

# Health-Related Quality of Life Outcomes of a Telehealth Care Coordination Intervention for Children With Medical Complexity: A Randomized Controlled Trial

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## ABSTRACT

The purpose of this study was to explore health-related quality of life (HRQL) and family impact in the context of an advanced practice registered nurse–delivered telehealth care coordination intervention for children with medical complexity (CMC). This was a secondary outcomes analysis of a randomized controlled trial with 163 families of CMC in an existing medical home. HRQL and family impact were measured using the PedsQL measurement model. Bivariate and analysis of

covariance analyses were conducted to explore associations at baseline and the intervention effect over 2 years. Significant predictors of Year 2 child HRQL were baseline HRQL and the presence of both neurologic impairment and technology dependence. There was no significant intervention effect on child HRQL or family impact after 24 months. Care coordination interventions for CMC may need to incorporate family system interventions for optimal outcomes in a range of quality of life domains. *J Pediatr Health Care.* (2017) ■, ■-■.

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**KEY WORDS**

Care coordination, children with medical complexity, health-related quality of life, telehealth

Children with medical complexity (CMC) are a subgroup of children with special health care needs (CSHCN) who experience severe chronic health conditions, substantial health service needs, major functional limitations, and high health care use, often involving multiple service providers (Cohen et al., 2011). As the level of complexity increases for children with chronic conditions, there is a corresponding increase in the number of absences from school, unmet health care needs, parental challenges, and family financial problems (Bramlett, Read, Bethell, & Blumberg, 2009). Poor coordination of care for this population of children is a driver of high costs of care (Cohen et al., 2012), poor caregiver health, and family stress (Adams et al., 2013; Arauz Boudreau, Van Cleave, Gnanasekaran, Kurowski, & Kuhlthau, 2012; Berry, Agrawal, Cohen, & Kuo, 2013). Effective interventions to buffer the effects of medical complexity are essential to the quality of life of children, parents, and families.

The degree to which families struggle or thrive in the context of chronic illness management is related to the adequacy of system-level resources and support. There is growing evidence that having an advanced practice registered nurse (APRN) coordinate care for individuals with high levels of complexity may lead to improved care delivery outcomes (Caicedo, 2016; Farmer, Clark, Drewel, Swenson, & Ge, 2011; Farmer, Clark, Sherman, Marien, & Selva, 2005; Looman et al., 2012, 2013). APRNs can reduce fragmentation of care through skilled coordination and a nursing orientation to health care practice with individuals who have complex health care needs (Bryant-Lukosius, DiCenso, Browne, & Pinelli, 2004). For CSHCN, coordination of care has been shown to positively influence health outcomes for children in general (Cady, Finkelstein, & Kelly, 2009; Farmer et al., 2005, 2011; Gordon et al., 2007; Palfrey et al., 2004; Peter et al., 2011; Wood et al., 2009).

Although there is growing consensus that care coordination is an important goal for families and systems, the evidence related to the benefits of care coordination

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on specific outcomes for CMC and their families is mixed. Studies of interventions aimed at coordinating care through specialized complex care programs have shown significant reductions in the number of emergency department visits (Klitzner, Rabbitt, & Chang, 2010), the frequency of unplanned hospitalizations (Cady et al., 2009; Gordon et al., 2007), and overall costs of care (Berman et al., 2005; Casey et al., 2011; Collaco et al., 2014; Gordon et al., 2007; Mosquera et al., 2014) for children in these programs. Studies of programs that enhance coordination of care for CMC tend to find a shift from inpatient to outpatient service use (Berry et al., 2011; Johanningmeir et al., 2015; Kuo et al., 2016), suggesting that care may be more proactive and planned when it is coordinated effectively. Outcomes of structured care coordination programs for CMC at the family level are less clear. Families of CMC in one such complex care program reported that their needs for respite care and knowledge for advocacy were met after enrollment in the program (Kuo et al., 2016). In contrast, a longitudinal cohort study of a similar complex care program for CMC found low family quality of life among this population that did not improve over the 2 years of the program (Johanningmeir et al., 2015). Similarly, families enrolled in a medical home clinic for CMC reported decreased needs for care coordination after a year in the program, but no associations with improved parent health or family impact were found (Kuo et al., 2013). This evidence suggests a need to understand program-level factors that may uniquely influence outcomes for children and families.

**PURPOSE**

The purpose of this study was to explore health-related quality of life (HRQL) and family impact in the context of an APRN-delivered telehealth care coordination intervention for CMC.

**Design and Methods**

This is a secondary outcome analysis of data from the TeleFamilies study. TeleFamilies was a three-arm parallel group randomized controlled trial with one usual care group and two intervention groups. A purposive, non-probability sample of 163 CMC and their primary family caregivers were randomized to the 30-month trial, which included a 6-month run-in and 24-month intervention period. The TeleFamilies study was designed to test the effects of (a) increasing levels of nursing practice (basic nursing in the control group vs. advanced practice nursing in the two intervention groups) and (b) increasing levels of telehealth technology (telephone-only telehealth in the control and one intervention group, telephone plus video telehealth in the other intervention group). We have reported previously on the effects of the intervention on the outcomes of health care

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