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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 advance practice registered nurse (APRN)-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 ANCOVA 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.

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Ethical Statement: This manuscript reports the results of research involving human subjects. Ethical approval was granted for the conduct of this research as a scientific study. Initial approval was granted from the Human Research Protection Program at the University of Minnesota on October 12, 2009 and renewed during all active phases of the trial.

Keywords

Children with medical complexity; care coordination; telehealth; health-related quality of life

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 utilization 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 et al., 2011, 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, Clark, Drewel, Swenson, & Ge, 2011; Farmer, Clark, Sherman, Marien, & Selva, 2005; Gordon et al., 2007; Palfrey et al., 2004; Peter et al., 2011; Wood et al., 2009).

While there is growing consensus that care coordination is an important goal for families and systems, the evidence related to the benefits of care coordination on specific outcomes for CMC and their families is mixed. Studies of interventions aimed at coordinating care through specialized complex care programs have demonstrated significant reductions in the number of emergency department visits (Klitzner, Rabbitt, & Chang, 2010), in the frequency of unplanned hospitalizations (Cady et al., 2009; Gordon et al., 2007) and in 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; Johaningsmeir 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 which did not improve over the 2 years of the program

(Johaningsmeir 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 advance practice registered nurse (APRN)-delivered telehealth care coordination intervention for children with medical complexity (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: 1) increasing levels of nursing practice (basic nursing in the control group versus advanced practice nursing in the two intervention groups); and 2) increasing levels of telehealth technology (telephone-only telehealth in the control and one intervention group, telephone + video telehealth in the other intervention group). We have reported previously on the effects of the intervention on the outcomes of health care service use (Authors, blinded) and parent perceptions of health care (Authors, blinded). This paper focuses on quality of life at the child, parent, and family levels as secondary outcomes of the original trial. Quality of life is conceptualized in this study as HRQL at the child level and family impact at the parent and family levels.

Participants

Enrolled participants in the TeleFamilies clinical trial were 163 CMC ages 2-15 years and their parental caregivers who were receiving primary care in an existing primary care clinic for children with special health care needs in a large, urban, ambulatory care clinic affiliated with a non-profit children's hospital in the Midwest. To be eligible, the identified child had to meet at least four of five CSHCN Screener criteria, which are: need or use of prescription medications; an above routine use of health care services; a functional limitation; need or use of specialized therapies or services; and treatment or counseling for a developmental or behavioral problem (Bethell et al., 2002). Infants and toddlers were excluded because many of the children in the Special Needs Program under the age of 2 years have conditions associated with prematurity which often resolve by this age. We also excluded children ages 16-18 who would transition out of a pediatric age group during the study. Once enrolled, participants completed a 6-month run-in period during which baseline data were collected. Prior to beginning the 24-month active trial, a statistician on the study staff allocated participants into one of three study groups using a stratified block randomization method with varying block sizes, with stratification by child age (2-5 years, 6-12 years, 13-15 years). Approval for the inclusion of human subjects in research was received through university

and hospital institutional review boards. Subject flow through the phases of the study is depicted in the CONSORT flow figure.

Usual Care

All participants in the TeleFamilies study continued to receive team-based primary care in an ambulatory care clinic through a Special Needs Program. The Special Needs Program is certified in the Minnesota Health Care Homes Program, which is an approach to the medical home model that focuses on linking primary care with wellness, prevention, self-management, and community services. Certification requires the following as a minimum standard of care: a personal primary care provider, screening for complex or chronic conditions, continuous access to care providers (on-call or triage care, 24 hours a day, 365 days per year), an accessible electronic health record, an electronic registry of participants, and a system of care coordination that promotes patient and family-centered care (Minnesota Health Care Homes, 2010).

Participants in the control group continued to receive care coordination in the usual care model. Care coordination in the Special Needs Program consisted of a half time care coordinator and two full time nurses who staff a triage call center in the clinic. The half time care coordinator was a licensed practical nurse (LPN) employed in a medical assistant role, with responsibilities that included scheduling and implementing delegated tasks such as messaging between providers and coordinating day-of-visit activities in the clinic. The full time call center providers were registered nurses (RNs) whose responsibilities included responding to calls from parents and caregivers with questions about acute health issues, relaying information between providers and from providers to caregivers, and calling in prescriptions, lab results, and appointments.

Intervention

The intervention groups included those who were randomly assigned to the APRN-delivered telephone care coordination intervention (“telephone group”) and those who received the care coordination intervention using both telephone and interactive video (“telephone + video group”). The only difference between the two intervention groups was the option to add video as a mode of interaction between the family and the APRN. Families in the telephone + video group were provided with a netbook with webcam and high-speed Internet access which they could use in addition to telephone contact. The APRN care coordinator responded to calls from families of children in the study for acute and chronic condition management in addition to providing proactive care coordination and case management services for these families. Activities of the APRN interventionist included: developing and maintaining individualized care plans with families; connecting families with community resources to implement the plan of care; promoting information exchange with community agencies, schools, and health care providers; communicating with families regarding diagnostic and laboratory findings; and identifying the need for and initiating appropriate referrals to other health care providers or community services, as appropriate (Authors, Blinded).

Data Collection

Data were collected through mailed surveys using the Tailored Design Method (Dillman, Smith, & Christian, 2014), which includes personalized correspondence and monetary incentives. Survey data were collected at baseline, 12 months, and 24 months. The survey booklets included a compilation of existing measures and demographic questions. The survey included 146 questions; time needed to complete the survey packet was 30 to 60 minutes. Monetary incentives were gift cards worth \$20 to a large retailer. The overall response rate for surveys across all groups and time points was 82%, with the lowest response rate in the control group (74%). The response rates for the telephone group and the telephone + video group were 83% and 89%, respectively (Authors, Blinded).

Measures

Health-Related Quality of Life—For the purposes of this study, health-related quality of life was operationalized using the PedsQL™ measurement model as described by Varni, Seid, and Rode (1999). The developers of this model conceptualized health-related quality of life as “perceptions of the impact of disease and treatment [on] functioning in a variety of dimensions including physical, mental, and social domains” (p. 126). The PedsQL™ measurement model includes measures of the impact of health conditions on child, parent, and family daily life. For this study, we used the PedsQL 4.0 Generic Core Scales (Varni, Seid, & Kurtin, 2001) to measure the impact of the child's health condition on the child, and the Family Impact Module (FIM, Varni et al., 2004) to measure the impact of the child's health condition on the parent and family. The child measure consists of four subscales that assess functioning in the physical, emotional, social, and school domains. A physical health summary score (8 items) and psychosocial health summary score (15 items) can be created from these subscales, and all 23 items are summed for a total score (Table 1).

Developmentally appropriate versions for four age groups (2-4 years, 5-7 years, 8-12 years, and 13-18 years) were used in this study, with the parental caregiver completing the parent-proxy report for the child. Six subscales (28 items) in the FIM assess parent functioning in the following six domains: physical, emotional, social, cognitive, communication, and worry. Two scales measure daily activities (e.g., household tasks, 3 items) and family relationships (e.g., solving problems, 5 items). All scales use a 5-point response scale with responses ranging from *never a problem* to *almost always a problem*, reverse-scored and linearly transformed to a 100-point scale, with higher values representing higher functioning. The developers of the PedsQL measure (Varni, Burwinkle, Seid, & Skarr, 2003) report that a difference of 4.5 points on the PedsQL measure is a minimally clinically important difference. This tool has demonstrated very good internal consistency reliability in similar samples (Varni et al., 2001; Varni et al., 2004). Internal consistency reliabilities for all subscales and total scales were at or above 0.70 in our sample (Table 1).

Functional status—Functional status of the child was operationalized as a score between 0 and 100 on the 14-item FS II(R) measure (Stein & Jessop, 1990), where higher scores indicate better functional status. This measure inventories behavioral manifestations of a health condition that interfere with an individual's performance on age-appropriate activities and is intended for use with children ages 2 to 18 years. Psychometric testing of the measure in a sample of children with chronic conditions (n=456) indicated strong internal

consistency reliability (.86). The developers report strong evidence for discriminant validity, construct and concurrent validity with morbidity and health indicators (Stein & Jessop, 1990). The items are scored as a percentage of the total possible points (0-100), with higher scores indicating better functional status. Internal consistency reliability for this measure in our sample was 0.78.

Condition complexity—Complexity of the child's condition was defined based on technology dependence, number of chronic conditions, and stability of the condition. *Technology dependence* was defined as medical technology used to maintain a child's health status (such as gastrostomy, tracheostomy, or pacemaker), and was coded as Yes/No based on medical record review at baseline. Devices solely used for communication or mobility were not included in this definition. *Complex chronic conditions (CCCs)* were operationalized based on the framework developed by Feudtner et al. (2001) as a medical condition that can be reasonably expected to last at least 12 months and to involve either several organ systems or one organ system severely enough to require specialty pediatric care and probably some period of hospitalization. Nine categories of CCCs based on body systems are identified (such as neurologic, gastrointestinal, and respiratory). Medical record review was used to classify each child as having one or more CCCs using diagnosis codes and problem lists. *Stability* of the child's condition was measured with a survey question and categorized as stable (needs *change once in a while*, or *usually stable*) or unstable (needs *change all the time*) based on parent report.

Data Analysis

Missing data—To be included in this analysis, subjects had to have complete data on QoL, functional status, and condition complexity measures at baseline and year 2. Scale scores for the PedsQL measure were not computed if more than 50% of the items on a scale were missing, based on the scoring algorithm indicated by the developers of the tool (Varni, Burwinkle, Seid, & Skarr, 2003). Participants were excluded from all analyses if they returned a baseline survey more than 180 days after the start of the trial or were missing data from the baseline or year 2 survey (Figure 1). Fourteen families (7 control and 7 intervention) who returned baseline surveys late were excluded from analyses. Fifteen families (8 control and 7 intervention) withdrew from the study prior to the end of year 2 due to child death or other family circumstances. Forty-five families were missing baseline or year 2 data. The final sample for analysis included 89 families: 23 in the control group, 32 in the telephone only group, and 34 in the telephone + video group.

Analysis—After excluding cases as noted above, all participants were included in the analysis in the groups to which they were originally assigned. Sample characteristics were summarized using means and standard deviations for continuous variables and proportions for categorical variables. Chi-square tests (for categorical variables) and ANOVA (for continuous variables) were used to determine whether control and intervention groups differed at baseline on variables of interest. Baseline associations between child total HRQL scores, FIM subscale scores, and child characteristics (functional status, stability, and technology dependence) were explored using Pearson correlations for continuous variables and independent *t* tests for categorical variables (Table 4). Within-group paired *t*-tests were

used to compare baseline and year 2 scores for each PedsQL subscale by intervention group, and ANCOVA was used to test for intervention group effects on year 2 scores adjusting for baseline scores. Change from baseline to year 2 in child total HRQL scores were calculated for each group and compared using ANOVA. Using child total HRQL at year 2 as a dependent variable, we explored the data for univariate associations with relevant potential predictor variables, and those with a p value of less than 0.2 were retained for potential inclusion in a final ANCOVA model to predict year 2 child HRQL. The final model was based on stepwise model selection. We used SAS (version 9.4) for statistical analysis of data, with a .05 level of significance.

Results

Characteristics of the Sample

Characteristics of the sample are summarized in Tables 2 and 3. Mean child age at baseline was 7.2 years ($SD = 4.2$). Mean functional status was 76.6 ($SD = 17.6$, range 32.1 – 100) at baseline, representing a relatively low functional status in this sample, consistent with the criteria for inclusion in the study. Ninety percent of the children in this sample had a neurologic impairment, 89% had more than one complex chronic condition, and approximately half (46%) used at least one kind of technology to maintain health.

The proportion of parents with a college education in the control group (57%) was significantly higher than the proportion of parents with a college education in the intervention groups (29%; $X^2 = 5.7$, $df = 1$, $p = 0.017$). The proportion of single parents in the control group (17%) was smaller than in the intervention groups (39%), and this difference approached significance ($X^2 = 3.7$, $df = 1$, $p = 0.055$). There were no other significant differences between groups at baseline on child demographic or condition characteristics based on Chi-square tests. Child physical quality of life scores in the video group ($M = 39.9$, $SD = 29.2$) were lower than those in the telephone group ($M = 56.5$, $SD = 31.6$) and the control group ($M = 54.0$, $SD = 27.6$), and this difference approached significance ($p = 0.059$). All other mean baseline subscale scores for parent, family, and child quality of life were not significantly different by intervention group.

Associations with Child HRQL at Baseline

Child total quality of life scores at baseline were significantly associated with parent, family, and child-level variables (Table 4). At the parent level, higher parent physical and cognitive functioning were significantly correlated with higher child total HRQL. Parent social functioning was positively correlated with child HRQL at $p = .05$. Family daily activities scores were significantly positively associated with child total HRQL; higher child HRQL was associated with less difficulty with daily activities for the family. Younger child age and higher functional status scores were significantly associated with higher child HRQL. Based on independent samples t tests, mean child total HRQL scores were significantly higher for children without neurologic impairment, for those whose conditions were more stable, and for children who did not need technology assistance to maintain health. The lowest HRQL scores were for those children with neurologic impairment who were also dependent on technology.

Intervention Effects on HRQL and FIM

Mean FIM and child HRQL scores were not significantly different by intervention group at year 2, based on ANOVA (Table 5). Based on within-group paired t-tests, baseline and year 2 mean scores were also not significantly different for on any domain in any group.

ANCOVA tests for differences between groups adjusting for baseline scores were not significant for any of the subscale scores, suggesting there was not an intervention effect on child HRQL or FIM in this sample. Means and 95% confidence intervals [LL, UL] for child total HRQL score changes from baseline to year 2 for the control, telephone, and telephone + video groups were 1.7 [-3.9, 7.3], -3.4 [-12.6, 5.8], and 2.0 [-1.5, 5.5], respectively. These differences in mean change scores were not significantly different based on ANOVA ($F = .90, p = .409$).

Predictors of Child HRQL at Year 2

Based on associations identified at baseline, an ANCOVA model of child total HRQL was created (Table 6). Child age and baseline HRQL scores were significantly correlated ($r = 0.66, p < .001$), and for this reason the final model excluded age as a covariate. The model explained a statistically significant proportion of the variance (49%) in HRQL at year 2 ($F = 20.14, p < .001$). However, intervention group was not significant in the model. Significant predictors of year 2 child HRQL were baseline child HRQL and the presence of both neurologic impairment and technology dependence (Table 6). The largest effects were seen with condition characteristics: a child with both a neurologic impairment and technology dependence had an estimated HRQL score more than 9 points lower than a child with one or neither of these characteristics ($t = -2.51, p < .001$).

Discussion

Compared to usual care in the existing medical home with care coordination delivered by an LPN and RNs, a two-year telehealth care coordination intervention delivered by an APRN did not significantly improve HRQL scores in either intervention group. HRQL for CMC may be most closely associated with condition characteristics, and these may not be directly amenable to change through a care coordination intervention as delivered in this study. There were also no significant differences in quality of life outcomes between the telephone-only and the telephone + video groups, both delivered by the APRN. This may be due in part to low frequency of use of the video technology. The use of video during care coordination encounters with the APRN was an option based on parent and nurse preference. Analysis of encounter data at the end of the trial indicated that video was used in only 7% of all encounters in the telephone + video group. Future studies testing the effect of video over telephone-only interventions may benefit from a protocol that encourages more consistent use of video technology, and might be most effective for CMC and families for whom APRN coordination could bridge geographic barriers to care through telehealth.

The finding that intervention group membership was not significant in the model has several potential explanations. One explanation is that the sample size was too small to detect an intervention effect, representing a Type II error, or false-negative finding. An alternative explanation is that condition-related factors in this population are so variable that group-

level changes in scores may not be apparent if some members of the group have significant changes in health during the trial. For example, two children in the telephone-only group had declines in total HRQL scores from baseline to year 2 of over 60 points; both children died after completing the trial due to condition-related complications that would not likely have been greatly affected by care coordination. We also noted very large standard deviations in PedsQL scores in this sample, and large effects of condition severity and technology dependence in the final multivariate model. Finally, our findings may represent a true lack of intervention effect on child HRQL over time.

Scores on the child HRQL and family impact measures in this sample reflect the known challenges associated with pediatric complex chronic conditions on multiple aspects of life. Among the children in this sample, scores on the PedsQL measure were significantly associated with condition characteristics including neurologic impairment, technology dependence, and condition stability. Associations between child condition factors and child HRQL were in the expected direction and confirm what is known about the effects of medically complex conditions (Berry et al., 2013; Kuo et al., 2014). CMC who are dependent on technology have been shown to have poorer HRQL compared with children with chronic conditions who are not technology dependent (Houtrow, Okumura, Hilton, & Rehm, 2011; Kuo, Cohen, Agrawal, Berry, & Casey, 2011). Among children with chronic conditions, children with neurologic impairment who are also dependent on technology have the highest rates of hospital admissions and mortality rates and have significantly greater requirements for home care services (Cohen et al., 2012).

Child HRQL was associated with parent physical, cognitive and social functioning. Parents who reported lower child HRQL also endorsed symptoms such as feeling tired, getting headaches, difficulty with attention, and trouble remembering things. Parents who reported lower child HRQL also endorsed family level challenges related to daily activities taking more time and effort and difficulty finding time and energy to finish household tasks. These findings are consistent with the definitional framework presented by Cohen et al. (2011) in which CMC are characterized by substantial service needs that have a significant impact on the family unit. In addition to frequent medical provider visits, families of CMC have high out of pocket costs and are more likely to stop employment in order to care for the child with medical complexity (Kuo et al., 2011). Others have reported lower social functioning among parents of children with pervasive developmental disorders compared to parents of children with physical disabilities or mental retardation (Mugno, Ruta, D'Arrigo, & Mazzone, 2007). Many of the children in our sample had neurologic impairment with congenital anomalies, brain and spinal cord malformations, central nervous system disease, and cerebral palsy, indicating a high degree of medical complexity in this group of children.

Scores on the family impact measures in this study were similar at baseline to those observed by others who have measured family impact in samples with families of children with chronic conditions (Johaningsmeir et al., 2015; Medrano, Berlin, & Davies, 2013; Varni et al., 2004). In addition, FIM scores in this study did not improve significantly over time with or without intervention. Similarly, Johaningsmeir et al. (2015) reported that a two-year care coordination intervention for families of CMC did not lead to significant improvement in FIM scores. A care coordination intervention for families of children with persistent

asthma was effective in increasing child quality of life only when it was paired with a problem-solving skills training intervention, suggesting that a family intervention needs to include both system-level and family-level components for efficacy (Seid, Varni, Gidwani, Gelhard, & Slymen, 2010). Our intervention included proactive coordination activities such as advanced assessment to guide care planning and education to facilitate family management at home, but the intervention was not designed specifically as a family-level program. Future studies should incorporate family-level outcome measures with an aim to influence child, parent, and family quality of life through family system interventions.

Limitations

Families in this study were already enrolled in a structured program with high standards for family centered, coordinated care for children with special health care needs. Our results do not reflect those families who do not have ready access to this kind of program and who may benefit more from telehealth APRN care coordination intervention. The control group sample for this analyses was small and likely not representative. While the TeleFamilies study was adequately powered to detect differences in a primary outcome of health care service use, it was under-powered to detect statistically significant group differences in scores on the PedsQL measure. While low power increases the chance of Type II error, methodological rigor in the design and implementation of a trial can yield unbiased estimates that can be combined with similar trials in meta-analysis (Schultz & Grimes, 2005). Recruiting a larger sample was not feasible due to the need to limit the maximum caseload of the APRN interventionist in the study, and because we opted for a three-group design to enable three levels of telehealth care coordination delivery. Recruitment of families who have children with complex medical conditions is particularly challenging for a number of reasons, including the relatively small numbers in the population and the high levels of stress and caregiver burden in these families. Even with the potential benefits of the intervention, families may perceive the burden of data collection in a research study to be too great to outweigh the potential benefits of participation.

While attrition was relatively low (6% of families in the intervention groups and 15% of families in the control group were lost to attrition), missing data was a limitation in this study. Of the families who remained in the study through year 2, 35% of the intervention groups and 51% of the control group were excluded from analyses due to missing data. The reasons for missing data are unknown in many cases, but analysis of the characteristics of those who were in the final sample and those who were randomized but did not have complete data revealed that data may not be missing at random. The control group was represented by more parents who were married or partnered and by parents with more education compared to the intervention groups. It is possible that the families assigned to the control group who were excluded due to attrition or missing data were more likely to be single and less educated, or that families who have fewer resources dropped out or did not return surveys at a higher rate than those with more resources, and this may have biased our results. Specifically, this may have limited the ability of the intervention to impact child and family level outcomes when compared to the control group.

There are some important limitations to measuring HRQL which are particularly relevant for this population of children with functional limitations. First, many HRQL measures, including the PedsQL used in this study, measure problems with function. The meaning of quality of life changes with age and developmental level (Eiser & Jenney, 2007), yet few measures account for developmental disabilities in which chronological age is significantly greater than developmental age. Over time, the functional gap between CMC and healthy peers may widen as the effects of a chronic condition on a child's development accumulate. We found that age was significantly correlated with HRQL in this sample, with lower scores for older children. This may be due to declining health among the children in the sample, or it may reflect an increasing functional deficit as development plateaus for those children who have severe neurological impairment due to brain injury or congenital brain anomaly. Second, the PedsQL, like many measures of HRQL, includes items that reflect a child's functional status in areas that are not amenable to change through care coordination interventions. For example, *walking, participating in sports, and keeping up with schoolwork* are items in the PedsQL child measure that may not significantly improve for children with severe neurologic impairment that is chronic and stable. There is a need for quality of life measures that assess what parents perceive is most important to "a good life" for these children so that the impact of care coordination interventions can be evaluated for their ability to improve the lives of this population of children with complex conditions and their families.

Practice Implications

CMC are a small subset of children whose health needs have a significant impact on child, parent, and family quality of life. Structured clinical programs for CMC in children's hospitals are emerging as a model of care to meet the acute and chronic health needs of these children. While evidence suggests that care coordination interventions can improve outcomes for CMC in the areas of service use and parent satisfaction, there is not yet conclusive evidence that these programs improve quality of life for CMC and their families. Health care providers can support families by attending to parent and family health in addition to the needs of the child, recognizing the interdependence of individual and family system wellbeing. Parents caring for CMC with neurologic impairment and technology dependence are at particular risk for quality of life challenges in the physical, cognitive, and social domains.

Conclusions

Among families in this study, parents of CMC who had more difficulty with functioning in daily life reported more problems with their own physical and cognitive functioning, including feeling tired, getting headaches, and difficulty maintaining attention. Families of CMC with lower HRQL also experienced activities taking more time and effort and difficulty finding time and energy to finish household tasks. The lowest HRQL scores were for those children with neurologic impairment who were also dependent on technology. A two-year care coordination intervention delivered by an APRN via telehealth did not significantly improve scores on the child and family PedsQL measures. This finding may be related to a sample size with insufficient power to detect group differences on the PedsQL

measure, but it may also reflect the challenges in measuring outcomes amenable to change through care coordination interventions in this population of CMC and their families. Further research is needed to determine the most effective care delivery models for children with medical complexity, using measures that reflect outcomes that families identify are most important to their daily lives and wellbeing. Multi-site trials should test standardized protocols for care coordination for CMC and their families, specifying provider roles and scope of practice, technology use, and family involvement in care delivery innovations.

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Figure. CONSORT Flow Diagram for the Study

Table 1
PedsQL Items^a, Subscales, and Internal Consistency Reliabilities

Domain	# Items	General Content	α
Family Impact: Parent			
Physical	6	Feeling tired, getting headaches, feeling weak, and stomach problems	0.89
Emotional	5	Anxiety, sadness, anger, frustration, and feeling helpless or hopeless	0.86
Social	4	Feeling isolated, difficulty getting support from others, and finding time or energy for social activities	0.81
Cognitive	5	Difficulty maintaining attention, remembering things, and thinking quickly	0.89
Communication	3	Others not understanding the family's situation, difficulty talking about child's health condition, and communicating with health professionals	0.79
Worry	5	Worrying about child's treatments and side effects, about others' reactions to child's condition, about the effect of the illness on the rest of the family, and about child's future	0.75
Family Impact: Family			
Daily activities	3	Activities taking more time and effort, difficulty finding time and energy to finish household tasks	0.87
Family relationships	5	Communication, stress, and conflicts between family members, and difficulty making decisions and solving problems as a family	0.94
HRQL: Child			
Physical	8	Low energy, walking, participating in sports, hurts and aches	0.90
Emotional	5	Feeling afraid, sad, angry, trouble sleeping, worrying	0.79
Social	5	Getting along with other children, keeping up with others, playing with others	0.78
School	5	Paying attention, forgetting, keeping up with schoolwork, missing school	0.70
Total	23	(All child quality of life items)	0.93

^aPedsQL™ 4.0 Generic Core Scales and Family Impact Module, Copyright © 1998 JW Varni, Ph.D. All rights reserved, used with permission.
 HRQL: Health-related quality of life

Table 2**Characteristics of Children in the Sample by Group**

	Control n=23		Telephone n=32		Telephone + Video n=34	
	n	%	n	%	n	%
Gender						
Female	9	39.1	12	37.5	18	52.9
Male	14	60.9	20	62.5	16	47.1
Race						
White	20	87.0	22	68.8	25	73.5
Black or African-American	0	-	4	12.5	5	14.7
Asian	2	8.7	1	3.1	1	2.9
Multiracial	1	4.3	5	15.6	3	8.8
Neurological impairment (NI)						
Yes	21	91.3	30	93.8	29	85.3
No	2	8.7	2	6.3	5	14.7
Technology dependence (TD)						
Yes	11	47.8	13	40.6	17	50
No	12	52.2	19	59.4	17	50
NI and TD						
Yes	11	47.8	13	40.6	15	43.8
No	12	52.2	19	59.4	19	55.9
Number of complex chronic conditions						
Single	3	13.0	4	12.5	3	8.8
Multiple	20	87.0	28	87.5	31	91.2
Insurance						
Private	17	73.9	20	62.5	19	55.9
Public	6	26.1	12	37.5	15	44.1

Note. There were no significant differences between groups at baseline in these variables, based on Chi-square tests.

Table 3

Characteristics of Parent Respondents in the Sample by Group

	Control		Telephone		Telephone + Video	
	n	%	n	%	n	%
Relationship to child						
Biological father	1	4.3	0	0	2	5.9
Biological mother	18	78.3	27	84.4	31	91.2
Adoptive/step mother	4	17.4	5	15.6	1	2.9
Race						
White	21	91.3	24	75.0	25	73.5
Black	0	0	4	12.5	4	11.8
Asian	1	4.3	1	3.1	1	2.9
Multiracial	1	4.3	3	9.4	3	8.8
Missing	0	-	0	-	1	2.9
Age						
18-24	1	4.3	3	9.4	2	5.9
25-34	7	30.4	8	25.0	9	26.5
35-44	10	43.5	13	40.6	21	61.8
45-54	5	21.7	7	21.9	2	5.9
55-64	0	-	1	3.1	0	-
Marital status						
Married/partnered	19	82.6	20	62.5	20	58.8
Single	4	17.4	12	37.5	14	41.2
Educational level						
High school	2	8.7	8	25.0	6	17.6
Some college	8	34.8	16	50.0	17	50.0
4-year college	5	21.7	7	21.9	5	14.7
Graduate degree	8	34.8	1	3.1	6	17.6

Note. The proportion of parents with a college education in the control group (57%) was significantly higher than the proportion of parents with a college education in the intervention groups (29%; $\chi^2 = 5.7$, $df = 1$, $p = 0.017$). There were no other significant differences between groups on these variables at baseline.

Table 4
Bivariate Associations between Child Total Quality of Life (HRQL) Scores and Parent, Family, and Child Variables at Baseline

Variable	Correlation with Child HRQL ^a	Significance ^a
Family Impact: Parent		
Physical function	0.364	<.001
Emotional function	0.161	.132
Social function	0.208	.050
Cognitive function	0.324	.002
Communication	0.145	.174
Worry	0.262	.262
Family Impact: Family		
Daily activities	0.409	<.001
Family relationships	0.144	.179
Child age (in years)	-0.428	<.001
Functional status	0.362	<.001
Child Condition Severity	<i>Child QoL Mean (SD)</i>	<i>t</i> <i>Significance^b</i>
Neurologic impairment (NI)		
Yes	51.7 (19.7)	3.22 .002
No	73.4 (12.9)	
Technology dependence (TD)		
Yes	46.9 (22.0)	3.14 .002
No	59.8 (16.6)	
NI and TD		
Yes	45.9 (21.9)	3.51 .001
No	60.1 (16.4)	
Single CCC		
Yes	53.1 (28.3)	.125 .901
No	54.0 (19.2)	
Stability of condition		
Stable/changes once in a while	66.9 (16.8)	3.48 .001
Changes all the time	50.1 (19.6)	

^a Pearson product moment correlations (*r*).

^b independent samples *t*-tests (two-tailed). Significant associations are in bold font.

Table 5
Family Impact and Child HRQL scores at Baseline and Year 2, by Intervention Group

Domain	Control		Telephone		Telephone + Video	
	Baseline	Year 2	Baseline	Year 2	Baseline	Year 2
Family Impact: Parent						
Physical	57.6(18.1)	61.8(13.7)	59.5(21.3)	59.0(22.0)	59.2(22.0)	59.6(18.9)
Emotional	61.5(20.3)	62.2(17.6)	61.9(21.5)	61.9(25.1)	71.3(20.3)	69.6(19.3)
Social	59.8(21.0)	57.6(18.0)	61.7(24.2)	59.2(30.5)	64.5(25.2)	59.0(23.3)
Cognitive	68.9(18.2)	64.1(14.7)	69.5(22.4)	63.4(26.7)	72.6(21.7)	67.6(22.5)
Communication	60.5(21.8)	57.6(21.2)	58.1(24.8)	60.4(26.8)	61.5(24.4)	63.7(22.5)
Worry	53.5(16.3)	51.3(21.3)	49.5(22.3)	51.1(21.2)	56.5(17.7)	55.7(23.4)
Family Impact: Family						
Daily Activities	39.8(20.4)	49.3(17.4)	47.1(27.7)	49.0(28.2)	52.0(25.9)	46.1(28.1)
Family Relationships	63.9(23.1)	58.9(25.8)	63.3(27.4)	63.4(26.7)	73.8(21.3)	68.4(25.4)
Child HRQL						
Physical	54.0(27.6)	56.4(28.0)	56.5(31.6)	51.1(28.0)	39.9(29.2)	42.2(28.3)
Psychosocial	58.0(13.3)	58.3(18.3)	55.2(16.2)	54.0(27.0)	56.7(19.0)	56.8(19.4)
Total	57.6(15.7)	59.3(15.4)	55.5(21.8)	52.2(28.0)	49.8(21.2)	51.8(21.3)

Note. HRQL: health-related quality of life. Scores on the PedsQL measures range from 0-100, with higher scores indicating better quality of life. ANCOVA tests for intervention group effects on year 2 child HRQL scores adjusting for baseline HRQL were not significant on any domain. Within-group difference in means between baseline and year 2 (based on paired samples *t*-tests) were also not significant at $p < .05$.

Table 6
ANCOVA Results and Descriptive Statistics for Child Total HRQL at Year 2

Group Assignment	Year 2 Total Child HRQL			
	Observed Mean	Adjusted Mean	SE	n
Control	59.3	57.2	3.5	23
Telephone	52.2	50.7	2.9	32
Video	51.8	54.5	2.9	34
Parameter	Estimate	SE	<i>t</i> value	<i>p</i>
Baseline Child HRQL	0.7	0.1	6.96	<0.001
TD and NI (both)	-9.6	3.8	-2.51	0.014
Group Assignment ^a : Telephone	-6.5	4.6	-1.42	0.160
Group Assignment ^a : Video	-2.7	4.6	-0.59	0.558
Intercept	25.7	7.2	3.55	<0.001

Note. HRQL: health-related quality of life. $R^2 = .49$. Adjustments based on a child HRQL grand mean = 53.86.

^aReference is control group.