



Pediatric Research Reports Department

## Using MHealth to Improve Outcomes for Children Following Solid Organ Transplant

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*In this issue, Dr. Stacey Lerret, a nurse researcher affiliated with Children's Hospital of Wisconsin provides an overview of her ongoing program of research within the Division of Pediatric Gastroenterology, Hepatology, and Nutrition.*

[Rosemary White-Traut]

Solid organ transplantation, formerly a last option for terminally ill children, is the treatment of choice for serious conditions which result in end stage organ failure (Fine, Webber, Olthoff, Kelly, & Harmon, 2007). Medical advances in transplant have led to a reconceptualization of post-transplant care as chronic illness management due to the potential for life-long transplant related comorbidities. The post-transplant time period is challenging as a family trades a life-threatening pre-transplant medical illness with a post-transplant chronic medical condition and the associated uncertainties for potential transplant complications (Stuber, 1993).

As a pediatric nurse practitioner for the liver transplant program over the last 16 years, I saw firsthand the struggles parents had managing the post-transplant care for their child. In my practice, families reported feeling overwhelmed and needed additional support when they were told they could take their newly transplanted child home from the hospital. This clinical problem led to the development of my program of research that focuses on the discharge transition process during a critical juncture of the child's illness/recovery trajectory. At that time, literature described the concept of discharge readiness in the adult population (Weiss et al., 2007; Weiss, Yakusheva, & Bobay, 2010), but there was a paucity of literature on this same topic for the pediatric population.

Medically complex children account for the majority of hospital readmissions and costs at pediatric institutions (Srivastava & Keren, 2013). Our previous multicenter research investigated the discharge transition process and post-discharge outcomes including hospital readmission and family quality of life for parents of pediatric transplant recipients (Lerret et al., 2015; Lerret & Weiss, 2011). During the discharge transition process, parents who reported a lack of readiness for discharge had more difficulty coping and managing their child's medically complex care at home (Lerret & Weiss, 2011; Lerret et al., 2014). Additional stressors for parents of transplant recipients include worry about medical-related complications, balancing the child's medical care with family, role strain, and uncertainty for the child's future

(Lerret, Weiss, Stendahl et al., 2014; Lerret, Haglund, & Johnson, 2016; Lerret, Johnson, & Haglund, 2017).

Family self-management following transplant is a key consideration for post-discharge outcomes as families experience multiple psychosocial needs and parents report symptoms of emotional trauma (Stuber, Shemesh, & Saxe, 2003; Young et al., 2003). For parents to provide adequate complex care to their child, it is critical that these stressors are not only identified but also addressed via interventions that are feasible and acceptable (LoBiondo-Wood, Williams, Kouzekanani, & McGhee, 2000; Shemesh, 2008). In the adult lung transplant population, self-management strategies were enhanced when an mHealth intervention was provided (DeVito Dabbs et al., 2016). Focused and frequent contact through the use of mobile devices (mHealth) offers additional support, facilitates self-management and improves health outcomes for medically complex adult patients (DeVito Dabbs et al., 2016; Slaper & Conkol, 2014; Naylor, Aiken, Kurtzman, Olds, & Hirschman, 2011; West, 2012). However, this approach has not been studied in medically complex children and their families.

Extending the focus of discharge preparation to building knowledge, skills, self-efficacy and support for family self-management, the foci of the Individual and Family Self-Management Theory (IFSMT), is hypothesized improve family member and child outcomes following discharge (Ryan & Sawin, 2009). My next study evaluates the efficacy of a family self-management intervention that employs a mHealth approach as a strategy for improving management of the child's health care needs at home during the discharge transition process.

With funding from the National Institute of Nursing Research (K23NR017652), my team is implementing this intervention via a Smartphone application (app) called the Family Self-Management Intervention (*myFAMI*) and video call interaction for families of pediatric transplant recipients. The *myFAMI* app promotes daily communication initiated by a text message prompt and completed by the family for 30 days following discharge. Family members (primary and secondary, e.g.: mothers, fathers, and/or grandmothers) rate their coping (primary outcome), family self-management behaviors of complex care at home (difficulty with medication administration and difficulty managing the child's follow-up regimen), and management of the child's transplant symptoms (fever, pain, vomiting, diarrhea, other illness). Pre-identified critical responses trigger an alert and subsequent video call response from the study team nurse. Early identification of transplant

symptoms and difficulty coping allow the transplant nurse to address these issues, offer additional support and management strategies, and decrease use of healthcare resources. The study team is recruiting family units (family unit is defined as primary and secondary family member) at three major pediatric transplant centers. Our team employs a randomized controlled trial design to enroll 40 pediatric transplant family units who will be assigned to receive either *myFAMI* ( $n = 20$ ) or standard care ( $n = 20$ ).

Pediatric solid organ transplant recipients are a vulnerable population who are at high-risk for developing complications which can result in increased utilization of healthcare resources. Solid organ transplant has been identified as an ideal population to utilize and perform mHealth research (Fleming, Taber, McElligott, McGillicuddy, & Treiber, 2017). Family research experts have emphasized the role of utilizing a family theory based intervention for rigorous research (Knafl et al., 2017). Sophisticated technology can support research that trials mHealth interventions to engage and support parents of children that have a complex chronic condition. My research is the first to test a family self-management intervention that uses a mHealth approach for a high acuity pediatric patient population with complex post-discharge care needs at high risk for re-admission in the first 30-days following hospital discharge.

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