admitted to the hospital and the nurses caring for them were asked to participate in a series of interviews. The interviews were designed to elicit both nurse and parent perceptions of their communication with one another and whether or not, and to what degree this communication resulted in mutual understanding of the child's plan of care. This study is described in detail in Chapter Four.

#### **Section Four: Theoretical Underpinnings**

The theories used as foundations for this work emanate from both the nursing and communication disciplines as well as the previous grounded theory study of the process of communication between parents of hospitalized technology dependent children and their nurses. Communication is a process in which human beings engage each time they interact. When parents of hospitalized children and nurses interact, they communicate with each other about the care of the child. Guarded Alliance is a theory born of nursing research that describes communication between families' of chronically ill patients and their healthcare professionals, including nurses. The Theory of Shared communication emerged from the first grounded theory study regarding the process of communication that is specific to the parents of hospitalized technology dependent children and their nurses from the perspective of the parents. Through the use of all three of these theories, an understanding of the process of communication from the integrated perspectives of the parents and nurses was forged.

#### **Relational Dialectics Theory.**

The phenomenon of parent-nurse communication is aligned with the perspective of Relational Dialectics Theory (RDT). RDT is a non-prescriptive theory for understanding meaning

making within relationships through communication. The core premise is that “meanings emerge from the struggle of different, often opposing discourses,” or worldviews as expressed by the speakers (Baxter & Braithwaite, 2008, p. 351). According to RDT, every utterance in a dialogue is linked to other utterances that have gone before and will come after it and are influenced by the speakers’ worldviews. RDT describes four links in the chain of every utterance; distal already spoken, distal not-yet-spoken, proximal already spoken and proximal not-yet-spoken. The distal links are the cultural discourses of the speakers (already spoken) that inform their meaning of the current utterance and the speakers’ perspective of the future outcomes of this utterance for self and the community at large (not-yet-spoken). The proximal perspectives include the history of previous communication between the speaker and addressee or the context of the current utterance (already spoken) as well as anticipation of the addressee’s reactions to the speaker’s utterance (not-yet-spoken) (Baxter, 2011). Each parent and nurse brings all four of these perspectives to each dialogic exchange. In this way, each speaker’s distal and proximal perspectives inform their ability to and perhaps method for communicating with one another. Shared communication in this context is therefore defined as the aesthetic meaning making of a dialogue/utterance (Baxter & Braithwaite, 2008). Discovering the perspectives of both parents and nurses is but one step in understanding their shared communication.

### **Guarded Alliance.**

The second theoretical framework used for this proposed research is Thorne & Robinson’s (1988a, 1989) Guarded Alliance: Healthcare relationships in chronic illness theory which outlines a three stage pattern found in relationships among families experiencing chronic illness and healthcare professionals. The first stage is Naïve Trust. This stage occurs in the early portion of the development of a relationship between the family of a chronically ill child and

healthcare professionals. During this stage, families assume the healthcare professional has the same perspectives toward caring for their child that they have. This might include quality of life, reduction in pain or avoidance of invasive treatment.

In the second stage, the relationship between the families and healthcare professionals progresses, and is marked by disenchantment. The families now realize that the healthcare professionals have different perspectives and expectations of the care for their child than do they. This may include multiple medication use, long term therapies or palliative care versus aggressive treatment. The third and final stage is one of reconstructed trust which Thorne and Robinson have named guarded alliance. During this stage, the families determine that they need to work with the healthcare professional to obtain the needed care for their child. They also realize that as a family they must take some responsibility for the care of their child. Guarded alliance with healthcare professionals therefore, is the final stage families of chronically ill children achieve.

Thorne and Robinson (1989) found those treated for chronic illness identified four patterns of reconstructed trust with their professionals; hero worship, resignation, consumerism and team playing. Often, the use of more than one pattern was identified by each informant. These four patterns exist on a continuum of both trust in the healthcare professional and patient/family feelings of their own competence to make decisions about their care and manage their disease on a daily basis (Thorne & Robinson, 1988b). Having worked with their child's healthcare professionals for some time and establishing expertise about the care of their child, parents of technology dependent children may be in the final stage, guarded alliance. As such, the pattern of relationship they form with their nurse may be influenced by their satisfaction with and the efficacy of communication with that nurse in addition to their own perception of

competence. The theory of Guarded Alliance does not, however, explain the process of shared communication between parents and healthcare professionals, or more specifically, nurses.

### **Theory of Shared Communication.**

This study is framed by the first grounded theory study regarding the communication process used by parents of hospitalized technology dependent children with their nurses (Giambra, et al., 2014) from the perspective of the parents. The study from which this theory emerged is discussed in detail in Chapter Two. Findings from this grounded theory study demonstrate that these parents attempt to engage in shared communication with the nurse on the inpatient unit in order to ensure they have a mutual understanding of the plan of care for their child, thus optimizing the care the child receives. The parents endeavor to share the unique and expert knowledge they have accumulated over time by caring for their child at home with the nurses who also have unique knowledge about the care of the child.

The Theory of Shared Communication is predicated on each participant's perception of their own expertise and respect for the other's expertise. With that foundation, parents perceived shared communication as engagement in the following behaviors: questioning, listening, explaining, advocating, verifying understanding and negotiating roles. According to the parents, through shared communication, the plan of care for the child is constructed and mutual understanding of that plan is created by the partnership between the nurses and parents. The degree to which there is mutual understanding of the plan of care is dependent on the antecedents and use of the above communication behaviors.

## **Section Five: Conceptual definitions**

### **Antecedents.**

#### ***Perception of own and others expertise.***

As noted previously, parents become experts in their child's care over time. Their expertise, therefore, exists on a continuum from no skill or knowledge about the child's care to an abundance of skill and knowledge. Nurse's expertise also varies on a similar continuum. Variables that may influence a nurse's expertise include education, professional experience and age (life experience). The parent or nurse's expertise about caring for a particular child is measured by self-report.

### **Communication behaviors.**

#### ***Questioning.***

Parents in our previous study (Giambra, et al., 2014) engaged in questioning in several ways. They described asking questions of the nurses in order to get information. They also questioned the nurses in order to challenge them to give rationale for a statement or action. Additionally, parents wanted nurses to ask questions of them in order to provide their expertise about their child. Nurses often ask questions to obtain information, but it is not known if they also use questions in other ways when communicating with parents.

#### ***Listening.***

Listening is an activity. It requires effort to pay attention to the other and hear what they are saying. Parents described being listened to by nurses as a way to communicate information to them but also as a way for the nurses to show respect toward the parent. As stated previously, nurses are often educated to use active listening skills however the perspective of the nurse regarding listening in the context of caring for a technology dependent child and their family is unknown.



***Explaining.***

Explaining is a functional communication behavior during which information is imparted, clarified and made understandable. The explanation may include illustration or demonstration. Nurses often use explanation in their care of patients and families. The use of explaining as a behavior during communication was explored with the nurses.

***Advocating.***

Advocating is used by parents to plead a cause for their child, or provide support for a proposal or decision. Generally, parents use advocacy to protect their children from perceived negative consequences such as a painful procedure, or to make sure their child receives a positive consequence such as appropriate educational services. Advocacy is a well-recognized part of a nurse's professional role. Nurses may advocate for their patients to protect them from negative outcomes (Groves, Finfgeld-Connett, & Wakefield, 2012) in much the same way a parent might. Nurses may also advocate for their patient to receive services they believe will be beneficial from a variety of sources such as a change in treatment. Nurses were asked to describe their use of advocacy.

***Verifying understanding.***

Parents in our previous study (Giambra, et al. 2014) described verifying understanding as making sure the nurse understood the information given to them, that the nurse had enough expertise to safely care for their child and whether or not the nurse was providing accurate care. Parents may use any of several methods to verify the nurse understands the care the child required including questioning, listening and observing. Nurses may also verify the parent understands the child's care, particularly when changes to the plan of care are made. Nurses were asked to describe their perception of the use of verifying understanding in the context of communicating with parents of technology dependent children.

***Negotiating roles.***

As described previously, parents of technology dependent children fulfill a dual role; that of parent as well as provider of nursing care. When a child is hospitalized, nurses provide the nursing care, but may also provide some parenting if the parents or other family members are not readily available to fill that role. Negotiating who will fulfill what role at which time can reduce conflict and confusion for the parent, the nurse and the child. Nurses were asked whether and how role negotiation is a part of the process of communication with the parents.

**Relational outcome.**

***Degree of mutual understanding of the plan of care.***

A reciprocal understanding of the plan of care created for the child jointly by the parents and nurse is the desired outcome of the process of shared communication. Both parents and nurses will be asked to what extent they believe they have the same understanding of the plan of care as the other for a particular child. In this way, the perception of mutuality of their understanding was measured.

**Section Six: Significance of this series of studies**

The author hypothesized that care for the hospitalized technology dependent child will be optimal when nurses integrate the parent's expert knowledge of their child into the plan of care for that child. Optimal care includes the delivery of safe nursing care that moves the child and family toward established discharge criteria in a timely and satisfactory manner. The first grounded theory study demonstrated the process by which parents of technology dependent children attempt to communicate the care of their child to nurses when the child is hospitalized (Giambra, et al., 2014). The Theory of Shared Communication which emanated from the study has as its foundation parent and nurse perceptions of their own expertise and respect for the other's expertise. Parents, who perceived they had expertise, respected the nurse's expertise

and engaged in shared communication were found to state involvement in the following behaviors: questioning, listening, explaining, advocating, verifying understanding and negotiating roles. The second grounded theory study explored the parent's use of these concepts during a child's admission thus attempting to confirm the propositions of the theory, validity of its concepts, linkages of presumed relationships between the concepts and attainment of the outcome. The study also attempted to extend the Theory of Shared Communication by adding the nurse's perception of the process of communication with parents of hospitalized technology dependent children. Understanding the process of communication between parents of technology dependent children and their nurses will lay the foundation for future research to understand how nurses can best care for complex chronically ill children and their families.

**Chapter Two: The Theory of Shared Communication: How parents of technology dependent children communicate with nurses on the inpatient unit**

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Dr. Sabourin contributed to the design and data analysis, and provided substantive and critical advice for this study.

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Dr. Buelow contributed to the provided substantive and critical advice for this study.

## **Abstract**

Care may be compromised for hospitalized technology dependent children if nurses do not communicate with parents to include their knowledge in the child's plan of care. A qualitative study using grounded theory methodology was undertaken to identify parental perceptions and experiences of communication with nurses. The Theory of Shared Communication was the result of this study and includes questioning, listening, explaining, advocating, verifying understanding and negotiating roles to achieve the outcome of mutual understanding of the child's plan of care. Nurses should be aware of parent perceptions about communication when working with families to optimize the care they provide.

## **Introduction**

Parents of hospitalized technology dependent children become experts in providing their child's care at home. When technology dependent children are hospitalized their care may be compromised if nurses do not include the parents and their knowledge in the plan of care for the child. Safe, efficient, and optimal care for a technology dependent child depends on shared communication between the parents and nurses to create mutual understanding of the plan of care for the child.

## **Significance**

Technology dependent children currently fall under the distinction of children with special health care needs. The most recent published report focused on technology dependent children as a separate group in the United States was in 1987. At that time, the estimated number of technology dependent children was 18-30 thousand (Office of Technology Assessment, 1987). As healthcare has advanced, the population of children who are technology dependent grew. The Office of Technology Assessment (1987) defines technology dependent children as those who utilize a medical device to compensate for the loss of a vital bodily function and who require substantial and ongoing nursing care to avert death or further disability. Children may be dependent on one type of technology, such as an insulin pump, or more than one, such as a tracheotomy, ventilator and feeding tube.

Technology dependent children are most often cared for at home by their parents who are frequently the sole providers of the child's ongoing nursing care (Rempel & Harrison, 2007; Wang & Barnard, 2004). Research has shown that parents caring for technology dependent children experience financial burdens (Looman, O'Conner-Von, Ferski, & Hildenbrand, 2009), high risk for clinical depression (Toly, Musil, & Carl, 2012), fears of harming their child if they make a mistake (Bowie, 2004), disrupted home life (Kirk, Glendinning, & Callery, 2005), and

difficulty establishing trusting relationships with professional care providers (Avis & Reardon, 2008).

Children with special healthcare needs, of which technology dependent children are a subset, are more frequently hospitalized than children without special healthcare needs (Newacheck & Kim, 2005; Henry, 2008). Often, one or both parents stay with the child during the child's hospitalization. Given the complexity of care needs of these hospitalized children, parents must clearly communicate their routine care as well as the nuances with the nurses, to ensure the provision of excellent, individualized care for their child (Avis & Reardon, 2008; Reeves, Timmons, & Dampier, 2006).

The purpose of this study was to systematically analyze the perceptions of parents of technology dependent children as they relate to inpatient nurses to identify a theory explaining the process of nurse-parent communication.

### **Review of Literature/Background**

For more than two decades, nurses have recognized caregivers of chronically ill family members become experts in their care. Thorne and Robinson, (1988b) found in their landmark research that after caring for a chronically ill loved one, caregivers “developed numerous competencies with regard to illness management in the context of daily living” (p. 784). These findings were echoed by others who found parents of technology dependent child are expert in the care of that child; that is they provide safe care including monitoring, assessing and interpreting their child's signs and symptoms, problem solving issues that arise and making decisions about the care provided (Buford, 2005; Kirk, et al., 2005; Mullen, 2008; Reeves, et al., 2006; Shields, Young, & McCann, 2008; Sullivan-Bolyai, Sadler, Knafel, & Gilliss, 2004). Several authors (O'Brien, 2001; Kirk, et al., 2005; Reeves, et al., 2006) found in their respective qualitative studies regarding the perceptions of parents of technology dependent children that

these parents struggled, but eventually were able to manage the child's care needs despite having different types and level of knowledge than the nurses from whom they had learned the care; knowledge that also included parenting and ways to maintain a functioning family.

Thorne and Robinson (1988a) developed the theory of Guarded Alliance which describes the relationships of healthcare providers with chronically ill patients and their families.

According to the theory based on their research, as these patients and families engage with healthcare providers, they traverse three distinct stages; naïve trust during which they trust the provider unequivocally, disenchantment in which trust in the provider is shattered and finally, trust in the provider is reconstructed resulting in guarded alliance. Having worked with their child's providers for some time and establishing expertise about the care of their child, parents of technology dependent children may be in the final stage, guarded alliance. As such, the pattern of relationship they form with the nurse may be influenced by their satisfaction with and the efficacy of communication with that nurse in addition to their own perception of competence. However, the theory of Guarded Alliance does not describe or predict the process of communication between healthcare providers and chronically ill patients and their families.

Healthcare providers, including nurses must allow the parent to express their expertise and communicate with them about the child's baseline care, usual reactions to care and recent changes in addition to assessing the child's current care and any needs the child or family may have (Avis & Reardon, 2008; Godshall, 2003). Fisher and Broome (2011) noted that respectful communication between parents of hospitalized children and healthcare providers could "create an optimal environment for care" in their qualitative study of physician, nurse and parent communication on an inpatient pediatric hematology and oncology unit (p.66). Carter, Cummings and Cooper (2007), found in their appreciative inquiry study to determine best practices for working with families of children with complex needs that the quality of



communication shared between the parents and healthcare providers is one of the top ten keys to best practices.

High quality communication between healthcare providers and families may avert serious adverse events for the patient. Case studies documenting near miss medical errors, those that are discovered before patient harm results, have shown that family knowledge of the patient is crucial for optimal care (Campbell, 2004). The case of Josie King (Greenhouse, Kuzminsky, Martin, & Merryman, 2006), provides a startling account of how medical errors and lack of communication between the parent and the healthcare providers led to the death of this 18 month old girl. In 2012, The Joint Commission launched its “Speak Up” Initiative in an effort to help families become aware of their rights and ultimately receive safer, better, more satisfying care. The Joint Commission advocates for patients and their families to expect their opinions will be heard, be informed about the care they should expect and receive treatment with respect and courtesy, among other things. Shared communication between the family and healthcare providers may ultimately improve the safety of the care given to the child and the parent’s satisfaction with the child’s experience in the hospital.

Parents are known to be more satisfied when they are able to communicate about their hospitalized child’s care. In the United States (U.S.) a randomized controlled trial of 166 parents of hospitalized children on a pediatric service demonstrated significant increases in parent satisfaction with all aspects of care when a nurse responded to parental questions and explained laboratory results if necessary (Maisels & Kring, 2005). A descriptive study of 195 parents of acutely ill children found positive correlations between physician and nurse use of patient-centered communication behaviors and parents’ satisfaction with care and communication in a large U. S. children’s hospital (Wanzer, Booth-Butterfield, & Gruber 2004). In another descriptive study, parents of 300 hospitalized children on a pediatric unit in a Danish

hospital found parents' satisfaction with their child's care was dependent upon the perceived quality of communication with both physicians and nurses (Ammentorp, Mainz, & Saybroe, 2005). Each of these studies employed a different satisfaction survey to study the relationship between parent satisfaction and provider communication hindering direct comparison of results.

Despite the importance of good communication between nurses and parents of hospitalized children, there have been no studies to date that reveal the process of parent-nurse communication or its impact on the care of the child. Therefore, this study was undertaken to determine the process of parent-nurse communication from the perspective of the parents of technology dependent children who have been hospitalized.

## **Method**

### **Study design**

In order to uncover the nuanced nature of the communication relationship between parents of hospitalized technology dependent children and their nurses, a grounded theory approach was used for this study. Grounded theory is a qualitative study design first described by Glaser and Strauss (1967). The method is designed to develop theory which is systematically constructed and thus, grounded in the data. It is generally used to analyze a social process. During grounded theory the data collection and analysis are done simultaneously using the constant comparative method to discover the concepts within the social process (Charmaz, 2006; Coyne & Cowley, 2006; Glaser & Strauss, 1967). Theoretical memos are written to capture the researcher's synthesis of the data being analyzed. The purpose of grounded theory is to provide clear categories and hypotheses that fit the data, explain the behavior of interest, can be easily understood, are useful, relevant, meaningful, and can be verified through empirical research. The end result is either the discovery of a core concept or a theory of the social process

(Charmaz, 2006; Glaser & Strauss, 1967). Through application of the grounded theory method, the researcher was enabled to generate theory about both a social process and the meanings that individuals make through their interaction with one another while engaged in the process of communication.

### **Sample recruitment and setting**

Approval for the study was granted by the Institutional Review Boards of the children's hospital where subjects were recruited and the academic institution at which the first author was enrolled as a PhD student. Potential participants were recruited using a purposeful selection method and snowball sampling until saturation of the data was reached. English speaking parents 18 years of age or older, of technology dependent children ages 4-15 years who had been hospitalized in the last year and responded to a flyer were asked to participate by the researcher. For the current study, technology dependent children were identified as those who are dependent upon a feeding tube (nasogastric, nasojejunal, gastric, or gastrojejunal tube), oxygen, a ventilator, a tracheotomy tube or an insulin pump, including those who are dependent on more than one type of technology listed. Flyers were placed in the following areas in a large Midwestern children's hospital; the surgical waiting area, five inpatient units each with a large population of technology dependent children, and the waiting areas of two outpatient clinics that serve technology dependent children and their families. Data were collected from 11 participants in the form of audio-taped semi-structured interviews conducted either face to face in the setting of the participants choosing or via telephone. Two of the participants requested a face to face interview in a conference room at the hospital, 2 requested face-to face interviews in their child's hospital room and the remainder requested interviews via telephone. Field notes were recorded by the researcher during and after each interview to

capture additional information observed about the interview and the researcher's theoretical memos. Consent was implied by the completion of the interview.

### **Procedure**

All parents who responded to the study flyer and consented to be interviewed were asked for best dates and times and where they would like the interview to take place. An appointment for each interview was mutually decided upon by the researcher and parent. At the beginning of the semi-structured interview, all parents were asked a few demographic questions to determine the sample characteristics (see Table 1). While not all of the participants were the biological parent of the technology dependent child, they will all be referred to as parents throughout the remainder of this article. Three of the participants lived outside of the regional area generally served by the local children's hospital, and provided information about communication experiences with nurses at more than one hospital. After the demographic questions were completed, the researcher asked the parent to describe the story of their technology dependent child to set the context. Next, the parent was asked a variety of questions regarding communicating with the nurses while the child was hospitalized (see Table 2). The parent was encouraged to give examples of communication and interactions with the nurses. The researcher followed the lead of the parent and redirected or asked follow up questions as needed to elicit rich detail. Interviews lasted approximately 20 to 50 minutes each. The researcher recorded field notes throughout and just after each interview. A gift card in the amount of \$25 was provided to the participants in recognition of their time provided during the interviews. Participants were asked for permission to contact them again for clarification of their statements if necessary.

## **Data analysis**

Saturation of the data appeared to be achieved. Constant comparative analysis was used to code and sort the data (Charmaz, 2006; Coyne & Cowley, 2006; Glaser & Strauss, 1967). Data were coded by the researcher as they were collected through the use of field notes taken at the time of the interview, immediately following the interview and when the transcribed audiotapes were received. The transcripts were de-identified to ensure confidentiality. The audio-tapes were replayed by the researcher while reading the transcription to assure accuracy of the transcription and to review the content as a whole in relationship to the other interviews conducted. Theoretical memos were also kept by the researcher to document the analysis while it was ongoing. As subsequent data were collected, it was compared with previously collected data and open coding including line by line, focused and axial coding, was used to discover the emerging categories. The co-authors reviewed the coded transcripts and emerging categories. The categories were then analyzed for emerging thematic ideas. The categories and thematic ideas were discussed among the authors until consensus was reached. An audit trail was documented to record the decisions made regarding the analysis of the data and theory development (Lincoln & Guba, 1985). Member checking was also done with 3 participants to ensure confirmability. The thematic ideas yielded the social process of shared communication between the parents of hospitalized technology dependent children and the nurses who care for them. From the categories and thematic ideas, a model was developed to illustrate the communication process between parents and nurses (Figure 1). The Theory of Shared Communication is a product of this work.

## Findings

### The Theory of Shared Communication

As a result of this study the above mentioned model emerged with multiple elements rather than a core concept. As can be seen, the model encompasses 3 primary components; the antecedent inputs of respect for own and each other's expertise, communication behaviors including acts (questioning and listening), functions (explaining and advocating) and outcomes (verifying understanding and negotiating roles), and the relational outcome, the degree of mutual understanding of the child's plan of care. As a result of interviews with parents and analysis of their responses a number of communicative behaviors were identified. These behaviors, the antecedent condition and relational outcome are illustrated in the model of the Theory of Shared Communication.

#### **Inputs: Respect for own and each other's expertise.**

The antecedent inputs to the parent-nurse communication process include each individual's perception of their own expertise as well as their respect for each other's expertise. Parents who proffered stories of shared communication with nurses described their own expertise regarding the child's care as well as their level of respect for the nurse's expertise.

All of the parents who participated in this study perceived that they had significant expertise in the care of their technology dependent child. This expertise gave them confidence to communicate openly with the nurses to ensure the best care for their child. Parents who described situations in which they felt there was a lack of shared communication voiced concerns about either their own expertise, the nurse's expertise, or the nurse's perception of parent expertise regarding the care of the child. Despite years of experience caring for the complex needs of her child, one parent, when describing a situation in which communication with the nurses did not enhance the care of her child, felt that she herself must not know

enough and her lack of expertise was the reason for the lack of shared communication she experienced. This parent's lack of respect for and confidence in her own expertise at the time seemed to influence the way the nurses communicated with her about her child's care.

Without both parent and nurse perception of their own expertise and respect for one another's expertise, shared communication was not possible. One mother who experienced both situations related the following story.

Tatiana can't be on her back because of her surgery she has to lay on her side, from side to side. And the nurse had her on her back when I came in the room and she was really uncomfortable and I said, "Oh you're hurting (Tatiana), she has to come off of her back." And this particular nurse told me she could lay on her back regardless and we went round about for about 5 minutes, until I basically had to tell her to get out. She checked the orders and saw that she should not have been on her back. I haven't seen her since. I mean I know she is still here, but they probably put her somewhere else since they know I'm still up here. That kind of upset me a little bit. All in all they listen, mostly they listen. And how can I put it, the more mature nurses are more subject to listen to you than the younger ones. The younger ones act like because they are a nurse that we as parents don't know. Not true.

Parents often expressed extreme frustration when their expertise was discounted by the nurses. These parents know that they have expertise to share about the care of their child and they are anxious to have their expertise respected. The parents appreciated nurses who asked for and used their expertise. They expected the nurses they interacted with to have expertise as well. A mother who has been caring for her technology dependent child at home for over a decade described her frustration in the following example;

Hospital B, they would care less. They'll try to get, they really make me feel stupid, in a way like I'm bothering them. Because they want to tell me what to do and how it's going to be done. And then it always ends up to be I knew best, they were wrong, and I knew right. And finally the pediatrician, who she's seen since she was little, and it's for regular kids also, but they'll see her for little check-ups and stuff. They'll ask me, they're like "you know her best, does this hurt?" You know, that's what I appreciate.

Respect for each other's expertise was described as enhancing communication with the nurses by many of the parents. Every parent interviewed expressed that when they felt they

lacked knowledge or expertise about some aspect of their child's care, they did not hesitate to ask questions of the nurse. In this way, they showed respect for the nurse's expertise and improved their own understanding and expertise regarding the care of their child. Asking questions was very important from the perspective of these parents.

### **Communication Acts.**

Within the context of communication, six categories emerged from the data and appear to be nested within one another. The first two describe basic acts of communication regarding the giving or receiving of information; asking questions and listening.

#### ***Questioning:*** "Never be afraid to ask questions".

Parents asked questions to either describe the child's care needs to the nurse or to learn about the care of their child from the nurse. Parents were emphatic in their advice to other parents of technology dependent children, "never be afraid to ask questions." They found this to be the most beneficial way to communicate effectively with the nurse. Some parents described asking questions in order to learn more about the care of their children so they could be in concert with the nurse regarding the care of their child. This was uncomfortable for some but they felt it necessary.

When I kept asking the same questions over and over that's when they went in and brought different people to explain it to me until I got it right. Until they knew I was comfortable and understood. Which it took me a while, it was a ego thing I think. It took me a while to finally say forget it, and I asked what I thought was stupid, things I should have already known. And once I did we was all on the same page and it was so much easier. But they didn't make me feel stupid for it.

For other parents it was also a way to verify that the nurses understood what they had communicated about the child's care. While asking questions, parents who were less sure of their own expertise, and valued the nurses' expertise tested their knowledge against that of the nurses. As one mom stated;



Just ask a lot of questions, make sure their (the child's) needs are met. Or if a nurse is not doing what, something, maybe the way I don't like. I'm not sure if I like it that way, I ask why she's doing it that way, or why we need to do it that way. Or if I'm possibly doing it wrong, just to try to learn.

An information exchange of this sort could also lead to role negotiation which will be discussed later.

Other parents insisted on having the nurse ask questions of the parent about the child's care. This not only allowed the parent to communicate their expertise to the nurse, it also allowed the parent to determine the expertise of the nurse. Once the expertise of each party was established, dialogue was opened between the parent and nurse and shared communication flourished as explained in the following example:

Well, upon admission, being admitted into a room, a lot of questions are asked by the nurses just to get to know Tiffany and what her routine is as far as eating. So, there will be some back and forth there between us as parents and the nurse, communicating to how we feed Tiffany.

The parents clearly expected the nurse to demonstrate their expertise by answering questions appropriately. They also demanded respect for their own expertise by asking questions of the nurse.

***Listening:*** "Listen to me".

Parents of technology dependent children wanted their expertise to be heard. They appreciated being listened to because they felt they had something of value to offer. When speaking of communicating with the nurse, one mom stated, "I want them to listen to me and let me finish what I'm trying to say because if I don't get it all out there right on top of my mind, then I'm leaving something out." Parents became frustrated and felt the care provided by nurses who didn't listen was less than optimal. When describing how her daughter's treatment went wrong, one mother said, "(The nurse) maybe didn't listen to us well enough to consider every aspect of her diabetes." Another mother thought the nurses were listening but other healthcare providers were not. She attributed good care for her son to the fact that "I felt like

the nurses were listening to us and they kept going to the residents.” Because the nurses listened, communication was enhanced and what started out to be a serious safety event was subsequently resolved. Some parents described using listening as a way to learn new information or have information about the care of their child clarified by the nurse. Parents also described using listening as a way to verify that the nurse had heard what they had to say and understood the information. In this way, listening was often associated with asking questions and explaining as well as verifying understanding.

### **Communication Functions.**

The first two categories, the communication acts of questioning and listening are also necessary for the next two categories which are functions of communication; explaining or sharing information and advocating or persuading.

***Explaining:*** “I just tell them what it is”.

Explaining was used by these parents to impart their knowledge about their child’s care to the nurse and also to verify the nurses’ understanding of that knowledge. When asked to describe how she told the nurses about her child’s care, one mom stated, “Verbally first, then if they are not quite catching what I’m saying, if I’m not explaining myself right, I’ll show them something, and then they can see it and get it.” Another mother provided the following scenario that sums up the function of explaining.

Well, I always bring a lot of information with me about his care because he’s very complex and his system never matches reality, especially on medications, since he’s on so many. I always have it spreadsheeted by morning, noon and night so there’s no question on the way that we do it vs. the way the system says. That’s the first thing I do to communicate his care is I always turn in his medication list and then they go into the system to look and it is never the same. So, that’s one way that we communicate his care is through that. Then, I basically just explain it. Verbally go through everything that it is that he requires, his needs. And when they have questions on theory vs. reality, I just say, for example, one of his medications is time-released and we crush it. That does not compute. So, we say we have to crush it, it’s part of the instructions of the neurologist. This past time they asked if it was okay they didn’t crush it if

they came up with a different type. And I said actually that is a problem because of the way this seizure drug interacts with the two from France. So, they ended up calling the neurologist and he said crush it. At least they could do their job. At least they asked. So I just communicate it and I'm always there watching.

In this example we can see how explaining is tied to asking questions and listening as these two communication acts are necessary for the parents to not only explain their child's care but to ensure the nurse understands the care enough to incorporate it as part of the child's plan of care. When these parents felt unsure of the nurse's understanding, and worried that their child's needs may not be met they turned to advocacy.

***Advocating:*** "Be vocal".

"Being a parent, grandparent, we are the children's best advocate". When advocating for their child, the parent communicated with the nurse to ensure their child received safe, correct, and appropriate care. The parents described continuing to advocate for their child until they were confident that they and the nurse both had the same understanding of what the child needed and how best to provide that care. One mother stated, "But, yeah there are times when I have felt like I really had to step in and say she's not the property of the hospital, she's my baby, you're not going to do this."

Parents also noted that advocacy increased with their perception of their own expertise.

I think the more experience you have I think the easier it is to advocate and not question yourself as much. Yeah. You just have to be educated on the whole process... At the very beginning, maybe I never knew anything about the process, so the more I learned the better advocate I feel like I can be.

As this last quote shows, advocacy is entwined with asking questions and listening as well as explaining.

### **Communication Outcomes.**

Each of the previously discussed communication acts and functions also form the foundation for the outcomes of communication and the last two categories that emerged from the data; verifying understanding and negotiating.

#### ***Verifying Understanding:*** “I’m always watching”.

Every parent interviewed described how they verified the nurses’ understanding of their child’s care. As one mother said, “Well, they’ll verbalize their understanding of what we’re telling them. And then we will visually see if they are doing something right or wrong.” The parents needed to ensure their child received optimal care. The parents’ vigilance is evident in their descriptions of how they know if the nurse understood what they told them.

They (the nurses) typically repeat it and then if they don’t repeat it right then I explain it again. Then once it’s been repeated and often times I’m standing over them as they’re putting it into the system just to make sure we are all on the same page, and then at the same time it’s one thing for them to repeat it, then I watch. Are the right meds being pulled, are you using the right tubes, how much water are you using, how much formula are you using, what size?

It’s not just a repetition or summary of what you’ve said it’s also repeating it in slightly different format. Because that requires a higher level of thinking or comprehension in order to not just repeat but to add to or to think of it in a different way.

Nearly every parent interviewed stated they always stayed with their child while hospitalized in order to maintain their vigilance. One mother related that she did not even go to the cafeteria if she did not feel confident in the nurse’s expertise with her child. These parents were ever ready to communicate with the nurses. One mom stated, “I just always felt more comfortable staying up with him, even though I felt they were very competent.” Another, “Well, I always stayed in hospital 24/7 with her. And so I would always be there to describe what our routine at home was.”

Parents felt very responsible for making sure the care their child received was optimal. Their need to be vigilant was an expression of that feeling of responsibility. They also understood that while their child was hospitalized, they needed to share the responsibility for the care of the child.

***Negotiating Roles:*** “We usually want to do it ourselves”.

The parents felt ultimately responsible for their child’s care however, they recognized that the nurse also had a role to play in that care. As one mother stated,

In fact, whenever she was hospitalized whatever of her care I could do, I did. I mean, naturally they took her vital signs and did her monitoring but as far as all of her bathing and feeding, you know everything else, I did.

The parents expressed appreciation for being asked to be involved in the care of their child. “They’re (the nurses) just so good about that too, going down the list of what’s needed and kind of confirming how much involvement we want them to have.”

Through the lens of the experiences related by these parents, we can see that the communication acts of asking questions and listening are foundational for the communication functions of explaining and advocating. These functions are in turn necessary for the communication outcomes of verifying understanding and negotiating roles. Taken together, we can see that this process is not linear but the components (categories) are inter-related and entwined. While all may not be necessary to achieve shared communication with the nurse, layers of communication behaviors appear to be essential to the process of achieving shared communication.

**Relational Outcome – Mutual understanding of the plan of care.**

The relational outcome of the social process of shared parent-nurse communication is the degree of mutual understanding of the child’s plan of care. It appears that when parents perceive they have communicated through this process, the end result is shared communication

and this phenomenon is important to ensure their child's optimal care. Shared communication apparently results in a high degree of mutual understanding of the child's plan of care from the parent's perspective. When shared communication is not achieved, parents believe they have a different understanding of the plan of care than do the nurses. One parent felt that true shared communication amounted to cohesiveness between the parent and the nurse. Another described shared communication as working hand-in hand with the nurse.

I want communication to be more than just a ...divulging information at me to a dialogue with me. And an understanding that I respect your knowledge as a nurse is far beyond mine, mine is the G-tube part, but that the, truly I don't understand, sometimes I don't even know how sick Andrew is. I just expect you to respect me as a mom and to not just spit information at me but to incorporate me into the care or the communication about my son. A lot of it just comes down to the plan of the day, the plan of care. What they foresee or you know sometimes that plan of care involves me, you know. Really just telling me what they're doing, when they're doing it, and why they're doing it. That's really what's important to me.

### **Discussion and implications**

The Theory of Shared Communication was the result of this grounded theory study. It was clear from the parent interviews that parents believed they needed to engage in some or all of the communication behaviors in order to reach shared communication with the nurse. It also became clear that parents wanted nurses to engage in some of these behaviors as well; specifically questioning, listening, explaining and advocating to achieve mutual understanding of the child's plan of care. From the parent's perspective, when nurses engaged in these behaviors, parental respect for the nurse's expertise was enhanced and the parent felt respected as well. This process seemed to be ongoing throughout the child's hospitalization. Parents described the opportunities to engage in shared communication with the nurses at admission, daily during interactions at the child's bedside and especially when there was a change in the child's plan of care. Parent-nurse communication is frequent when a child is hospitalized and as such, the experience demands examination.

## **Relationship to communication theory**

The phenomenon of parent-nurse communication was found to be aligned with the perspective of Relational Dialectics Theory (RDT). RDT is a non-prescriptive theory for understanding meaning making within relationships through communication. The core premise is that “meanings emerge from the struggle of different, often opposing discourses,” or worldviews as expressed by the speakers (Baxter & Braithwaite, 2008, p. 351). Relational dialectics theory posits that trust is necessary for the relationship inherent in a dialogue. It was apparent from our interviews that the parents felt mutual trust and respect was necessary for shared communication to take place between themselves and the nurse. Dialectical tension is also a necessary component of dialogue according to RDT (Baxter, 2011). The dialectical tensions between the parents and nurses as described by the parents revolved around the care of the child. These tensions included the parent’s expertise versus the nurses’ expertise in many cases. Tension between the parent’s wishes for the child and the nurse’s wishes were also evident. Watson, Kiekhefer, & Olshansky (2006) found a similar dialectic tension between parents and providers needs when describing the communication between parents of special needs children and their primary providers. The same authors also found tension between parents wanting to know more information about what to expect for their child’s future versus concentrating on the here and now. Likewise, this tension of uncertainty about the child’s day to day and long-term chronic illness course was described by several authors who studied the perceptions of parents of medically fragile children and those with technology dependence (Henry, 2008; O’Brien, 2001; Rempel & Harrison, 2007; Tommet, 2003). Many parents in the current study also expressed uncertainty in the context of learning new information. Nearly all of the parents acknowledged that they may not know everything they need to about their child’s care and were more than willing to learn from the nurses. This seemed to be a tension of

knowledge uncertainty; having knowledge versus needing more. How this knowledge tension impacts the dialogue between parents and nurses is an area for further research.

### **Relationship to nursing theory and healthcare research**

The antecedents of the Theory of Shared Communication found in this study, respect for own and other's expertise, mirror the core concept of reciprocal trust in the theory of Guarded Alliance which resulted in effective care and was necessary for satisfying relationships between chronically ill patients and their families and their healthcare providers in Thorne & Robinson's study (1988b). Reeves, et al., (2006) found parents of hospitalized technology dependent children felt more empowered and confident to express their views as they became more expert in their child's care. It appears that trust as well as respect for and perception of expertise are necessary for effective and satisfying communication between patients, families and healthcare providers. Empirical studies to determine the effects of trust and expertise on effective communication between parents and healthcare providers and the resultant patient outcomes are needed to inform intervention studies of the future. The results of these studies will help nurses learn ways to improve their communication with and care they provide to patients and families.

The parents in our study described asking questions of and listening to the nurses in order to clarify and enhance their own understanding of their child's care. Patients in a grounded theory study by Larsson, Sahlsten, Sjostrom, Lindencrona, and Plos (2007) also expressed the importance of asking questions to understand the care provided, participate in their own care, and plan for future care and needs. Similarly, parents of children with developmental disabilities were found to ask questions to determine provider expertise and to gather information about their child's disability and care (Watson, et al., 2006). By asking questions about their child's care, parents focus on optimizing the child's plan of care not only



for the duration of the hospital stay, but also in anticipation of their return to the home environment where the parent continues as the expert in providing safe, optimal daily care for their child.

When describing the constructs explaining and advocating, several parents in the current study expressed their belief that the nurse's experience played a role in the nurse's openness to the parent's explanations and the parent's need to advocate for their child. These parents also voiced the conviction that the more mature, educated or experienced a nurse was, the more likely they were to respect the parent's expertise and partner with the parents to plan the child's care. Reeves and colleagues (2006) had similar findings of increased parental comfort with and feelings of being respected by experienced, competent nurses caring for their technology dependent child. Exploration of the relationship between nurse's education, maturity, experience and willingness to engage in shared communication might uncover factors that influence the nurse's ability to communicate with parents.

The parents we interviewed felt they should be providing the everyday care for their child, such as giving routine medications and feedings, changing diapers and comforting their child. Kirk and colleagues (2005) found parent's perception of their role as a parent when caring for a technology dependent child was influenced in part by the complex care they provided for their child. For the parents in the current study, complex care was integrated in their role as parent and this multifaceted role did not stop when the child was hospitalized. Role negotiation between parents of hospitalized technology dependent children and their nurses is therefore an important skill for both parties to develop. Simulation studies may help nurses improve their skills and create best practices for engaging in negotiation with parents.

## **Limitations**

While the results of this study may be transferrable to other populations of families of hospitalized chronically ill children, the generalizability of the findings of this study are limited by the small sample size and the relative homogeneity of the sample. Fathers and grandfathers of technology dependent children may have different perspectives regarding the process of communication with nurses as their worldviews likely differ from those of the mothers and grandmothers. The male perspective would add to the body of evidence on this topic. Also, most of our participants experienced hospitalizations with their child at the study setting. The few that had experiences at other hospitals were able to make comparisons among those experiences and this would be an important area for future research. Additionally, gathering the perspectives of parents from different regions of the United States as well as from other countries would enhance the credibility of the findings.

## **Conclusions**

The purpose of this study was to identify and systematically analyze the perceptions and experiences of communication of parents of technology dependent children as they relate to and communicate with nurses. The results of this study informed the creation of the Theory of Shared Communication. This theory includes the antecedent of mutual respect for expertise and the inter-related categories of listening, questioning, explaining, advocating, verifying understanding and negotiating roles. While it is not necessary to have all of these components in a dialogue to achieve shared communication, each plays a significant role from the parent's perspective.

Through shared communication, the plan of care for the child is constructed and a mutual understanding of that plan is created through the collaborative relationship that forms between the nurses and parents. Nurses need to be aware of the parent's perception when

working with families in order to enhance communication with the parents and the care they are able to provide for the child. Future research should focus on intervention studies designed to verify the findings of this study and discover the impact of shared communication on parent satisfaction with care and patient outcomes.

The knowledge gained from this study will provide a foundation for future research and begin the process of understanding the phenomenon of shared communication and how it can impact outcomes for children and their families.

### **Chapter Three: An Integrative Review of Parent-Nurse Communication**

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## **Abstract**

**Background:** With advances in healthcare, the population of children who are technology-dependent is increasing and therefore the need for nurses to understand how best to engage in communication with the parents of these children is critical. Shared communication between the parents of hospitalized technology dependent children and their nurses is essential for providing optimal care for the child. The components and behaviors of the parent-nurse communication process which improve mutual understanding of optimal care for the child are not yet known.

**Research Question:** Among parents of hospitalized technology dependent children and their nurses, what communication behaviors, components, concepts or processes improve mutual understanding of optimal care for the child?

**Methods:** An integrative review of both qualitative and quantitative studies was conducted. Key words including communication, hospitalized, nurse, parent, pediatric, technology dependent were used to search databases such as Cumulative Index to Nursing and Allied Health and Medline for years 2000 to 2014. The data regarding the process of parent-nurse communication were extracted as it related to the mutual understanding of optimal care for the child. The data were grouped into themes and compared across studies, designs, populations and settings.

**Results:** Six articles were found that provide information regarding the processes of shared communication among the parents of hospitalized technology dependent children and their nurses. Providing clear information, involving parents in care decisions, trust and respect for each other's expertise, caring attitudes, advocacy and role negotiation were all found to be important factors in shared parent-nurse communication.

**Conclusions:** The results of this integrative review inform our understanding of the parent-nurse communication process. The findings will provide nurses with an understanding of strategies to

better engage in respectful, engaging and intentional communication with parents of hospitalized technology dependent children and improve patient outcomes.

Key Words: Review, Parent, Nurse, Communication, Pediatric, Hospitalized, Technology dependent

## **Introduction and Background**

As healthcare advances and the population of children who are technology dependent grows, the need for nurses to understand how best to engage in communication with the parents of these children also grows. The considerable expertise of the family who cares for their chronically ill, technology dependent child has been well established (Buford, 2005; Kirk, Glendenning, & Callery, 2005; Mullen, 2008; Shields, Young, & McCann, 2008). Children who are technology dependent are considered to have special healthcare needs and as such, frequently require hospitalization (Newacheck & Kim, 2005). These children are usually accompanied by their parents when they are admitted to the hospital. Communication that is shared between the parents of hospitalized technology dependent children and their nurses is essential for the nursing assessment of the patient and family and for the family to convey the usual care and needs of the child. (Caris-Verhallen, Timmermans, & van Dulmen, 2004; Plumridge, Goodyear-Smith, & Ross, 2009).

The partnership which forms between nurses and parents through communication processes is necessary for the provision of optimal care and attainment of best outcomes for the child during the hospitalization. (Avis & Reardon, 2008; Carroll & Dowling, 2007; Greenhouse, Kuzminsky, Martin, & Merryman, 2006; Institute for Patient- and Family- Centered Care, 2010). According to Feeg (2007) this partnership includes parent-nurse communication about the child's needs, the parent's needs and readiness for learning, the parent and child's values and preferences and their impact on the plan of care for the child. The communication processes in which parents and nurses engage to make decisions regarding optimal care of the child is vitally important.

## **Purpose**

The purpose of this integrative review was to discover the evidence regarding factors that are essential for optimal communication between parents of hospitalized technology-dependent children and their nurses, and the effect of communication on their mutual understanding of optimal care for the child. Therefore, the following research question guided this review: Among parents of hospitalized technology dependent children and their nurses, what communication behaviors, components, concepts or processes improve mutual understanding of optimal care for the child?

## **Method**

### **Search strategy and sample of studies**

To discover the evidence regarding communication processes between parents and nurses of hospitalized technology dependent children and the effect of communication on mutual understanding about optimal care for the child, an extensive search was undertaken (see Figure 2). The following search terms were used: child, chronic disease, communication, family, family-centered care, health care personnel or health care provider, hospitalized, medically fragile child, nurse(s), parent, pediatric, nurse-patient relationship, professional-family relations, special healthcare needs and technology dependent. The following databases were searched: Cumulative Index to Nursing and Allied Health (CINAHL), Medline, Communication and Mass Media Complete, and PsychInfo. The search was filtered for English language articles dated from 1/2000-2/2014. A hand search of the reference lists of relevant articles was completed. All research study designs were included to ensure a comprehensive review.

From this search, 420 unique articles were identified. The titles and abstracts were reviewed and 134 articles were examined by the first author in their entirety for relevance to



the concept. Exclusion criteria included unpublished manuscripts, reports of expert opinion, adults, home care, studies of neonates who had not yet been discharged from the hospital, children who did not have a chronic illness or technology dependence, or studies of communication that did not include both parents and nurses. Studies that identified the hospitalized child of interest as one with special healthcare needs or chronic illness were included in this analysis. Six articles were found that provided information regarding the processes of communication among the parents of hospitalized technology dependent children and their nurses.

### **Study evaluation, data extraction and analysis**

The LEGEND system (Clark, Burkett, & Stanko-Lopp, 2009) was used to determine the quality of included studies based on the evidence levels as described in Table 3. The quality level of each study is included in Table 4. From the included studies, data were extracted about sample characteristics, method, and the communication behaviors used by either parents, nurses or both, to communicate with each other about the child's plan of care. Additional categories extracted included aspects of the process of parent-nurse communication; related antecedents, components, concepts and the outcomes of mutual understanding of optimal care for the child. The data were entered into synthesis tables (Table 4), grouped into themes and compared across studies, designs, populations and settings (Whittemore & Knafl, 2005). Themes that were common among the six studies are reported in this review.

## **Findings**

### **Study Characteristics**

Shared communication between nurses and the parents of hospitalized technology dependent children has been assessed in several qualitative, one cross sectional and one

descriptive study. The studies included a variety of designs, settings and populations and ranged in year of publication from 2001-2014 (See Table 4). Three studies included in this review reported only the perceptions of parents, one reported only the perceptions of nurses and two reported both. The reviewed studies included a total of 253 parents and 105 nurses. Two studies were completed in Australia, three in the United Kingdom, and one in the United States. Most of the investigators were nurses, one was a professor of communication and the authors of one study did not list credentials but worked in the Child Health Department of their trust in the United Kingdom.

### **Synthesis**

Both qualitative and quantitative studies have been conducted to describe the behaviors, components, concepts or processes associated with parent-nurse communication from the perspectives of both parents and nurses.

#### **Provision of information.**

Providing clear information regarding the plan of care for the child was the most often noted behavior associated with parent-nurse shared communication that improved mutual understanding of optimal care for the child (Avis & Reardon, 2008; Giambra, Sabourin, Broome, & Buelow, 2014; Shields, Hunter, & Hall, 2004; Shields, et al., 2008). This included telling the parents not only everything being done for the child, but also the reasons for the care (Shields, et al., 2008). Studies found that both nurses and parents believed that parents should have an active role in decisions about their children's care. In the study by Margolan and colleagues (2004), parents expressed the importance of being fully involved in the discharge process for their hospitalized technology dependent child. Giambra and colleagues (2014) also found parents wanted to verify that the information they had provided about the child's care was understood by the nurses.

### **Parent-nurse relationships.**

The creation of parent-nurse relationships was found by several authors to be important to both parents and nurses (Avis & Reardon, 2008; Ford & Turner, 2001). Along with the creation of the relationship, trust and respect for each other's expertise were found to be important for those relationships (Avis & Reardon, 2008; Giambra, et al., 2014; Ford & Turner, 2001, Shields, et al., 2004). Shields and colleagues (2004) found trust to be the most important need expressed by both parents and nurses in their study of perceived parental needs among children hospitalized in England.

### **Emotionally supportive behaviors.**

In addition to positive communication behaviors, nurses' caring attitudes including compassion, empathy, immediacy and kindness were found to positively impact parental and nursing perceptions of parent-nurse communication (Avis & Reardon, 2008). Providing emotional support, such as the ability to handle outbursts of feelings, was a related theme that was found to be important for nurse-parent communication (Avis & Reardon, 2008; Margolan, et al., 2004). Sensitivity to, and understanding of, parental needs was also found to be important (Shields, et al., 2004, Shields, et al., 2008). Nurses with caring attitudes who are sensitive to parental needs may convey emotional support for parents through the behaviors they demonstrate. One strategy in particular that was found to be important was nurses listening to parents (Giambra, et al., 2014). In addition to listening, parents wanted to be allowed by nurses to ask questions, have them answered, and give suggestions for and explanations of their child's care (Giambra, et al., 2014, Shields, et al., 2004). By asking for suggestions, nurses would be able to learn about the child's care and needs from the parents, which was seen as important for quality nurse-parent communication (Ford & Turner, 2001).

### **Demonstration of competence in care.**

After providing information about their child's care, parents want to see nurses demonstrating high quality care to ensure their understanding of the information imparted (Giambra, et al., 2014; Ford & Turner, 2001). Nurses' ability to demonstrate expertise in caring for the child, as well as their ability to educate the parents, helped build trusting relationships according to both parents and nurses (Giambra, et al., 2014; Ford & Turner, 2001). For most parents in these studies, observing the nurse providing care influenced their feelings of the nurse's competence and expertise with their child.

### **Advocating for optimal care.**

Advocacy was an area of importance among the studies for improving mutual understanding of optimal care for the child through the shared communication process. Parents expressed the need for both parties to engage in advocacy. Both parents and nurses believed parents should have the opportunity to advocate for their child, and express their concerns and questions without judgment (Giambra, et al., 2014, Shields, et al., 2004, Shields, et al., 2008).

### **Negotiation of care roles.**

Both nurses and parents also articulated the importance of role negotiation or mutual understanding of the expectations of each around care provision for the child (Avis & Reardon, 2008; Giambra, et al., 2014; Margolan, et al., 2004). There was no clear description in this literature about what the differences are between the care parents are expected to do for the child and nursing care. It is likely that parent's perspectives of the care they can and should provide for their child will be different from that of nurses just as their perspectives of shared communication may differ.

### **Additional factors influencing parental perception.**

Avis and Reardon (2008) found two themes that had a bearing on the parent's perspective of communication with the nurse: prior experience of hospital care and perceptions of nurses and nursing. Parents of hospitalized technology dependent children often have multiple experiences with hospital care, many times at different institutions. Their perceptions and expectations of parent-nurse communication are influenced by those prior experiences. Additionally, those experiences play a role in their perceptions of nurses and nursing which in turn can color their views of communication with nurses. The impact of past experiences on present communication was also discussed by Ford and Turner (2001) and Giambra and colleagues (2014). Parental perceptions regarding nurses and nursing may impact the respect and trust parents have for the nurse caring for their child when hospitalized.

### **Limitations of the studies reviewed**

Most of the studies were high quality (quality level a), however, some limitations were found. Recall bias was a possibility noted in two studies as parents were asked to remember communication with nurses from a previous hospitalization (Avis & Reardon, 2008; Giambra, et al., 2014). Although the quantitative studies by Shields and colleagues (2004 & 2008) did not achieve the number of participants indicated in their power analyses, however, many findings achieved statistical significance. All of the qualitative studies had very small sample sizes (Avis & Reardon, 2008; Ford & Turner, 2001, Giambra, et al., 2014; Margolan, et al., 2004). However, each qualitative study was conducted with a very specific population and findings are not intended to be generalizable across settings. Since only published studies were included in this review, a publication bias exists. Variability in the study designs, methods and data analysis limits the ability to directly compare findings. The themes presented here, however, were found across studies implying their relevance to the overall concept of the process of communication

between parents of hospitalized technology dependent children and their nurses and its effect on the mutual understanding of optimal care for the child.

### **Discussion**

The literature reviewed provided information to help answer the question upon which the integrative review was based; among parents of hospitalized technology dependent children and their nurses, what communication behaviors, components, concepts or processes improve mutual understanding of optimal care for the child? Both the qualitative and descriptive articles included identified experiences, attitudes and behaviors that are relevant to the process. No single study has described the process of shared communication between parents and nurses in its entirety. Based on the synthesis of the included studies, several points bear discussion, such as trust in nurse-parent relationships and the influence of past experiences on those relationships.

In the studies reviewed, the creation and development of parent-nurse relationships was influenced by both the parent's and nurse's perception of each other's expertise, respect for one another, and trust in one another. Parental perceptions were also influenced by their prior experiences, as well as their attitudes regarding nurses. Technology dependent children are hospitalized more often than their healthy counterparts (Wise, 2004); therefore, their parents have many experiences upon which to base their attitudes about nurses and expectations of the care they will provide. Past communication experiences can be a powerful influence on current and future parent-nurse communication (Baxter, 2011). The relationship between nurses and parents is an essential component in the care of the child, and poor communication can have a dramatic impact on the outcomes for the child, including safety and satisfaction (Greenhouse, et al., 2006; Maisels, & Kring, 2005).

Thorne and Robinson (1989) found expertise and trust were important for the development of alliances or partnerships between parents and healthcare professionals. These partnerships are especially important in families of children who are dependent on technology and hospitalized more frequently than most children. Many authors have found parents of technology dependent children want professionals, especially nurses, to partner with them to create a shared reality for the care of their child. The included studies demonstrate that nurses also want to partner with parents to provide optimal care for their children. Both nurses and parents expressed the importance of advocacy, role negotiation, including parents in care decisions about their child and that each can and should learn from the other. Similarly, Lee (2007) found effective partnerships for care could not be established when nurses did not have a positive attitude, respect for the parent, good communication with the parent or when the parents did not understand the nurse.

The explicit acknowledgement of nurses' caring attitudes, friendly behaviors and provision of emotional support as part of the process of communication was unexpected. Behaviors such as empathy and caring support are inherent parts of the traditional work of pediatric nurses but often are assumed rather than being expressed as integral to the care of children and their families. However, Harbough, Tomlinson, and Kirchbaum (2004) found parents of children in an intensive care environment had a more positive experience when nurses demonstrated affection and caring in addition to being vigilant about the care the child received. These fundamental aspects of nursing care are therefore important for both parent-nurse communication and the delivery of optimal care.

### **Future Directions**

Through the process of parent-nurse communication, the plan of care for the child is jointly constructed and a mutual understanding of optimal care is created through the

collaborative relationship that forms between the nurses and parents. The results of this integrative review validate the model of the process of parent-nurse communication developed in the grounded theory study by Giambra, et al. (2014) and expand our understanding of that process. Nurses can use the process and key components within the process to facilitate communication with parents of technology dependent children who are hospitalized. Nurses should partner with parents to establish a trusting relationship and set the foundation for good communication. Nurses who display caring attitudes and friendly behaviors in addition to providing emotional support for the parents will enhance their relationship as well as the outcomes of the communication process. Despite the evidence reviewed, the process of communication shared between these parents and nurses has not yet been explicated in its entirety and empirical studies to confirm such a process are lacking.

Future research needs to combine the nurses' and parents' perceptions of shared communication as the process is relational and includes the dynamic interactions between both parties. Additionally, studies should be designed to explore whether differences exist among different populations regarding the use of or need for key components in the parent-nurse communication process. Measurement of the process of parent-nurse communication and its outcomes also needs to be further developed. Knowledge of the process of parent-nurse communication will help nurses provide optimal care for hospitalized technology dependent children and their parents.



## **Chapter Four: Confirmation of the Theory of Shared Communication**

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Dr. Stiffler contributed to the design of this study.

## **Abstract**

Grounded theory methods were used with nurses caring for hospitalized technology dependent children to discover and integrate their perspectives into the Theory of Shared Communication. Data were collected during semi-structured interviews with nurses. Additionally, data were collected from parents of technology dependent children through daily journals and interviews to confirm the propositions of the Theory including the validity of the concepts, the presumed relationships among them and attainment of mutual understanding of the child's plan of care. Constant comparative analysis was conducted. The Theory's concepts and relationships were enhanced by the perspectives of the nurses. Through the perspectives of the parents, the propositions of the theory were confirmed. The attainment of mutual understanding of the child's plan of care was articulated by the nurses and parents and is an outcome both should strive for to provide the most safe and optimal care for children who are technology dependent.

Key Words: Parent, Nurse, Communication, Pediatric, Technology Dependent

## **Introduction**

Hospitalized children who are technology dependent are usually accompanied by their parents who know their child and their child's care needs best. Nurses must communicate effectively with these parents to provide the safest and most optimal care for their children. The Theory of Shared Communication was developed based on a previous study of the perceptions of parents of technology dependent children regarding their communication with nurses while their child was hospitalized (Giambra, Sabourin, Broome, & Buelow, 2014). The current study was conducted to confirm the propositions of the theory and add the perspectives of the nurses who care for these children and their families.

### **Shared Communication**

The Theory of Shared Communication describes the process of communication between parents of hospitalized technology dependent children and their nurses from the perspective of the parents (Giambra, et al., 2014). The theory is predicated on the antecedent inputs of perception of own expertise and respect for other's expertise. The communication process delineated by the theory includes the communication acts of asking and listening, functions of explaining and advocating and outcomes of verifying understanding and negotiating roles. The relational outcome of this communication process is parent and nurse mutual understanding of the child's plan of care. The communication acts, functions and outcomes are interrelated and the process is non-linear. Despite its title, however, the Theory of Shared Communication was derived only from the perspectives of the parents.

A recent integrative review of the literature regarding the communication between parents of hospitalized technology dependent children and their nurses and its effect on their mutual understanding of optimal care for the child supports the inclusion of perception and respect for one another's expertise in the theory (Giambra, Stiffler, & Broome, under review).

Other concepts in the theory that are supported by the review are explaining, advocating, verifying understanding through observation of high quality care, and role negotiation. Additional ideas noted in the review as important to the communication process and found in the theoretical concepts include the parent-nurse relationship, parent's prior experiences with nurses, nurses' attitudes and behaviors toward the family, and nurses' emotional support of the parents. Each of these ideas fit within the antecedent input of respect for own and other's expertise and the communication behavior of listening in the Theory of Shared Communication.

No studies were found that described the process of communication between parents of hospitalized technology dependent children and their nurses in its entirety or with the perspectives of both parents and nurses. Therefore, further study of this shared communication process model was warranted.

The purpose of this study was two-fold. First, the perspective of the nurses caring for hospitalized technology dependent children were discovered and incorporated into the theory to enhance its relevance, usefulness and ability to be meaningful for nurses. Second, confirmation of the propositions of the Theory of Shared Communication, the validity of its concepts, the presumed relationships among them and attainment of the relational outcome of mutual understanding of the child's plan of care was sought. To uncover the nuanced nature of the communication relationship between parents of hospitalized technology dependent children and their nurses, both perspectives are necessary.

## **Methods**

### **Design and sample**

Grounded theory methods were used to expand and confirm understanding of the previously constructed Theory of Shared Communication. Grounded theory is a qualitative study design first described by Glaser and Strauss (1967). The method is designed to develop

theory which is systematically constructed from the collected data and therefore, 'grounded' in that data.

Potential participants were recruited using a purposeful selection method. English speaking nurses and parents 18 years of age or older, caring for a technology dependent child (defined for this study as a child with dependence on a tracheotomy, oxygen, ventilator or feeding tube or any combination of these) 4-15 years of age who were admitted to a participating study setting were invited to participate. Nurses who were the parent of a child with a chronic illness and parents who were nurses were excluded. Consent was implied by their completion of the interview. Human subjects approval was received from the Institutional Review Boards of Cincinnati Children's Hospital Medical Center and Indiana University. A \$25 gift card for each was provided to participants after their interview was completed.

#### **Data collection procedure**

Data were collected from the participants through semi-structured interviews (nurses and parents), journals (parents only), field notes and a demographic survey. Semi-structured interviews lasted 30—60 minutes and were designed to elicit the perceptions of the nurses regarding their communication experiences with the parents and perceptions of the parents regarding their communication experiences with the nurses (See Table 5 for exemplar questions). Parents were asked to complete journal entries in composition books given to each, with prompts for the daily writing (See Table 6 for exemplar prompts).

#### **Procedure**

Semi-structured interviews were conducted with both parents and nurses until saturation of the data was reached. Five parent participants and nine nurse participants were enrolled and interviewed. Interviews took place in a conference room in the organization or by phone (nurses), or the child's hospital room (parents). During each interview, the participants

were reminded that if they felt uncomfortable at any time they could stop the interview and terminate their participation or reschedule the interview for a different time. All sessions were audio taped with the participants' permission to enable accurate capture of the data from the interviews. Field notes were recorded to aid in the analysis of the data. Recordings were transcribed verbatim and de-identified using a transcription service.

Upon enrollment, parents were given a journal with daily prompts and instructions for recording their thoughts and observations of communication with their child's nurses during the admission. The prompts were the same for each day and based on the identified components of the Theory of Shared Communication (Giambra, et al., 2014) included the following questions: "I asked the nurse these questions today ..."; "I learned or found out this today..."; "I explained this to the nurse today..."; "I noticed the nurse did this today..."; The nurse and I decided we would each do these things for my child today..."; "I felt as though I had to stand up for my child about this today...". The last question on each page was, "Today, the plan of care for my child is..." and was followed by the following response item "I think the nurse and I have the same understanding of the plan for my child". The possible responses for this last item were; not at all the same, a little bit the same, almost the same and exactly the same.

### **Data analysis**

Constant comparative analysis, aided by N-Vivo software, was used to sort and code the data (Charmaz, 2006, Coyne & Cowley, 2006, Glaser & Strauss, 1967). As data from nurses were collected, they were compared with previously collected nurse interview data and field notes. Open coding was used to discover the emerging categories. The categories were analyzed for evolving theoretical ideas. These ideas were merged with the components of the Theory of Shared Communication. Theoretical memos were kept to document the analysis. Data collected from parents were coded as they were collected through the interview transcript

readings, daily journals, and completed field notes. Theoretical memos were kept to document the analysis. Data obtained from parents were compared with the components of the Theory of Shared Communication.

## **Findings**

### **Participants**

The nine nurses interviewed cared for families similar to those represented by the parent participants and their children. Five nurses were interviewed over the phone and four were interviewed in person. Eight nurses were white, one was black. Five were 18-30 years, three 31-40 years, and one was 41-60 years of age. Nursing degrees reported included associates (4), bachelor's (3), and master's (2). Experience as a nurse and in pediatrics ranged from 8 months to 10 years. Three of the nine nurses were certified pediatric nurses.

Three mothers and two fathers whose technology dependent child had been admitted to the hospital agreed to keep a daily journal of their communication with the nurses caring for their child for 1-3 days and be interviewed face to face on the day their child was discharged. All the parents were white and between 41-60 years of age. The highest education achieved by all but one parent was some high school or technical school, with one completing high school or a GED. Their children were admitted to a variety of units including one dedicated to complex airway issues, one providing care and education for children who are discharged with ventilator support and one focusing on those with neurological issues or traumatic injuries. Three of these parents' children were between 4—7 years, one 8—10 years and one 11—15 years of age. All five children had tracheotomies, three required feeding tubes, and two required oxygen and a ventilator.

## **Integration of the perspectives of the nurses**

Interviews with the nurses demonstrated they use the same process for communication as the parents and no new major concepts were identified based on the nurses' responses. It became apparent during the interviews that the nurses shared the parent's desire for the child to receive the safest and best care possible. One nurse summed it up well stating,

I think with families communication is so, so important because if there is no communication, then you're either going to miss something or you're not going to be able to take care of this child. I think it's imperative that the staff communicate with the families to give them the safest care that we can.

In discussing safe and optimal care, both parents and nurses commented on the role institutional policies play in the child's care while hospitalized. Occasionally policy driven care was in conflict with the home care routine for the child. This created some tension between the nurse and parent because the nurses wanted to include the parents in the care and follow the home routine but felt obligated to follow hospital policy. One nurse stated, "... usually as long as it's done in a safe manner I'm all about if that's how they want it done I'll do it their way ... as long as it's safe for the child of course."

Nearly every nurse expressed the importance of family centered care; including the parents in the child's care and care decisions. Many nurses described doing whatever they could to adapt the home care routine into the hospital routine as they wanted to make the parent and child feel as comfortable as possible in the hospital environment and generally valued the parent's expertise. The nurses who perceived themselves as expert in the care of technology dependent children more frequently expressed that they believed the parents had expertise than nurses who did not perceive themselves as expert.

### **Antecedent Inputs: 'Perception of Own and Respect for Others' Expertise'.**

Six of the nurses interviewed specifically expressed confidence in their own expertise to care for technology dependent children and three did not. The three who did not feel confident



had been nurses for the least amount of time (8 months, 3 years and 4 years). One of the three was the oldest interviewed, and had a master's degree in nursing. The other two were some of the youngest, certified pediatric nurses, and completed a master's degree (1) and a bachelor's degree (1) in nursing. All three felt comfortable admitting their lack of knowledge with parents and actively engaged other medical professionals when they had questions; "I will again always consult someone who I know has even more knowledge than I do." Interestingly, when asked about how she communicated with these expert parents, the newest nurse stated, "I guess I don't communicate a lot with them if they already know what's going on."

Many of the nurses gave examples of how they established their expertise with the parents. Some discussed building a relationship while others stated they worked specifically to gain the parent's trust. The importance of a trusting relationship for shared communication was illuminated by one nurse who said, "But if I break that trust and I don't do what I told them I was going to do then it doesn't work. It just causes friction."

Most of the nurses interviewed spoke very highly of the expertise of the parents of technology dependent children. One nurse stated, "...they're (the parents) very knowledgeable ... so it's helpful when the parents have been out at home with their child and when they come back in I feel like they know appropriate questions to ask on rounds." One of the nurses who did not feel as expert caring for technology dependent children described her views of parental expertise with g-tube feedings; "there are some parents that want to flush between each medication with water and I don't think that they understand...the anatomy of it all."

The more expert nurses spoke of using the parent's expertise to further their own understanding or help others. "They also help us to learn as well.... They give us pointers on how to teach the parents for their home, their transition to home, so we learn from each other." While it is expected that parents whose children are admitted to the hospital will learn care

from nurses, what nurses learn from their patients and families is much less frequently acknowledged. Clearly parents of technology dependent children and their nurses learn from one another.

**Communication Acts: 'Ask' and 'Listen'.**

For the nurses, asking questions was integral to learning the optimal care for the child and understanding the parent's expectations. Nurses stated they asked the parents questions about the child's medications, home routines, what is normal for the child and how the parent wants the care done. Many nurses said they asked questions to understand equipment or rationale for care from the parent's perspective. Others, however, used questions to assess the child and current needs; "I learned a long time ago, you need to ask the parents. So what brings you back? What's going on? Tell me what's going on, and they will." Some of the nurses that expressed less confidence in their own expertise were less likely to ask for or trust the parent's input. One of these nurses, however, had this to say about the parents: "They ask questions, bring up issues, they can shoot down what I say sometimes, which is legitimate though, if they've had issues in the past." Nurses also discussed the importance of the parents questions to them, and being ready for these; "And if we do anything different they (parents) usually ask why, so you have to know why you are doing something."

Both parents and nurses expressed the importance of nurses and parents listening to one another. One nurse related her experience with a child whose parents insisted something was wrong despite all tests being negative. The child was discharged. A day or so later, the child was readmitted and the cause of the problem the parents were concerned about was identified. This nurse said, "I just think that you need to listen to them (parents). Even if it's the craziest idea that you've ever heard. You need to listen and know that they know their child."

### **Communication Functions: 'Explain' and 'Advocate'.**

In addition to discussing how they learn from parental explanations, the nurses identified how they explain things to these expert parents. Several nurses stated they assessed the parent's learning style before trying to explain something new. Many said they used evidence or explained the rationale for a particular treatment or care process to help parents understand why it was being initiated or changed. Some nurses used handouts and demonstrations in addition to hands-on experiences and verbal explanations. One nurse stated, "When we have some new information to offer up, we'll kind of refer back to the way they have done it and we'll either say this is an evidence - best practice or it has come from the doctor's suggestion." This reference to the doctor's suggestion highlights the hierarchical environment in which the nurses work.

Often, the nurses spoke of calling on the doctors or advanced practice nurses to help explain changes in the child's care to the parent. They also used this hierarchy when advocating for the child or parent's wishes. In describing her advocacy, one nurse stated, "I'm usually, not taking the parent's side, but these experienced parents, that I'm really having to advocate for them, because they can't go up and knock on the doctor's door, that's my role." Knowing the parents are watching everything the nurses do, one nurse advocated for the way the parent wanted things done; "And so I just wrote it down exactly the way she told me and then I had the doctors put in an order and then I also passed that on to the next nurse."

### **Communication Outcomes: 'Verify Understanding' and 'Negotiate Roles'.**

According to the nurses in this study, the component of verifying the care for the child was divided into two distinct sub-categories. The first was verifying the child's home routine, including the medications and feedings. The second was verifying that the parent understood the care required for the child and could carry it out. As one nurse pointed out, "...observing is a

big thing. Because you could say you are going to do something and you can agree, but I think if you say you're going to do something it has to be observed."

Despite the volume of care most technology dependent children require, the nurses, like the parents, had less to say about negotiation of roles between the nurse and parent than other aspects of the communication process. Some nurses stated that they always asked the parent what care they expected or wanted the nurse to do while others never did. One nurse spoke of negotiating the dressing care for a child with the parent, stating, "I'm bringing this up is because this is what we've been taught for using this piece of technology but I respect what you have been doing in the past, not that it's wrong". Negotiation of roles related to the child's care is just one aspect of the communication process that leads to mutual understanding of the child's plan of care.

**Relational Outcome: 'Mutual Understanding of the Child's Plan of Care'.**

Achievement of parent-nurse mutual understanding was difficult for parents to define and articulate, but when it was achieved, they knew it. The nurses interviewed had multiple ways of explaining the achievement of mutual understanding of the child's plan of care. All the nurses tried to include the parents in creating or defining that plan. Nearly all the nurses stated they knew they were on the same page when both they and the parents were comfortable with the plan. Most of the nurses felt mutual understanding went beyond comfort to hearing the parent communicate the plan to others. In one nurse's words, "It's really hearing the parents say that they're comfortable...and able to stand up, and when they are talking to the doctors, having that conversation, having that interaction between them, knowing that the communication is all the same." The nurses, like the parents, seemed to know when mutual understanding of the plan of care had been achieved. Their descriptions of the process of

communication encompassed the same major concepts, but their perceptions of those concepts were often different from those of the parents.

Based on the perceptions of the nurse participants in this study, no new concepts were added to the Theory of Shared Communication, but our understanding of the process of communication between the parents of hospitalized technology dependent children and their nurses was expanded.

### **Confirmation of the propositions of the Theory of Shared Communication**

Most of the parents reported that they had completed the journal entries at the end of the day or the following day rather than at the time communication occurred. The entries of the parents demonstrated that while many did not use all of the components of the theory every day, they used several components each day and most used all of the components throughout their relatively short hospital stays of 1—3 days.

#### **Antecedent Inputs: Perception of Own and Respect for Others' Expertise.**

All five parents, when interviewed, expressed they had expertise in the care of their child. When asked, "How comfortable do you feel doing the medical care (your child) requires at home?" one parent responded, "More comfortable than a lot of the nurses." When asked about the expertise of the nurses caring for their child, all the parents were quick to voice their thoughts. Several had only praise for the nurses; "The nursing staff around here is very, very good." One was less impressed; "I would expect them to know what they're doing and how to do it. They've met my expectations." A few had concerns; "He just has some newer nurses and they're not real familiar because they're new". Parents often used questioning and listening to discover the expertise of the nurse.

### **Communication Acts: 'Ask' and 'Listen'.**

Each day, all the parents wrote in their journals the questions they asked the nurses, and the answers or other information they heard. The questions parents asked the nurses showed that they were either trying to establish a relationship, establish the expertise of the nurse, learn from the nurse, or verify the child's care. One dad did several of these as shown in the questions he recorded in his journal. Questions on the day of admission were "how long has she been working as a nurse; where is she from; how long is her shift?" On day two, the same dad asked "are you sure about his feeding; what was his urine output?" A few parents discussed reasons for asking questions of the nurses during the interviews. Most often parents were clarifying aspects of their child's care, but occasionally they questioned what the nurse was doing. The parents also discussed being listened to by the nurses. One mother summed it up this way; "Especially with a child with disabilities I really think they have to hear the parents. Because I did have a previous admission when he was sick and it didn't go well initially in the beginning because they were not really listening."

### **Communication Functions: 'Explain' and 'Advocate'.**

Three of the five parents recorded in their journals the explanations they expected the nurses to listen to each day; their child's history, feeding schedules, daily routines, favorite positions, special needs, unique equipment, concerns about care and reasons they wanted something done. During the interviews, parents discussed not only what and how they explained their child's care to the nurses; they also discussed the nurse's explanations. Two parents described challenges with having the nurses understand or accept what they were trying to explain. One dad described the methods he used to explain to nurses; "Sometimes you have to physically demonstrate and sometimes you just explain and they catch on." A mom had this advice for nurses, "I think that's really important to not be afraid to take constructive

criticism and not be afraid to take suggestions because we (parents) know our kids best.”

Parents expressed appreciation for the nurses’ explanations, particularly if the nurse made them easy to understand.

Not every parent recorded advocating for their child daily. Entries in the diaries showed parents advocated for clarifications about medications and feedings, for the home routine to be maintained and for less invasive care or procedures. While reading the journal entries, it became apparent that some parents wrote they did not feel they needed to stand up for their child, but other items they recorded that day seemed to demonstrate advocacy. For instance, one mom wrote that she wanted her child’s “healing fracture” addressed on this admission, but recorded this as something she explained rather than advocated for to the nurse. During interviews, parents expressed that when advocating for their child it was important to not be argumentative with the nurse. They wanted to cooperate as much as possible, especially when the nurse was advocating for care according to policy. On occasion, parents discussed trying to negotiate policy driven care with the nurses as the policies were not always congruent with the child’s home routine.

**Communication Outcomes: ‘Verify Understanding’ and ‘Negotiate Roles’.**

Before advocating or negotiating for aspects of the child’s care, parents verified the safety and accuracy of the care the nurses were providing. Parents also recorded in their journals what they noticed the nurses doing each day when caring for their child. They noticed the nurses doing a variety of tasks including routine vitals, assessments, interactions between the nurse and child, medication checks with other nurses, problem solving skills, and attempts to improve the child and parent’s experience. During the interviews, parents discussed how they verified that the nurse was doing the correct care for their child. One parent summed it up best saying, “We always watch. We don’t sit back, we always watch what they (nurses) do.”

Parents also noticed that the nurses often verify the child's home routine with the parents. A mother stated, "It's pretty much they tell you what the routine is and then they're kinda making sure it is the correct routine ... and it works out good that way."

Not every parent felt they needed to negotiate roles with the nurse, but those that did recorded in their journals negotiating basic care, such as repositioning, suctioning and giving medications or feedings. Parents said little about this communication outcome during the interviews. The instances parents discussed in which they negotiated with the nurse were also instances during which they were advocating for the continuation of the child's home care routine, or otherwise optimal care from their perspectives.

**Relational Outcome: 'Mutual Understanding of the Child's Plan of Care'.**

Each parent related their own understanding of the plan of care for the child that day in their journal although whether that plan was considered optimal was not indicated. Only two parents responded to the Likert-like scaled prompt in their journal, "I think the nurse and I have the same understanding of the plan for my child" and both answered "exactly the same". One parent referenced the "Plan for the Day" sign in the child's room, in response to the prompt, but did not comment on the perception of mutual understanding. It was unclear why the other two parents did not respond to this prompt.

When interviewed on the day of discharge, each parent was asked if they felt they had the same understanding of the plan of care for the child as the nurses. While every parent said yes, they had the same understanding, a few added statements indicating that achieving mutual understanding of the plan of care took some work. As one mom stated, "...there was a little bit of confusion when we first came up, but it got sorted out fairly quickly." Another parent explained, "I think we both kind of shared ideas." Parents were subsequently asked how they



knew that they had achieved mutual understanding with the nurses. According to one mother, “when they got it, they got it... they were calmer.”

The propositions of the Theory of Shared Communication were confirmed through the journal entries and interviews with the parents of currently hospitalized technology dependent children. The inter-relatedness and non-linearity of the concepts also were supported as not every parent used each concept every day, but those concepts they used were often intertwined with one another. One example of this is found in the words of a mother who recorded in her journal a question she asked the nurse; “Can we get RT (respiratory therapy) to bring a cough assist machine to our room since this is something we use as our daily routine at home?” This was an example of the communication act of asking along with the communication functions of explaining and advocating.

Through the daily journal recordings and the words of the parents interviewed, it appears that the concepts of the Theory of Shared Communication, the interrelated nature of the concepts and attainment of the relational outcome of mutual understanding of the child’s plan of care are upheld.

### **Dialectic Tensions**

Communication has been defined as co-construction of reality (Jacoby & Ochs, 1995). The Theory of Shared Communication describes the process by which parents of hospitalized technology dependent children and their nurses co-construct the reality of care for the child. The co-construction of this reality is neither easy nor is it one-sided. Both the nurses and the parents bring with them the experiences they have had in the past and their expectations for the type and quality of care for the child. Since their experiences and expectations are not the same, tensions can exist and be evident in their communication. Dialectic tensions are contradictions that are given voice during communication and through which relational meaning

is created jointly (Baxter, 2004). In the context of communication between parents of hospitalized technology dependent children and their nurses, many dialectic tensions can be identified. Specifically during this study, dialectic tensions were most notable regarding care routines; home vs. hospital, family centered vs. policy driven care, and being in control vs. being open to suggestion.

The home vs. hospital routines dialectic tension is created when parents want their home routines maintained, but understand that may not be possible in the hospital setting. This tension was illustrated by a nurse who said, "So I know when parents come in, they say we want to be on our home schedule, and I say that's perfectly fine. Trying to adapt to that home schedule makes a big difference to parents." A parent also described this tension and it's perceived effect on her child, "I think he knows the routine that I have. When other people do things drastically different, if everything's different for him, I think that would affect you."

The tension between family-centered and policy driven care is similar to home vs. hospital in that parents want to care for their child just the way they do at home, but hospital policy precludes a particular aspect of the care. A dad described having to have new, boxed tracheotomy tubes at his child's bedside, despite having brought the ones they use from home. This Dad stated, "Okay, we're still in the hospital, this is what we had to do." On a similar note, a nurse described talking with a parent saying, "I know you do this at home and that's fine but here we need to do it this way. That's how we do policy, this is what we do, and we have to follow."

Both parents and nurses described the dialectic tension of control vs. being open to suggestion. One nurse observed, "they (parents) want a lot of the control and you have to really figure out how much control they want and how much we're able to give them." When asked about communicating well with nurses, a mother stated, "As long as they're just open to

suggestions.” The struggle over who decides what is optimal care for the child is highlighted in these tensions. Shared communication results from the interplay of these tensions and their resolution as nurses and parents strive to achieve mutual understanding of what is best care for the child.

### **Discussion**

The interviews with nurses who care for hospitalized technology dependent children reflected the same concepts identified by parents upon which the Theory of Shared Communication was originally grounded (Giambra, et al., 2014). The ways in which the nurses expressed their perceptions of each concept were often quite different, however, from those of the parents. For example, nurses described using the explanations of the parents about particular aspects of care for the child to enhance how they explained that care to other parents. Ford and Turner (2001) also found nurses learned from parental explanations of their child’s care. In a study of pediatric nurse perceptions, Young and colleagues (2006) found 100% of their sample of nurses agreed with the statement “Parents should be asked for information that may assist nursing staff in the ongoing assessment of their child.” With the addition of the nurses’ perspectives, the Theory of Shared Communication has become more richly developed.

Both parents and nurses expressed that they knew when mutual understanding had been achieved when they observed the other incorporating the information into the way they expressed the plan to others and into how they cared for the child. Verbal communication about the plan was not enough, they both made sense of each other’s understanding through observation as well. Ford and Turner (2001) also found parents observed the care each nurse gave to determine whether or not they were providing high quality care and whether or not they could trust the nurse.

The importance of the development of the parent-nurse relationship, and parent's prior experiences with nurses as found by other authors, were found in the words of both the parents and nurses and were incorporated in their respect for each other's expertise (Avis & Reardon, 2008; Fisher & Broome, 2011; Ford & Turner, 2001). Nurses' attitudes and behaviors toward the family were noted by both parents and nurses as important in the context of the development of a relationship as well as in their ability to learn from one another. The idea that nurses should provide emotional support for the parents did not emerge as an important concept in this study despite it being found as important in others (Ammentorp, et al., 2005; Avis & Reardon, 2008; Margolan, Fraser, & Lenton, 2004; Simons, 2002).

The findings of this study can be used to further understand the communication process used by parents of hospitalized technology dependent children and their nurses as explicated in the Theory of Shared Communication. With the integration of the nurses' perspectives with those of the parents', the theory becomes more useful for nurses working with these families when the child is hospitalized. Nurses can use the Theory upon admission to better elicit and understand the child's history, home care routines, and parental expectations of care for their child during the hospitalization. When changes in the child's care are necessary, nurses can use the Theory to help teach parents new care and achieve shared decision making for the child's continued care. Prior to discharge, nurses can use the Theory to determine the parents' understanding of the child's care and assess barriers to optimal care for the child at home.

Still unknown is whether or not the parents and nurses caring for the same technology dependent child achieve mutual understanding of the plan of care at the same time. Future research is needed to answer this question as well as how mutual understanding is achieved. Although the communication process is now described, the number and nature of the

components necessary to achieve mutual understanding in specific situations needs to be further defined.

Future research is also needed to determine interventions, based on the theory, for improving parent-nurse communication, and the amount of time it takes to achieve mutual understanding of the child's plan of care. Subsequent research will be needed to discover whether or not the child's length of stay is shorter if mutual understanding can be achieved more quickly. Additionally, research is warranted to discover whether or not achievement of mutual understanding of the child's plan of care enhances the safety of the care provided. Additionally, improved communication and achievement of mutual understanding of the child's plan of care may improve nurse and parent satisfaction.

An additional area for future research is to determine whether or not the Theory of Shared Communication also describes the process of communication between nurses and parents of other chronically ill pediatric populations. Children who are technology dependent are a subset of those with special healthcare needs. Research will be needed to determine if the propositions of the Theory of Shared Communication continue to hold true for nurses caring for parents of children with other special healthcare needs or chronic illnesses such as seizure disorders, cystic fibrosis or asthma.

Our understanding of parent-nurse communication has been enhanced through confirmation of the Theory of Shared Communication. Many more aspects of communication between parents of complex, chronically ill children and their nurses are yet to be explored. Engaging in this exploration will continue to enhance the care nurses provide for hospitalized children and their parents.

## Chapter Five: Conclusion

Barbara K. Giambra

This chapter will discuss and highlight how the work in each of the three components in this program of research (i.e. manuscripts) contributed to the understanding of communication that is shared between parents of technology dependent children who are hospitalized and their nurses. Additionally, the strengths and weakness of the studies, implications for nursing and future directions for research on the process of parent-nurse communication will be explored.

### **Section One: Integration of three studies**

Each of the studies outlined in the previous three chapters had its own purpose and design and contributed unique knowledge about the communication process found between parents of hospitalized technology dependent children and their nurses.

The first grounded theory study was designed to capture the perspectives of the parents as their knowledge about and satisfaction with their child's care is critically important. Based on anecdotal parental accounts of poor communication with inpatient nurses about the care of their child, which led to interest in the topic, this seemed an appropriate place to start to understand the process of parent-nurse communication. As described in Chapter Two, the Theory of Shared Communication emerged from the data offered by the parents of technology dependent children about the communication process with nurses they had experienced during their child's recent hospitalization (Giambra, Sabourin, Broome, & Buelow, 2014). In subsequent discussions of the results with pediatric nurses, my committee, nurse educators and nurse researchers, questions arose about whether or not the concepts in the theory were exclusive to communication between parents of technology dependent children and their inpatient nurses. It was postulated that these concepts may be similar to those found in communication between parents of any chronically ill hospitalized child and their nurses.

Therefore, as a second step an integrative review was undertaken to discover whether the concepts found in the Theory of Shared Communication were similar to those found among other populations of chronically ill hospitalized children's parents and their nurses (Giambra, Stiffler, & Broome, under review). Details of that review and critical analysis are found in Chapter Three and have been submitted for review for potential publication to *Worldviews on Evidence-Based Nursing Practice*. The same concepts found in the grounded theory study were reflected in the literature analyzed in the integrative review. Some of the concepts were described slightly differently, while others fit within the existing concepts. For instance, establishing a respectful and trusting relationship between the parent and nurse was defined as an important concept in the integrative review and fell into the realm of the antecedent input of respect for own and other's expertise in the Theory of Shared Communication. It became clear, based on the findings from the integrative review, that many similar components of the process of communication between parents of hospitalized chronically ill children and their nurses have been explicated by various investigators, but the process itself has not. Additionally, the Theory of Shared Communication only included the perspectives of the parents and not those of the nurses. It was clear then that the word "shared" in the title of the theory mandated that the perspectives of both the nurses and parents be taken into account. Therefore, another grounded theory study was designed to facilitate inclusion of the perceptions of the nurses regarding the process of communication with parents of technology dependent children for whom they provide care on the inpatient unit.

The third study integrated the voices of the parents from the first study, the concepts found among the studies included in the integrative review and the voices of the nurses, based on interviews with nurses. Additionally, parents of currently hospitalized technology dependent children were also asked to confirm the propositions of the theory through interviews and daily

journal entries. Findings of this grounded theory study can be found in Chapter Four. This paper will be submitted for publication to the *Western Journal of Nursing Research*.

The results of the latest study confirmed the propositions of the Theory of Shared Communication. The antecedent inputs of respect for own and other's expertise were found to be foundational for the communication process in the last as well as the first two studies. In the grounded theory studies, these inputs were necessary for parent-nurse communication to result in mutual understanding of the child's plan of care. The six communication behaviors; ask, listen, explain, advocate, verify understanding and negotiate roles were prominent in each of the studies, although they did not all need to be present or demonstrated in each instance of communication for mutual understanding of the plan of care for the child to be achieved.

In both grounded theory studies these behaviors were nested among one another; for instance, asking and listening were foundational for the other four behaviors and explaining began verifying understanding and is linked with both advocating and negotiating roles. Each individual communication behavior could happen in a reciprocal or back and forth manner between the parent and nurse. There could also be back and forth movement between the behaviors. For instance a parent's explanation could then lead to the nurse asking questions. The parent listens to the question and may explain further. The communication behaviors could also lead from one to another. In this instance, the parent explanation may lead to the nurse listening, and then asking clarifying questions. Next, the parent may feel the need to advocate for the care they are trying to explain, after which the nurse may attempt to verify the parent's understanding of the appropriate or necessary care for the child. In this way, each of the components of this non-linear communication process, individually and collectively, helped the parent and nurse co-create the meaning and therefore mutual understanding for the child's plan of care.



## **Section Two: Contribution of the theory to knowledge**

The complex process of shared communication happens with each chain of utterances in a given dialogue between the parent and nurse (Baxter, 2011). The co-creation of the relational outcome of mutual understanding of the child's plan of care may take but one utterance or many. The communication process can encompass several utterance chains in a moment, a shift, a day or those in an entire admission. As the child's plan of care changes throughout the admission, mutual understanding of the plan of care is co-created in each parent-nurse dialogue through the shared communication process.

The dialogue between parent and nurse is also influenced by the relationship that develops between them. According to Relational Dialectic Theory (Baxter, 2011), each party in a dialogue brings with it their cultural discourses or worldviews and their discourses inform the meaning that is created from the utterances between them. These world views are based on prior experiences. Avis and Reardon (2008) found in a study of parents of recently hospitalized children with special healthcare needs, that parents' previous experiences with hospitalizations, and perceptions of nurses and nursing care influenced the relationships they formed with nurses.

Similarly, Thorne and Robinson (1988a) found in their study of families with chronically ill loved ones (both adults and children) that the quality of relationships that develop between the family and healthcare providers is dependent upon the experiences of the family with the provider. The family-healthcare provider relationships all began with naïve trust. The relationships evolved into disenchantment when the families discovered their perspectives about the care for their loved ones were different from those of the healthcare provider. The relationships ended in guarded alliance as the family recognized the need for a continued relationship with the provider in order for care for their loved one to be optimized. This process

is termed Guarded Alliance. Thorne and Robison (1989) further developed the final stage of reconstructed trust in healthcare providers, guarded alliance, in subsequent research. The authors found families at this stage employed one of four different types of reconstructed trust in maintaining the relationship with their loved one's healthcare provider; hero worship, resignation, consumerism and team playing. These four relationship types exist along a continuum of both trust and belief in their own competence. Thorne and Robinson (1989) also found there is fluidity among these four relationship types. In other words, families may use one type or the other to suit their needs at any given moment in the care of their loved one. These needs will likely change over time leading to a shift in the relationship type. Regardless of the relationship type, respect for own and others' expertise ultimately influences the relationship that develops between the provider and the family of the chronically ill patient. These concepts were also found to be antecedents of the Theory of Shared Communication verifying that Thorne and Robinson's groundbreaking work with families of chronically ill adults and children continues to have utility.

### **Section Three: Strengths and weaknesses**

Each of the studies conducted has both strengths and weaknesses. In the first grounded theory study, only female caretakers (mothers, grandmothers, adoptive mothers) were enrolled as participants. The lack of the male perspective was thought to be a limitation as the perspectives of fathers, and other male caretakers, may differ from that of their female counterparts. The second grounded theory study however, included two fathers in the sample of five parent participants. The father's answers mirrored those of the mothers interviewed in both studies which add to the credibility of the findings. The addition of the male perspective contributes to the strength of this study. One other qualitative study of parent-provider communication included in the integrative review included fathers and labeled their quotes as

such but did not specifically assess differences in perspectives between the mothers and fathers of the hospitalized children (Fisher & Broome, 2011). Several other qualitative and quantitative studies of parent-nurse communication reported including fathers in the sample but did not differentiate their findings from those of the mothers (Ammentorp, Mainz, & Sabroe, 2005; Clark & Fletcher, 2003; Margolan, Fraser, & Lenton, 2004; Michelson, et al., 2011; Shields, Young, & McCann, 2008; Wanzer, Booth-Butterfield, & Gruber, 2004).

A strength of the 2<sup>nd</sup> grounded theory study was the diversity of perspectives of not just the parents but the nurses. Including nurse participants from a variety of inpatient settings in which care is provided for these children adds to the credibility of the findings from this sample. Many children who are technology dependent have complex medical conditions and these children may be admitted to a variety of units depending on the underlying cause of their admission rather than on the technology on which they are dependent. Each unit has its own culture and norms that may influence not only how the nurse communicates with the parent but also the parent's perception of that communication. Only one other study of parent-nurse communication on the inpatient unit also included nurses from a variety of settings (Young, et al., 2006). Inclusion of nurse participants from several different units added to the richness and depth of the data gathered and improved the credibility of the findings.

The credibility of the findings in both grounded theory studies could be limited by the lack of perspectives of parents from different areas of the country. While a few parent participants were able to speak to the differences they had observed in parent-nurse communication at different hospitals, their narratives were generally about their experiences at one hospital. However, the addition of the integrative review, which encompassed studies from around the world strengthened the overall body of work by adding the perspectives of parents not only from different regions of the United States, but globally, provided a broader perspective of this

phenomenon. The synthesized findings of all three studies demonstrate homogeneity of the concepts included in the Theory of Shared Communication and the importance of each to the parent-nurse communication process in order to achieve the goal of mutual understanding of the hospitalized technology dependent child's plan of care.

The integrative review had multiple limitations including publication bias, variability in study designs, samples and methods, and inconsistency in the outcomes measured and measurements (Clark, Burkett, Stanko-Lopp, 2009; Whittemore & Knafel, 2005). Despite these considerable limitations, the review highlighted the research already accomplished regarding parent-nurse communication on the inpatient unit and the global significance of this area of study. The review also clearly identified the gaps in knowledge that still exist about the process of communication between parents of hospitalized chronically ill children and their nurses. In addition, the review supported the need for an additional grounded theory study to add the perspectives of the nurses with those of the parents. Yet, the existent knowledge gap is wide, and the current studies have only begun to narrow the aperture by laying the foundation for understanding this communication process.

A limitation of the second grounded theory study was the lack of data regarding the mutuality of the understanding of the child's plan of care among the parents and nurses caring for the same child. Discovering if the nurse and parent of the same child both understood the plan of care for that child and believed the other also had the same understanding would have strengthened this study. It became apparent during the design of the study however, that patients in the study setting generally have a relatively short length of stay with a mean of 4.8 days (Mumford, Nixon, Taylor, Davies, & Helping, 2013). Nurses in the study setting who work full time work twelve hour shifts and therefore three days per week on the unit. The combination of short patient length of stay and infrequent nursing days on the unit during that

same time made pairing of the nurses and parents caring for the same child very challenging. Given that this trend will continue, and that transitional care models across settings will develop further, this is an area to explore in future research endeavors.

#### **Section Four: Implications for nursing practice**

The process by which parents of technology dependent children communicate with the nurses when they are hospitalized is important for nurses to understand. Care for the child is optimized when the parents are able to share their expert knowledge about their child with the nurses and nurses are able to impart their expert knowledge to the parents who will continue to care for their child after discharge. Both parents and nurses can learn from one another. Nurses can use what they learn from parents of technology dependent children to help explain aspects of care to parents of other children with similar care needs. Additionally, nurses should listen to and use the expert knowledge the parent has about their child to ensure the child's care is as safe as possible. Family knowledge about the patient has been linked to reduction of medical errors (Campbell, 2004; Greenhouse, Kuzminsky, Martin, & Merryman, 2006). Parents who feel as though healthcare professionals have listened to them are also known to be more satisfied with their child's care (Wanzer, et al., 2004).

In the last study, nurses who had more nursing experience felt more confident in their care of the child as well as their ability to communicate well with the parents. With this in mind, nurses with more experience caring for technology dependent children could be assigned to children whose parents have increased learning needs to enhance communication. Likewise, nurses with less experience may benefit by caring for a child whose parent has considerable expertise to share.

Knowledge and use of the Theory of Shared Communication and the behaviors which enhance achievement of mutual understanding of the child's plan of care may also improve

nurse's ability to communicate with parents of technology dependent children. Improved communication may improve outcomes for the child such as safety and time to reach discharge goals leading to shorter lengths of stay. Improved parent-nurse communication may also improve parent understanding of the child's care needs, engagement in care, and satisfaction with their child's care as well as reducing the time required for the parent to learn care and be ready for discharge. All of these are critically important outcomes to document as being influenced by nursing care.

#### **Section Five: Future directions for research**

Through this dissertation we have begun to lay the foundation for understanding the communication process between parents of hospitalized technology dependent children and their nurses. Armed with the Theory of Shared Communication, case studies conducted to observe the communication that occurs (or not) between a parent and nurse on the inpatient unit would provide a vivid picture of the process in action. Additionally, future studies might broaden our knowledge of this communication process by including samples of parents and nurses from different regions or countries and how communication, a concept so embedded in culture, might be different. Ultimately, an intervention study based on the communication process elucidated by the Theory of Shared Communication should be designed to shed light on methods for improving nurse parent communication and outcomes for the hospitalized technology dependent child. These children can be expected to access the health system repeatedly over their childhood and adolescence, and poor communication will become a barrier to optimal care. Moreover, it has been suggested that the process of communication discovered through this dissertation work may be applicable to other populations of chronically ill children. Studies with additional populations would enhance the transferability of the results and further inform nursing practice.

## Appendix

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- U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. (n.d.). Fact Sheet. Retrieved from:  
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- VanDyck, P. C., Kogan, M. D., McPherson, M. G., Weissman, G. R., & Newacheck, P. W. (2004). Prevalence and characteristics of children with special health care needs. *Archives of Pediatric and Adolescent Medicine*, 158, 884-890.
- Wang, K. K., & Barnard, A. (2008). Caregivers' experiences at home with a ventilator-dependent child. *Qualitative Health Research*, 18(4), 501-508.
- Wanzer, M. B., Booth-Butterfield, M. B., & Gruber, K. (2004). Perceptions of health care providers' communication: Relationships between patient-centered communication and satisfaction. *Health Communication*, 16(3), 363-384.
- Watson, K. C., Kiekhefer, G. M., & Olshansky, E. (2006). Striving for therapeutic relationships: Parent- provider communication in the developmental treatment setting. *Qualitative Health Research*, 16(5), 647-663.
- Wise, P. H. (2004) The transformation of child health in the United States. *Health Affairs*, 23(5), 9-25. doi: 10.1377/hlthaff.23.5.9.
- Whittemore, R., & Knafl, K. (2005). The integrative review: Updated methodology. *Journal of Advanced Nursing*, 52(5), 546–553.

Young, J., McCann, D., Watson, K., Pitcher, A., Bundy, R., & Greathead, D. (2006).

Negotiation of care for a hospitalized child: Nursing perspectives. *Neonatal, Paediatric and Child Health Nursing*, 9(3), 7-14.

## Curriculum Vitae

Barbara Klug Giambra

### EDUCATION

PhD, Nursing, Indianapolis, Indiana, May, 2014

MS, Child Health Nursing, University of Buffalo, State University of New York, February, 1999

BSN, Nursing, Vanderbilt University, Nashville, Tennessee, May, 1986

### PROFESSIONAL EXPERIENCE

EVIDENCE-BASED PRACTICE MENTOR—RESEARCH – January 2012 to present

Center for Professional Excellence, Research and Evidence Based Practice

*Cincinnati Children's Hospital Medical Center – Cincinnati, Ohio*

Providing mentorship regarding evidence-based practice and research including one on one mentoring, hands-on workshops, lectures and interactive teaching for nurses, nursing management and allied health professionals.

EVIDENCE-BASED PRACTICE MENTOR – August 2007 to January 2012

Center for Professional Excellence, Research and Evidence Based Practice

*Cincinnati Children's Hospital Medical Center – Cincinnati, Ohio*

Providing mentorship regarding evidence-based practice including lectures and interactive teaching for nurses, nursing management and allied health professionals.

PEDIATRIC NURSE PRACTITIONER, II – July 2008 to present

Pulmonology

*Cincinnati Children's Hospital Medical Center – Cincinnati and Liberty Township, Ohio*

Perform history and physical on children and young adults prior to admission for diagnostic, research or titration sleep study.

PEDIATRIC NURSE PRACTITIONER, II – January 2000 to August 2007

Otolaryngology/Aerodigestive and Sleep Center

*Cincinnati Children's Hospital Medical Center – Cincinnati, Ohio*

Focused on children and young adults with otolaryngologic problems including assessment, treatment and education before and after surgical intervention; in both inpatient, acute as well as outpatient, chronic settings. Specialized in children from around the world, the nation and locally with airway problems including children with multiple chronic conditions.

NURSE RESEARCH COORDINATOR – February, 1999 to January, 2000

*Patient Services, Children's Hospital and Medical Center – Cincinnati, Ohio*

Transition to Nipple Feeding Study. Implemented collection and collation of research data.

STAFF/CHARGE NURSE – January, 1993 to May, 1998

*Dialysis Unit, Children's Hospital of Buffalo – Buffalo, New York*

Cared for, educated and trained patients/families on hemodialysis, CAPD and CCPD in both the inpatient and outpatient setting. Educated patients/families prior to transplantation.

STAFF NURSE – June, 1989 to January, 1993

*Pediatric Intensive Care Unit, Children’s Hospital of Buffalo – Buffalo, New York*

REGISTERED NURSE – November 1991, to November 1992

*Western New York Visiting Nurse Association*

Early Maternity Discharge Program

REGISTERED NURSE – Spring, 1989

*Lawrence I. Sugarman, M.D., Pediatrician – Brighton, New York*

STAFF/CHARGE NURSE – January, 1988 to May, 1989

*Pediatric Intensive Care Unit, Strong Memorial Hospital – Rochester, New York*

STAFF/CHARGE NURSE – June, 1986 to September, 1987

*Pediatric Intensive Care Unit, Medical College of Virginia Hospitals – Richmond, Virginia*

#### **LICENSURE / CERTIFICATION**

Licensed Registered Nurse, Ohio, 1998 to current

Certificate of Authority, Ohio, 1999 to current

Certificate to Prescribe, Ohio, 1999 to current

Certified Pediatric Nurse Practitioner, Pediatric Nursing Certification Board, 1999 to current

Certified Nephrology Nurse, 1995 – 2001

#### **GRANTS**

Carolyn Stoll Research Fund Grant, 2013

“The Process of Communication: How parents of technology-dependent children and nurses communicate on the inpatient unit”

Graduate Student Nursing Research Award, Indiana University, 2011-2012.

“The process of communication: How parents of technology dependent children communicate with nurses on the inpatient unit”

#### **AWARDS**

First place award for Research Poster “The Process of Communication: How parents of technology dependent children communicate with nurses on the inpatient unit” presented at the Cincinnati Children’s Nursing Profession Inquiry Council Research, Evidence-Based Practice and Quality Improvement Poster Day, Cincinnati, Ohio, May 21, 2012.

Third place award for Evidence-Based Practice Poster “Self-Scheduling: Evaluating An Evidence-Based Change” presented at the Cincinnati Children’s Nursing Professional Inquiry Council Conference – Inquiry: You Can’t Change the Outcome Without It, Cincinnati, Ohio, May 10, 2010.

Marita G. Titler Conduct of Research Poster award for Poster “Exploration of Relationships Between Medical Health History and Risk of Aspiration” presented at the Fifteenth National Evidence-Based Practice Conference in Iowa City, Iowa, April 25, 2008.

#### **EDITORIAL AND REVIEW ACTIVITIES**

Manuscript review for the *Journal of Pediatric Nursing*, 2011 – present

Manuscript review as a reviewer-pair with nurse scientist mentor for the *Journal for Specialists in Pediatric Nursing*, 2009 – 2011

#### **PUBLICATIONS**

Giambra, BK, Sabourin, T, Broome, ME, Buelow, J. (2014). The Theory of Shared Communication: How parents of technology dependent children communicate with nurses on the inpatient unit. *Journal of Pediatric Nursing*, 29(1), 14-22.

O’Quinn, L & Giambra, BK. (in press). Evidence of Improved Quality of Life with Pediatric Palliative Care. *Pediatric Nursing*.

Clark, E, Giambra, BK, Hingl, J, Doellman, D, Tofani, B, Johnson, N. (2013). Reducing risk of harm from extravasation: a three-tiered evidence-based list of pediatric peripheral intravenous infusate. *Journal of Infusion Nursing*, 36(1), 37-45.

Giambra, BK & Meinzen-Derr, J; (2010). Exploration of the Relationships Among Medical Health History Variables and Aspiration. *International Journal of Pediatric Otorhinolaryngology*, 74, 387-392, DOI: 10.1016/j.ijporl.2010.01.010.

White, DR; Giambra, BK; Hopkin, RJ; Daines, CL; Rutter, MJ; (2005). Aspiration in Children with CHARGE syndrome. *International Journal of Pediatric Otorhinolaryngology*, 69, 1205-1209.

Hartnick, CJ; Giambra, BK; Bissell C; Fitton, CM; Cotton, RT; Parsons, SK; (2002). Final Validation of the Pediatric Tracheotomy Health Status Instrument (PTHSI). *Otolaryngology Head and Neck Surgery*, 126(3), 228-233.

#### **EVIDENCE-BASED DOCUMENTS**

##### **Authored**

Giambra, BK & Huth, MM (2010, September 1). Cincinnati Children's Hospital Medical Center. Guided imagery for pediatric post-operative pain. Cincinnati (OH): Cincinnati Children's Hospital Medical Center. Retrieved from: <http://www.guidelines.gov/content.aspx?id=24534>.

#### **EDUCATIONAL DOCUMENTS**

Giambra, BK. (2007, October 24). Cincinnati Children's Hospital Medical Center. Health Topic: Ear, Nose and Throat Tests and Procedures: Elective Decannulation. Cincinnati (OH): Cincinnati Children's Hospital Medical Center. Retrieved from: <http://www.cincinnatichildrens.org/health/info/ent/procedure/decannulation.htm>

#### **PRESENTATIONS**

Giambra, BK, Broome, ME, Sabourin, T, Buelow, J, Stiffler, D. The Integration of Nurse and Parent Perspectives: the Theory of Shared Communication. Poster presented at the Midwest Nursing Research Society 38<sup>th</sup> Annual Research Conference, St. Louis, MO, March 28, 2014.

Giambra, BK, Meier, M, Besuner, P, Baker, R. Developing Future evidence-Based Practice Leaders. Poster presentation at the Sigma Theta Tau International 42<sup>nd</sup> Biennial Convention, Indianapolis, IN, November 18-19, 2013.

Giambra, BK. Evidence-Based Practice: PICO Question Development. Invited lecture given at Xavier University, School of Nursing. October 10, 2013, Cincinnati, OH.

Giambra, BK. Evidence-Based Practice. Invited lecture given for College of Mount St. Joe BSN to RN class. October 9, 2013, Cincinnati, OH.

Giambra, BK. The Theory of Shared Communication. Invited lecture given at University of Cincinnati, Communication class. October 1, 2013, and March 26, 2014, Cincinnati, OH.

Giambra, BK. Theory to Practice Change. Invited lecture given at University of Cincinnati College of Nursing. March 26, 2013, Cincinnati, OH.

Giambra, BK, Sabourin, T, Broome, ME, Buelow, J. The Theory of Shared Communication. Podium presentation at the Midwest Nursing Research Society 37<sup>th</sup> Annual Research Conference, Chicago, IL, March 9, 2013.

Giambra, BK, Sabourin, T, Broome, ME, Buelow, JM. The process of communication: How parents of technology dependent children communicate with nurses on the inpatient unit. Poster presented at the Society of Pediatric Nurses 22<sup>nd</sup> Annual Convention, Houston, TX, April 21, 2012.

Giambra, BK, Sabourin, T, Broome, ME, Buelow, JM. The process of communication: How parents of technology dependent children communicate with nurses on the inpatient unit. Poster presented at the Midwest Nursing Research Society 36<sup>th</sup> Annual Research Conference, Dearborn, MI, April 14, 2012.

Giambra, BK. How good is this study? Workshop presented at the Applying Health Care Inquiry: Evidence-Based Practice, Research and Quality Improvement conference, Cincinnati, OH, October 7, 2011.

Giambra, BK, Smith, C. How to Ensure Patient Education Materials are Evidence-Based. Co-presenter for the Cooking Up Patient Education Materials: A Recipe for Success workshop at Cincinnati Children's Hospital Medical Center, May 19, 2011 and October, 11, 2011.

Combs, C, Bourgraf, A, Burkhart, C, Giambra, BK, Gosney, M, Hautman, K, Kinstler, A, Koons, M, Martin, B. Length of Time the Enteral Feeding Administration Set is in Use. Poster presented at the 2010 Summer Institute on Evidence-Based Practice, San Antonio Texas, July 8-10, 2010.

Hall-Haering, A, Honn, G, Willoughby, J, Devoto, L, Frank, L, Giambra, BK. Temperature Rising...Accuracy of Axillary Temperatures, Searching the Evidence. Poster presented at the 10<sup>th</sup> Annual Summer Institute on Evidence-Based Practice University of Texas Health Science Center, San Antonio Texas July 8-10, 2010.



Giambra, BK, Laramie, P, Newman, S. Self-Scheduling: Evaluating An Evidence-Based Change. Poster presented at the Cincinnati Children's Nursing Professional Inquiry Council Conference – Inquiry: You Can't Change the Outcome Without It, Cincinnati, Ohio, May 10, 2010.

Long, L, Giambra, BK, McGee, S, Meier, M. Mentoring Healthcare Providers Through the Maze of EBP. Poster presented at the 20<sup>th</sup> Annual National/International Society of Pediatric Nurses Conference –Pediatric Nursing: Exploring the Next Decade, Orlando Florida, April 29 – May 2, 2010.

Giambra, BK, Laramie, P, Newman, S. Self-Scheduling: Evaluating An Evidence-Based Change. Poster presented at the 20<sup>th</sup> Annual National/International Society of Pediatric Nurses Conference –Pediatric Nursing: Exploring the Next Decade, Orlando Florida, April 29 – May 2, 2010.

Giambra, BK, McGee, S, Long, L, Meier, M. Overcoming Barriers Through Mentorship. Poster presented at the National Association of Pediatric Nurse Practitioners 31<sup>st</sup> Annual Conference on Pediatric Health Care, Chicago, IL, April 15-18, 2010.

Long, L. & Giambra, BK. Validating Social Work Strategies Through Evidence-Based Practice. Invited Speaker at the National Hemophilia Foundation's 61<sup>st</sup> Annual Meeting in San Francisco, California, October 29, 2009.

Giambra, BK, & Meinen-Derr, J. Aspiration Suspicion Index: Predictor of Risk for Aspiration. Poster presented at the Cincinnati Children's Hospital Medical Center Nursing Research/EBP/QI Poster Day, Cincinnati, Ohio, May 13, 2009.

Giambra, BK, Laramie, P, Newman, S. Self-Scheduling: The Evidence for Change. Poster presented at the 10<sup>th</sup> Annual National/International Evidence-Based Practice Conference – Translating Research into Best Practice with Vulnerable Populations: Innovations in Evidence-Based Practice, Glendale Arizona, February 19-20, 2009.

Giambra, BK. & Meinen-Derr, J. Aspiration Suspicion Index: Predictor of Risk for Aspiration. Poster presented at the Cincinnati Children's Hospital Medical Center Pediatric Dysphagia Series: Practice Patterns in the Evaluation and Management of Pediatric Dysphagia, Cincinnati, Ohio, September 26 – 27, 2008.

Giambra, BK. & Meinen-Derr, J. Exploration of Relationships Between Parental History and Aspiration. Poster presented at the Fifteenth National Evidence-Based Practice Conference in Iowa City, Iowa, April 25, 2008.

Giambra, BK. Evidence-Based Practice. Ongoing lecture series given to nursing residents as part of their orientation, Cincinnati Children's Hospital Medical Center, January 15, 2008 – current.

Long, L, McGee, S, Burkett, K, & Giambra, BK. Bringing Evidence To The Bedside. Co-presenter to Interdisciplinary Hematology/Oncology staff, Cincinnati, Ohio, December 1-2, 2007.

Rutter, MJ, Giambra, BK, & Saalfeld, A. The Difficult Airway. Co-presenter at the 35<sup>th</sup> Annual meeting of the Society for Ear, Nose and Throat Advances in Children, Milwaukee, WI, November 29-December 2, 2007.

Giambra, BK. Aspiration Suspicion Index: Exploration of the Relationship Between Parental History and Aspiration. Podium presentation at the 35<sup>th</sup> Annual meeting of the Society for Ear, Nose and Throat Advances in Children, Milwaukee, WI, November 29-December 2, 2007.

Giambra, BK. Tracheotomy. Lecture given to Versant Registered Nurses, Cincinnati, Ohio, September 6, 2005.

Giambra, BK. Critique of a Research Article. Lecture given to Outpatient Department Research Council, Cincinnati, Ohio, July 21, 2005.

Giambra, BK. Aspiration and Suspicion Index : A pilot project. Presentation given at Pediatric Otolaryngology Staff/faculty meeting, Cincinnati, Ohio, June 22, 2005.

Gallagher, M & Giambra, BK. The Reliability and Validity of the Aspiration Suspicion Index. Co-presenter at Society of Otolaryngology – Head and Neck Nurses Spring Pediatric Meeting, Las Vegas, Nevada, May 27, 2005.

Giambra, BK. Tracheotomy Care – A Hands-On Approach. Lecture given to Pulmonary Fellows and Attending physicians, Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio, March 14, 2005.

Giambra, BK, Fitton, C, Saalfeld, A, Byzkowski, T, Cotton, R. Development and Implementation of the Nurse Practitioner Role to Assist in the Management of Hospitalized Pediatric Otolaryngology Patients. Poster presented at the Nursing Research Poster Day, Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio, February 8, 2005.

White, DR; Giambra, BK Aspiration in Children with CHARGE syndrome. Poster presented at the Society for Ear, Nose and Throat Advances in Children, Toronto, Canada, December, 2004.

Cotton, R, Fitton, C & Giambra, BK. Building a Better Pyramid. Panel member at Grand Rounds, Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio, December 8, 2004.

Giambra, BK. Aspiration Suspicion Index. Presented at the First Annual Cincinnati Pediatric Dysphagia conference, Cincinnati, Ohio, September, 2004

Giambra, BK. & Saalfeld, A. Development and Implementation of the Nurse Practitioner Role to Assist in the Management of Hospitalized Pediatric Otolaryngology Patients. Poster presented at the American Society of Pediatric Otolaryngology Annual Meeting, Phoenix, Arizona, May 1-2, 2004.

Giambra, BK. Pediatric Airway. Lecture given to pharmacists, Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio, December 15, 2003.

Giambra, BK. Tracheotomy. Podium presentation, Nursing Grand Rounds, Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio, July 8, 2003.

Giambra, BK. Tracheotomy Care. Lectures given to Interdisciplinary staff on adolescent psych, March 7-8, 2002; Sleep Lab respiratory therapists, April 15, 2002; Nursing staff on inpatient airway unit Sept 26-27, 2002 and Interdisciplinary Dental staff, October 17, 2002, Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio.

Giambra, BK. A Novel Approach to Caring for Chronically Ill Children. Podium presentation at Advanced Practice Nursing Conference, Cincinnati, Ohio, November, 17, 2000.

Giambra, BK. HME's and PMV's: What you need to know. Poster presented at Cincinnati Children's Hospital Medical Center Outpatient Department conference, Cincinnati, Ohio, May 15, 2000.

### **PROFESSIONAL MEMBERSHIPS**

Society of Pediatric Nurses, 2007 – current

    Research Committee Member, 2010 – current

Midwest Nursing Research Society, 2010 – current

    Pediatric Interest Group 2010 – current

National Association of Pediatric Nurse Practitioners, 1999 – current

Sigma Theta Tau, International Honor Society of Nursing, 1999 – current

Society of Otorhinolaryngology, Head & Neck Nurses, 2000 – 2008

American Nephrology Nurses' Association, 1994 – 2000

### **PROFESSIONAL LEADERSHIP OPPORTUNITIES**

Chair, Evidence-Based Practice Conference, 2012 – current

Evidence Collaboration Steering Committee, 2011 – current

    Chair 2012-2013

President, Ohio River Valley Chapter of the society of Pediatric Nurses, 2010, 2011, 2013

    Chair, Community Service Task Force, ORV Chapter, 2008 – 2010

    Nominating Committee, ORV Chapter, 2007 – 2008

Member, Advanced Practice Nurses Professional Inquiry Council, 2003 – current

Evidence-Based Practice Liaison, Medical-Surgical Cluster Coordinating Council, 2011 – current

Evidence-Based Practice Liaison, Peri-operative Cluster Coordinating Council, 2012 – current

Ad Hoc Member, Nursing Professional Inquiry Council, 2008 – 2010

Ad Hoc Member, Outpatient Professional Inquiry Council, 2007 – 2009

Cincinnati Pediatric Dysphagia Series Planning Committee, 2003 – 2008

    Chair, Poster committee, 2006

Member, Nursing Research Council, 2003 – 2005

Member, Outpatient Research Council, 2002 – 2007

    Chair, 2005 – 2006

### **ADVISING AND MENTORING GRADUATE STUDENTS**

2009 – 2012. Waynesburg University, Doctor of Nursing Practice Program, Capstone Project "Determining Nursing's Caregivers and Family's Preference on Axillary Temperature Measurement". Chair, Lynette Jack, PhD, RN. Successfully defended February 6, 2012.

2008 – 2012. Wright State University-Miami Valley College of Nursing and Health, Doctor of Nursing Practice Program. Capstone “Development of a Best Evidence Statement (BEST) for Confirmation of Nasogastric (NGT) or Orogastric Tube (OGT) Placement”. Chair, Tracey Brewer, PhD, RN. Successfully defended March 15, 2012.