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The Transitional Experience of Family Caring for Their Child With a Tracheostomy¹

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Purpose The purpose of this qualitative study was to describe the family experience of caring for their child with a tracheostomy due to a compromised airway during the transition from hospital to home, and to identify types of support that families request to be successful caregivers.

Design and methods: This study used a qualitative descriptive design with focus groups to answer semi-structured interview questions. The investigators followed basic content analysis to interpret descriptive data using three-person consensus.

Results: Eighteen family members participated. Four themes emerged: “This is not the life I had planned: coming to accept the new reality;” “Don’t make the hospital your home; don’t make your home a hospital;” “Caregivers engage with providers that demonstrate competence, confidence, attentiveness, and patience;” and “Participants value the opportunity to give back and help others.”

Conclusions: Growth in the family caregiver role leads to personal transformation demonstrated by increased confidence, finding joy from their child, becoming an advocate for their child, and a resource for others. Family members described the transition to being ‘in charge,’ the relationship with the provider, and being able to advocate for getting the resources they needed in the home.

Practice implications: Relationships are as critical as teaching skills to families during hospitalization. Family members see considerable value in connecting with care providers. In addition, there is a desire to share their experience with other families that are beginning a similar journey. Participants requested a support approach that included competent providers, Web-based video education for skills training, family-to-family connection, and continued family group support after discharge.

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Life changes in an instant for family members when a child receives a tracheostomy for a compromised airway. The family is suddenly faced with the enormous responsibility of having to care for their child with a tracheostomy,

first while the child is hospitalized and then at home between hospitalizations (Montagnino & Maurico, 2004). In-hospital training and home care services are essential as family members become more confident in the unexpected role of caregiver to a medically fragile child.

Little is known about the experiences of family members during the transition from the hospital environment to home where the family members become the responsible care providers. There is a significant amount of knowledge and

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skill that must be imparted to family members at a vulnerable, emotional period in the family's life (Graf, Montagnino, Hueckel, & McPherson, 2008).

Nurses are in a key position to facilitate the transition from hospital to home. Nurses need to understand the demands being placed on the family in order to provide the appropriate education, skills training, and support (Reeves, Timmons, & Dampier, 2006). The purpose of this study was to describe the family experience of caring for their child with a tracheostomy due to a compromised airway during the transition from hospital to home, and to identify types of support that families request to be successful caregivers.

Background

Family members of children who are dependent on health care technology are under a great deal of pressure, not only while the child is in the hospital, but particularly when they must care for the child at home. 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 are at risk for chronic physical, developmental, behavioral, and emotional conditions that will require health and related services of a type and amount beyond that required in general by children (McPherson et al., 1998).

The family members of technology-dependent children serve multiple roles: family members, nurses, advocates, activists, educators, and case managers for their children. These family members report stress, strained relationships with care providers, changed meaning of their home, and significant burden to the entire family (Kirk, Glendinning, & Callery, 2005; Looman, O'Connor-Von, Ferski, & Hildenbrand, 2009; Rehm, 2013). As the family prepares for the transition of their child from being hospitalized to living at home with technology, family members must gain the knowledge and skill required to care for their child as outlined in a comprehensive plan of care (Fiske, 2004).

Several researchers demonstrated that good management of patients in and out of the hospital has a significant positive impact on their quality of life (Hartnick, Bissel, & Parsons, 2002). Others have also shown that a multi-disciplinary approach and use of a tracheostomy tube care plan contributes to reduced morbidity and mortality and a shorter time to decannulation (Graf et al., 2008).

Recognizing the need to establish and communicate best practices to family members who care for their child with a tracheostomy tube in the home, a multi-disciplinary panel of nine experts representing pediatric and adult otolaryngology, advanced nursing practice, respiratory therapy, and emergency medicine established the "Clinical Consensus Statement: Tracheostomy Care" (Mitchell et al., 2013). The goal of this guideline was to improve care of pediatric patients with a tracheostomy by physicians, nurses and other stakeholders.

This guideline includes a list of required information and skills for family members to possess before taking their child

home from the hospital. A comprehensive plan of care that details tracheostomy tube care protocols was strongly suggested in this guideline. According to the guideline, the comprehensive plan of care should include respiratory assessment, proper care of the tracheostomy tube, airway suctioning, and a checklist of required emergency supplies that should be with the child at all times (Mitchell et al., 2013). Prior to discharge, the family should receive a written home care instruction manual for tracheostomy tube care. The family members need to be competent in tracheostomy tube procedures, care of their child and plans for emergency care. The family members and other caregivers should receive training and assessment with respect to these components of the plan of care prior to discharge from the hospital.

Preparing for the Transition From Hospital to Home

Preparation for the transition from hospital to home for these children and their families is a process that begins on the day of admission. Nurses teach family members to assume increasingly greater responsibility for their child's care during the hospitalization period in order to build the confidence that they will need at discharge. A successful transition requires building collaboration and trust between hospital nurses and family members. Researchers suggest that there may be an imbalance of power between family members and nurses. Nurses can feel threatened by family members' knowledge and skills, and these nurses are more likely to become controlling and may limit family involvement (Reeves et al., 2006). This relationship between family members and nurses can work against a successful transition.

Family members must be prepared to meet the increased burden of providing safe care for technology-dependent children at home. Family members must monitor, assess, and interpret their child's health responses, make clinical decisions and provide both physical and emotional care (Kirk et al., 2005; Reeves et al., 2006). Mendes' (2013) qualitative research identified four themes from seven parents of technology-dependent children that lessened parental stress and anxiety in the home care setting: competence; caring; parental control; and home care nurses "fitting in" to their home and family life. Family members stress the importance of the competence of the hospital nurse caring for their child. In addition, families appreciate a nurse who cares for the child as an individual. These families also voiced the need to maintain a sense of control over the care and parenting of their child while in the hospital. A more recent study found that nurses are in a unique position to enhance the competence and confidence of family members to carry out their post-discharge responsibilities (McDonough, Callans, & Carroll, 2014). Nurses and family members can work together to enhance the transition process, thereby improving the confidence of both nurses and family members in their respective roles, and ultimately improving the quality of care for children with a tracheostomy.

The prior studies present the unique challenges of the family with a technology-dependent child. However, there

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