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The Theory of Shared Communication: How Parents of Technology-Dependent Children Communicate With Nurses on the Inpatient Unit¹

Barbara K. Giambra MS, RN, CPNP^{a,*}, Teresa Sabourin PhD^b,
Marion E. Broome PhD, RN, FAAN^c, Janice Buelow PhD, RN, FAAN^c

^aCincinnati Children's Hospital Medical Center, Cincinnati, OH

^bUniversity of Cincinnati, Cincinnati, OH

^cIndiana University, School of Nursing, Indianapolis, IN

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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. © 2014 Elsevier Inc. All rights reserved.

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.

As healthcare advances, the population of children who are technology dependent grows; however the current number of children who are technology dependent is unknown. 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. Technology-dependent children currently fall under the distinction of children with special health care needs, or "...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). The most recent published report focused on technology-dependent children as a separate group in the United States (U.S.) was in 1987. At that time, the estimated number of technology-dependent children was 18,000 to 30,000 (*Office of Technology Assessment, 1987*). 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

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* Corresponding author: Barbara K. Giambra, MS, RN, CPNP.
E-mail address: Barbara.giambra@cchmc.org.

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 (Henry, 2008; Newacheck & Kim, 2005). 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.

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 that parents of a technology-dependent child are experts 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, Knafl, & Gilliss, 2004). Several authors (Kirk et al., 2005; O'Brien, 2001; 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; naive 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 within the relationship 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 key contributions 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 what can happen when healthcare providers do not listen to the parent's concerns. In Josie's case, medical errors were not caught before harm was done and ultimately 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 stresses that patients and their families should expect that their opinions will be heard, be informed about the care that may be required and receive treatment with respect and courtesy, among other things (The Joint Commission, 2012). 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 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,

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