

# Effects of a Telehealth Care Coordination Intervention on Perceptions of Health Care by Caregivers of Children With Medical Complexity: A Randomized Controlled Trial

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## ABSTRACT

**Introduction:** The purpose of this study was to evaluate the effect of advanced practice registered nurse (APRN) telehealth care coordination for children with medical complexity (CMC) on family caregiver perceptions of health care.

**Method:** Families with CMC ages 2 to 15 years ( $N = 148$ ) were enrolled in a three-armed, 30-month randomized controlled trial to test the effects of adding an APRN telehealth care coordination intervention to an existing specialized medical home

for CMC. Satisfaction with health care was measured using items from the Consumer Assessment of Healthcare Providers and Systems survey at baseline and after 1 and 2 years.

**Results:** The intervention was associated with higher ratings on measures of the child's provider, provider communication, overall health care, and care coordination adequacy, compared with control subjects. Higher levels of condition complexity were associated with higher ratings of overall health care in some analyses.

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**Discussion:** APRN telehealth care coordination for CMC was effective in improving ratings of caregiver experiences with health care and providers. Additional research with CMC is needed to determine which children benefit most from high-intensity care coordination. *J Pediatr Health Care.* (2015) 29, 352-363.

## KEY WORDS

Medical complexity, chronic conditions, care coordination, telehealth, satisfaction

Children with medical complexity (CMC) have substantial family-identified service needs, characteristic chronic and severe conditions, functional limitations, and high health care usage (Cohen et al., 2012; Cohen et al., 2011; O'Mahony et al., 2013). Because of many sources of unavoidable costs of care for CMC, the effects of coordinating care for CMC will likely fall first on families rather than on payors (Berry, Agrawal, Cohen, & Kuo, 2013). The pediatric health care/medical home is the recommended model of care for all children (Antonelli & Rogers, 2014; National Association of Pediatric Nurse Practitioners, 2009; Turchi et al., 2014). Growing evidence indicates that for children with chronic conditions, coordinated care in a medical home is associated with improved child health outcomes, efficient and effective use of services, and improved caregiver and family outcomes (Antonelli, McAllister, & Popp, 2009; Antonelli, Stille, & Antonelli, 2008; Katz, Laffel, Perrin, & Kuhlthau, 2012; Okumura, Van Cleave, Gnanasekaran, & Houtrow, 2009; Wehby & Ohsfeldt, 2007).

For CMC and their families, specialized centers that provide coordinated care using a team-based model are being explored as a way to maximize the efficiency of health care service use (Lobas, 2014). Evidence for the effectiveness of such models of care for CMC is growing, but randomized clinical trials with control groups are needed to test this model of care delivery against a "usual care" model. The effectiveness of models of care for individuals with severe chronic conditions is a national research priority (Institute of Medicine, 2009); yet, according to Berry and colleagues (2013), few studies of interventions for CMC have included control groups of similarly complex children for comparison, indicating a need for controlled studies of care coordination in medical homes for CMC and the impact on families.

The relatively low prevalence and geographic dispersion of CMC (Lobas, 2014) necessitate models of care that make use of telehealth technology combined with team-based care coordination to connect with children and families outside the physical clinic space. Telehealth enables increased access to care and decreased cost to families in terms of lost work

and school missed for travel and clinic visits. Effective care coordination tailors the frequency and location of interactions, using telephone technology supplemented by in-person primary care visits with a multidisciplinary team designed to meet both medical and psychosocial needs (Hong, Siegel, & Ferris, 2014). Few studies have explored this strategy for the population of CMC. Experts agree that there is a need for multi-year, rigorous, controlled studies of the effectiveness of telehealth in changing health outcomes, particularly for persons with chronic conditions (Center for Connected Health Policy, 2014).

The TeleFamilies study was designed in response to this need for scientifically rigorous studies of telehealth care coordination for children with CMC. Specifically, TeleFamilies incorporated a randomized control design to test the effects of adding a high-intensity telehealth care coordination intervention to an existing medical home for CMC. The purpose of this article is to report findings from the TeleFamilies study related to the effects of that intervention on family caregiver perceptions of health care. In addition, we sought to explore the role of condition complexity in caregiver perceptions of care before and after the intervention.

## CONCEPTUAL FRAMEWORK

The behavioral model of health service use by Anderson (1968) guided the TeleFamilies study. This model focuses on individual and system level factors that influence access to, use of, and outcomes of health care services. At the individual level, predisposing, need, and enabling factors have an impact on health behaviors and health outcomes. Predisposing factors are existing conditions such as demographic characteristics, social characteristics, and socioeconomic status. Need factors are conditions such as physical symptoms and medical complexity. Enabling factors are conditions that facilitate or impede use of services, such as income and insurance. At the system level, organizational structure and coordination of services are a context in which access to care is either facilitated or impeded. Outcomes of health care service use include improved health and the patient experience. In this study, we consider Advanced Practice Registered Nurse (APRN) telehealth care coordination as a system level process that should lead to an improved experience of health care for children with CMC, controlling for predisposing, enabling, and need factors.

## AIMS

The purpose of this study was to test the effect of telehealth care coordination for children with CMC. Specifically, in an existing medical home model of care for CMC, what is the effect of *adding* a high-intensity, APRN-delivered telehealth care coordination intervention? This article expands on previous analysis (Cady et al., 2014) to include consideration of the role of

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