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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 2–15 (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 one and two 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

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to controls. Higher levels of condition complexity were associated with higher ratings of overall health care in some analyses.

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.

Keywords

medical complexity; chronic conditions; care coordination; telehealth; satisfaction

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Children with medical complexity (CMC) have substantial family-identified service needs, characteristic chronic and severe conditions, functional limitations, and high health care usage (Cohen, Berry, Camacho, et al., 2012; Cohen, Kuo, Agrawal, et al., 2011; O'Mahony, O'Mahony, Simon, et al., 2013). Due to 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 healthcare/medical home is the recommended model of care for all children (Antonelli & Rogers, 2014; National Association of Pediatric Nurse Practitioners (NAPNAP), 2009; Turchi et al., 2014). There is growing evidence 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). There is growing evidence for the effectiveness of such models of care for CMC, 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 et al. (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 individuals 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 paper 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 Andersen (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 impact 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 paper expands on previous analysis (Authors [blinded], 2015) to include consideration of the role of condition complexity on baseline satisfaction and on the effect of the intervention. Specific aims for this paper were:

1. Determine the associations between predisposing, need, and enabling factors on caregiver satisfaction scores at baseline;
2. Determine the effect of the intervention on caregivers' experience of health care after one and two years in the study; and
3. Determine the role of condition complexity on the effect of the intervention after one and two years.

Methods

Design

The TeleFamilies study was a randomized controlled trial with three study groups: (a) a usual care control group; (b) an APRN-delivered, telephone-based care coordination intervention group; and (c) an APRN-delivered, telephone plus interactive video-delivered care coordination intervention group. These groups are differentiated by the intensity of care coordination due to the scope of practice of the care coordinator (control versus intervention groups) and the mode of telehealth technology available (telephone versus telephone-plus-video intervention groups).

Sample and Setting

The TeleFamilies study received IRB approval from the University and hospital institutional review boards. Recruitment began in 2010, and the study ended when the last subject concluded data collection in mid-2014. The target population for this study was CMC and their families. Participants were recruited from a group of approximately 800 children receiving care at the special needs clinic (SNC) of a large, urban, general pediatrics clinic affiliated with a non-profit children's hospital. Within the general pediatrics clinic, the SNC serves as a state certified medical home. The children enrolled in the SNC have a variety of complex health conditions and needs, with multiple diagnoses and technology needs at home; most would be considered CMC. One primary family caregiver was identified as the respondent for data collection from surveys.

The children with special health care needs (CSHCN) screener (Child and Adolescent Health Measurement Initiative, 2007) was used to identify eligible participants. The screener identifies children who experience one or more of five common health consequences due to a health condition lasting at least 12 months. To be eligible for this study, at least four of the five criteria needed to be met by the child (the fifth - need or use of mental health counseling - was not required). Children also had to be a part of the SNC and be between the ages of 2 and 15 years at the time of enrollment in the study. Children under 2 years were not included in this study because prematurity-related health issues resolve in many of these children who then "graduate" from the SNC. The upper age limit of 15 years at enrollment was to ensure that children would not transition out of the pediatric clinic during the trial. The target sample size of 150 was determined based on a power analysis using the outcome of health care service use (not reported here). Subject flow through the screening, recruitment, enrollment, and completion of the study is depicted in Figure 1. Characteristics of the children and their primary caregivers are presented in Tables 1 and 2.

Measures

Predisposing factors—

Indicators of predisposing factors included in this analysis were: child age, and caregiver age, marital status, and race. Child and caregiver age were measured as continuous variables, calculated based on date of birth and randomization date. Marital status and race were based on caregiver report in a baseline survey; response options were collapsed into dummy variables (married or partnered/single, and white/not white) for analysis based on distribution of data.

Need factors—

Indicators of need were based on condition complexity. Complexity was operationalized using three clinical categories as defined by Cohen et al. (2012) in their study of health care use by CMC. The three categories were: neurologic impairment (NI), number of complex chronic conditions (CCCs), and technology assistance (TA). NI is a classification based on diagnoses consistent with static or progressive neurologic, genetic, or other disease that typically results in either functional and/or intellectual impairment (Cohen et al.). CCCs are conditions that are expected to last at least 12 months and involve either multiple organ systems or one organ system severely enough to require specialty pediatric care and hospitalization. CCCs are subdivided into nine subcategories based on body system (Table 3); children were classified as having a single CCC or multiple CCCs. TA for this study was defined as medical technology used to maintain a child's health status (technology for mobility or communication was not included). Types of TA and the frequencies in this sample are listed in Table 3. Each child's medical record was reviewed to ascertain NI, CCC, and TA status based on diagnoses and problem lists.

Enabling factors—Health insurance status was considered an enabling factor. Insurance status (private or public) was determined based on caregiver response in the baseline survey; missing data were gleaned from the patient record when possible.

System level process—The system level process was operationalized as whether the child was in the usual care or one of the intervention groups.

Outcomes—This paper focuses on the family caregiver experience with health care, defined as the primary caregiver's satisfaction with health care services and perceived adequacy of care received relative to care needed. Indicators of satisfaction included seven measures from the Consumer Assessment of Healthcare Providers and Systems Clinician and Group survey (CG-CAHPS, Agency for Healthcare Research and Quality, AHRQ, 2014) and two items that comprise the help discrepancy score (Looman, 2006). Items in each measure are listed in Table 4. The CAHPS survey asks about patient and caregiver experiences with health care in the patient-centered medical home primary care setting. For this study, we used the children with chronic conditions item set, which tailors items to this population. Among the CAHPS measures used in this study there are three single-item measures and four composite measures consisting of two to five items each (two items are included in both the family centered care composite and the provider communication composite; see Table 4).

The help discrepancy score consists of two visual analog scales that ask the respondent to indicate: 1) how much help the family has needed, and 2) how much help the family has received in the past 12 months, using the anchors, "none" and "a lot". A score is derived by measuring the distance (in millimeters) from the bottom anchor ("none") for help needed and help received; the discrepancy score is the difference between help needed and help received. This item was used as an indicator of the caregiver's perception of how closely the amount of help received matches the amount of help needed, in general; it does not specify care coordination as a context and considers the family as the unit of analysis.

Reliability and validity—The CAHPS core item set and chronic condition supplement have demonstrated construct validity and composite measure internal consistency reliability in heterogeneous samples, and have been recommended for use across care settings and for benchmarking (Co, Sternberg, & Homer, 2011). In the current sample, internal consistency reliability ranged from 0.57 for the two-item *getting needed care* composite to 0.75 for the five-item *family centered care* composite. The Cronbach's alpha for the *getting care quickly* and *provider communication* composites were .73 and .63, respectively. In a previous study with families of CSHCN, the help discrepancy measure demonstrated acceptable test-retest reliability, and construct validity through significant correlations with other validated measures of support needs and resources (Looman, 2006).

Procedures

Data were collected using a mailed survey to the primary family caregiver at three time points. The survey included a set of measures in multiple-choice and Likert-type formats; the year 2 survey included a set of open-ended items related to the respondent's overall experience of the study. Survey data were collected at baseline and annually at 12 months and 24 months. The Tailored Design Method (Dillman, 2007) was used to maximize survey return rates; this method incorporates personalized mailings, small monetary incentives, and reminder postcards. These strategies yielded return rates of 77%, 88%, and 73% for baseline, year 1, and year 2 surveys, respectively. Surveys were considered late and excluded from analyses if they were received more than 180 days after their delivery date (Figure 1).

Intervention—The intervention consisted of access to an APRN care coordinator who was on-site full time during business hours and available to caregivers through telehealth technology (telephone or telephone plus web-based video). There was a single APRN interventionist with a maximum caseload of 105 families. Families in the video group received a netbook with webcam, and high-speed internet service to the home was covered by the project. Video encounters utilized a HIPAA-compliant, web-based platform (Virtual Interactive Families©, Cedar Falls, IA). Families in the video group could contact the APRN by telephone and at the discretion of the caregiver or APRN, the video could be added. For all families in the intervention, the APRN was available during the child's clinic visits as needed, and the APRN connected with some children and families during acute hospitalizations.

For both the telephone and video groups, encounters with the APRN could be initiated by either the family or the APRN and replaced services that would have otherwise been provided by the SNC triage call center (staffed by registered nurses) and an LPN care coordinator. Based on the role defined for the TeleFamilies study, the APRN care coordinator activities included: (a) developing and maintaining individualized care plans with families; (b) connecting families with community resources to implement the plan of care; (c) promoting information exchange with community agencies, schools, and health care providers; (d) communicating with families regarding diagnostic and laboratory results; and (e) identifying the need for and initiating appropriate referrals to other health care providers or community services as appropriate. For all children in the intervention groups, the APRN maintained a collaborative relationship with the primary care providers and specialists in the clinic, and engaged in decision-making as appropriate for her scope of practice with regular communication and consultation to the team via email, telephone, and in-person communication.

Usual care—Families in the control group received care coordination that included team-based telephone triage and follow-up support, as delegated by the primary care provider to SNC clinic personnel such as RNs, LPNs, schedulers, medical assistants and referral coordinators. Between visits, SNC triage nurses (RNs) were available to take calls from families during business hours, and after-hours calls were managed by an off-site triage system. Contact was initiated by parents or caregivers, with follow-up calls only initiated by the triage nurses as needed to "close the loop" on a parent- or provider-initiated issue or request. Families in the usual care and intervention groups continued to receive clinic-based care consistent with the medical home model of care, with the primary care provider as a key contact and with ongoing team-based collaboration with specialty services within and outside the children's hospital system. All children in SNC have regular well child visits with extended visit times to accommodate chronic health condition management.

Randomization—Following consent and enrollment into the study, subjects were randomly assigned to one of the three study groups (usual care/control, APRN telephone-based care coordination intervention ("telephone"), or APRN telephone plus video-based care coordination intervention ("video"), stratified by age group (2–5, 6–12, 13–15 years).

Data Analysis

We conducted bivariate analyses to confirm that the intervention and control groups did not differ significantly at baseline on variables of interest (i.e. predisposing, need, enabling, and outcome variables), and to determine whether predisposing, need, or enabling factors were significantly associated with satisfaction scores at baseline. Analysis of variance (ANOVA) was used to test for group differences in satisfaction scores at year 1 and year 2. When significant ($p<.05$) group differences were present we conducted post hoc pairwise comparisons (t-tests) using the Tukey-Kramer method to adjust for multiple comparisons. Unadjusted and adjusted random intercept models were used to test for the overall group effect across the study periods, controlling for covariates. Adjusted models included complexity variables (number of CCCs, NI, and TA), child age and gender as covariates as well as baseline scores on the dependent variable. We examined the effect of complexity in multiple linear regression models at year 1 and year 2, using the same covariates as above, looking specifically for significant effect of number of CCCs, NI, and TA on the dependent variables.

Results

Characteristics of the Sample

Characteristics of the children in this sample are presented in Table 1, and characteristics of the caregiver respondents are in Table 2. Mean child age in years at baseline for the total sample was 7.1 (*SD* = 4.1). Based on the complexity coding scheme described above, children in this sample have a high degree of complexity: 50 percent of the children in this sample have 3 or more CCCs, 84 percent have a neurologic impairment, and 47 percent are dependent on technology such as gastrostomy, tracheostomy, and venous access devices to maintain health (Table 3).

Group Differences at Baseline

No significant group differences were present at baseline in predisposing factors (child age; caregiver age, marital status, and race), need factors (NI, TA, and single/multiple CCCs), or the enabling factor (insurance status). Based on ANOVA tests comparing control, telephone, and video groups, there were no significant differences in any of the dependent variables at baseline (Table 5).

One independent variable – number of CCCs – was significantly associated with satisfaction scores on one measure at baseline for the total sample. On the *provider communication* composite scale, children with multiple CCCs had significantly higher mean scores (M = 3.74, SD = .35) than children with a single CCC (M = 3.51, SD = .39, $t(96)$ = 2.16, $p < .05$). Because the *provider communication* score is calculated as a composite of responses to five items, we examined each of these items separately, comparing mean ratings on each item for children with single CCCs and children with multiple CCCs. Of these five items, two items in particular were significantly associated with CCC status: *listened carefully to me* and *spent enough time with the child*. On both items, mean ratings were significantly higher (more positive) for children with multiple CCC versus a single CCC (Table 6).

Group Comparisons at Year 1 and Year 2

Group comparisons at year 1 and year 2 are presented in Table 7. Unadjusted mean score comparisons by group using ANOVA indicated significant differences at year 1 on three measures: *global personal doctor rating, family centered care*, and *provider communication*. On all three measures, mean scores for the telephone group were significantly higher than mean scores for the control group. Mean scores for the video group were also higher than mean scores in the control group for these measures, but these differences did not reach significance in post hoc comparisons. At year 2, the significant group differences between the telephone and control groups remained for two measures – *global personal doctor rating* and *provider communication*. Scores on the *family centered care* measure remained high for both the intervention groups at year 2, but there was also a small (nonsignificant) increase in mean scores on this measure in the control group from year 1 to year 2. At year 2 there were significant differences between the telephone group and control group on the *global health care* rating, with the telephone group having higher scores. On the *adequacy of care coordination* measure at year two, the video group means were significantly higher than the mean scores in the control group.

Modelling Change Over Time

In the random intercept models (accounting for repeated measures, group and interaction effects, and adjusting for covariates), there were significant group effects for five of the outcome measures (Table 8). For the *global health care* rating and *provider communication* measure, the telephone group had significantly higher scores compared to the control group. For *the global personal doctor* rating and *adequacy of care coordination* measure, scores for both intervention groups (telephone and video) were significantly higher than scores in the control group. On the *family centered care* measure, there was a significant interaction between year and group in the unadjusted model: in year 1, the telephone group had significantly higher scores than the control group. The interaction between complexity and group in the random intercept model for global health care rating approached significance at p=0.081.

Condition Complexity

Compared to absence of NI, having NI was associated with significantly higher predicted scores on ratings of *global health care* in the multiple linear regression at year 2 (F = 7.02, p = .010); baseline scores were significant in the model, but group was not. In the multiple linear regression models, there was an interaction between complexity (single versus multiple CCCs) and group on the *global health care* rating at year 1 (p=0.004) but not at year 2 (p>.05). Number of CCCs, NI, and TA were not significant in any of the other models as interaction effects or covariates.

Discussion

These results demonstrate that the APRN telehealth care coordination intervention was effective in increasing family caregiver satisfaction with health care in several domains over time, compared to a control group receiving usual care. What is notable about these findings is that this occurred in a setting where usual care was a specialized medical home model for CMC. There was significant intervention effect for dimensions of satisfaction that are related to provider engagement with the child and family (e.g. *provider communication* and *global personal doctor rating*), but not for measures that asked about *getting needed care* and *getting care quickly*. This may reflect the nature of the role of the care coordinator in our intervention, which was to facilitate collaboration and communication but was limited in terms of affecting appointment availability and timeliness of care with specialists. The lack of significant effect on these items may also reflect the relatively high scores that were present at baseline and the underlying high capacity of providers in this clinic to manage the complex needs of CMC.

The significant intervention effect for *adequacy of care coordination* was expected, given the nature of the intervention and the intensity of the care coordination provided to the intervention groups. Despite this finding, however, the ratings on the adequacy of care coordination measure have room for improvement, with scores below 3.0 on a 4-point scale. This suggests that even with a high intensity, full time APRN coordinating care for these children, there are still unmet needs for care coordination. It may be that this need reflects the high complexity of the conditions and/or the fact that these children receive care in multiple systems and there are needs for care coordination beyond what our intervention could provide.

The predisposing factors (child age; caregiver age, marital status, and race) and enabling factor (insurance status) were not significantly associated with satisfaction ratings in this sample at baseline. While some studies (Haviland, Morales, Dial, & Pincus, 2005, e.g.) have suggested that demographic factors may be related to ratings of satisfaction with health care, results are not consistent and may be more related to actual differences in healthcare delivery than to perception of care (Hasnain, Schwartz, Girotti, et al., 2013; Hausman, Kressin, Hanusa, & Ibrahim, 2010). Our findings may reflect the fact that our study was limited to one clinic. This clinic had a history of efforts to improve quality locally and at the start of the study was a well-established medical home which may be reflected in the generally high levels of satisfaction at baseline. In addition, the families of the children in this study were well-known to the providers and high users of services.

Only one need factor was significant in baseline ratings of satisfaction. Specifically, the number of CCCs was associated with higher ratings of satisfaction on items related to providers *listening* and *spending enough time* with the child (these items are included in both the *family centered care* and *provider communication* composite measures). It is not clear whether these differences reflect actual differences in provider behaviors or caregiver perceptions (or both). Because the clinic had made changes to scheduling to allow for longer appointments for children with special needs, all children in the study (at baseline and for the duration of the intervention) had access to extended appointments with providers who were familiar with the care of CMC. Children with multiple CCCs may have increased exposure to providers over time, facilitating development of a relationship. Additional analyses of our data on health care service use and care coordination encounters will explore these differences in more depth.

The lack of significant findings on the discrepancy score measure may reflect a true absence of intervention effect, or it may be related to a shift in caregiver perception of how much help was available prior to the intervention. One parent in the intervention wrote in an exit survey, “You don’t realize how much help you needed until you get it. There was so much I was managing on my own [before the study]”. Lawson, Bloom, Sadof, Stille, and Perrin (2011) conducted a similar study that provided a care coordination intervention for CSHCN. They found that CSHCN receiving the intervention utilized primary and specialty services more than CSHCN not in the intervention, suggesting that targeted care coordination may reveal and enable access to previously unmet needs for services. Lawson et al. also noted that the presence of a care coordinator may address a need at the clinic level for assistance in identifying and referring families to community resources. In our study, the presence of an APRN care coordinator potentially increased awareness of an existing gap between the help currently received and the assistance that was available in the community.

Another possible effect of the intervention over time was an increase in caregiver confidence and knowledge in managing their child’s needs at home. The APRN interventionist in our study provided frequent health education and family support for managing their child’s condition. Some caregivers in the intervention groups commented at the end of the study that they felt more confident in managing their child’s condition and in making decisions. One caregiver wrote, “I know more about my daughter’s health than before [the study]”. Another caregiver noted, “Telehealth gave support and helped make my child’s health manageable to the point we feel comfortable with it and are no longer stressed and exhausted because of it.” Future research is needed to examine the evolution of perceptions of help needed and help received and the ability of interventions to affect this family outcome measure.

Because there was a high proportion of children in our study with NI and with multiple CCC, analyses comparing outcomes by complexity was limited, with few children in the groups with no NI or a single CCC. In general, complexity was not a significant covariate, but there was an interaction effect by group on the *global rating of health care* and having multiple CCCs. Having a neurologic impairment was also associated with higher ratings on this item at year 2. It is possible that high intensity care coordination in specialized medical homes may be of particular value to those children with the highest levels of complexity, filling a more critical gap in service for these children and families (Authors, 2015).

This study was designed with three arms to test the effect of adding video technology to the APRN-delivered intervention (in essence, an intervention group and an “intervention plus” group). There were no significant differences in satisfaction-related outcomes or relative benefits of one mode of intervention over the other (telephone versus video). Both intervention groups had higher satisfaction scores than the control group, but the video group scores were not significantly better than the telephone group scores. For the outcome of satisfaction, what seems to have been most beneficial was the care coordinator role rather than mode of encounter. There may have been specific unmet needs in this group of CMC that were addressed by the APRN’s ability to manage aspects of the condition that required advanced role preparation and by her ability to carry a relatively low caseload compared to the usual care group. Access to a single individual who was consistently available was important to families who noted that it was helpful to talk with someone (the APRN) who knew her child on every call. One caregiver noted,

> “It makes all the difference in the world to be able to talk to one person who knows my daughter and her issues, because with that one person, better decisions could be made regarding my daughter’s health. This one person is the same person on each and every call, instead of ER visits/urgent care/primary/ specialists etc. Having one person to talk to and help me manage my daughter’s health is probably the reason we feel almost normal – that’s a big deal!”

Limitations

Subjects were recruited from a single clinic and participation in the study was voluntary, so there may have been a selection bias. Non-English speaking participants were excluded from the study. Because the sample consisted of children with high levels of complexity, the number of children with a single CCC was small which limited our ability to draw conclusions about this group. Similarly, most of the children in the sample had a neurological impairment, so generalizability is limited to this unique subset of CMC. Including a wider range of complexity may help clarify the role of increasing complexity on the potential effectiveness of high-intensity care coordination such as TeleFamilies provided. Increasing the sample size would enable larger subgroups of children with varying levels of complexity that might enable more complex analyses of the intervention effect on caregiver satisfaction as well as other outcomes, including health care service use and health outcomes.

An unanticipated finding was that there was relatively little use of the interactive video technology in the telephone-plus-video intervention group. The protocol was that video could be initiated as an option but was not mandatory. Video encounters were described as “helpful” and “easy to use”, but for a large majority of encounters in this group, communication was initiated by telephone and the video was not turned on. Future studies may need to consider prompts to use the video and a more consistent protocol for initiating video encounters in order to determine whether this technology significantly improves satisfaction.

Conclusions and Recommendations

The Institute for Healthcare Improvement's Triple Aim initiative (Berwick, Nolan, & Whittington, 2008) posits that improving the US health care system requires attention to improving the experience of health care, improving the health of populations, and reducing per capita costs of health care. Efficient access to health care is achieved when both health status and consumer satisfaction increase relative to the amount of health care consumed (Anderson, 1995). For CMC and other populations who need and use high levels of health care, simply lowering health care use is not sufficient to improve efficiency; health status and satisfaction must also be a primary focus. An improved relationship with the health care system and providers may ultimately lead to more efficient use of services with improved family confidence in providers and comfort with the accessibility of help when needed.

Health care reimbursement is increasingly tied to outcomes that include benchmarks for the patient and family experience of health care. Complex care clinics - specialized primary care clinics, operating as team-based medical homes serving CMC – may be an effective model of care for this high-need, high-cost population of children, but additional evidence is needed to identify best practices and long-term outcomes (Lobas, 2014). Future studies should focus on caregiver and family-level outcomes in addition to satisfaction, and consider measuring outcomes more frequently than annually, given the frequently changing nature of the conditions for many of these children.

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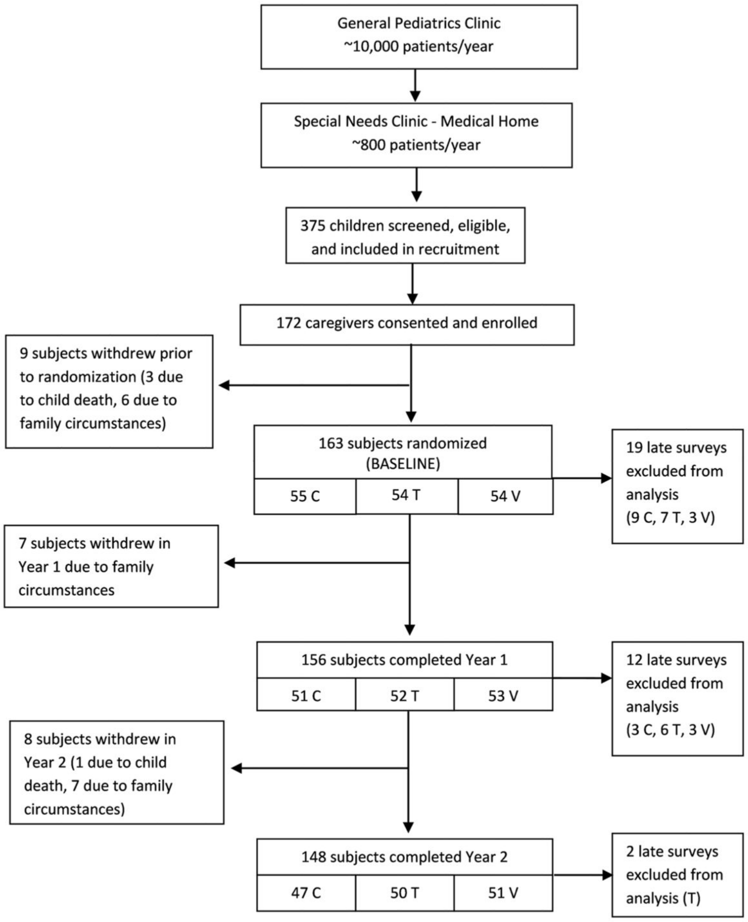

Figure 1.

Subject Flow Diagram (C: control; T: telephone; V: video). Surveys were considered late if received more than 180 days beyond the due date

Table 1

Characteristics of Children in the Sample by Intervention Group (N = 148)

	Control *n* = 47		**Telephone** *n* = 50		**Video** *n* = 51	
Characteristic	***n***	**%**	***n***	**%**	***n***	**%**
Sex						
Male	27	57	29	58	24	47
Female	20	43	21	42	27	53
Age at randomization						
2–5 years	21	45	22	44	23	45
6–12 years	19	40	22	44	20	39
13–15 years	7	15	6	12	8	16
Primary insurance						
Private	28	60	27	54	22	43
Public	18	38	23	46	29	57
Uninsured/self pay	1	2	0	0	0	0
Neurologic impairment[a]						
Yes	40	85	43	86	41	80
No	7	15	7	14	10	20
Number of complex chronic conditions[a]						
Single	7	15	7	14	7	14
Multiple	40	85	43	86	44	86
Technology assistance[b]						
Yes	23	49	21	42	26	51
No	24	51	29	58	25	49
Race						
White	29	62	32	64	33	65
Black or African American	2	4	8	16	10	20
Asian	4	9	1	2	3	6
Multiracial	1	2	8	16	4	8
Missing	11	23	1	2	1	2

[a] Classification based on the publication by Cohen, Berry, Camacho, et al. (2012); see text for details.

[b] Requiring medical technology to maintain health (*e.g.* gastrostomy, tracheostomy, vascular access device).

Table 2

Caregiver and Household Characteristics by Intervention Group

	Control *n* = 47		Telephone *n* = 50		Video *n* = 51	
Characteristic	***n***	**%**	***n***	**%**	***n***	**%**
Relationship to child						
Biological mother	28	60	41	82	40	78
Biological father	2	4	2	4	3	6
Other	6	13	6	12	7	14
Missing	11	23	1	2	1	2
Race						
White	30	64	35	70	34	67
Black or African American	2	4	8	16	9	18
Other	4	8	6	12	6	12
Missing	11	23	1	2	1	2
Age						
18–34 years	16	34	22	44	15	29
35–54 years	20	43	25	50	33	65
55–64 years	0	0	2	4	2	4
Missing	11	23	1	2	1	2
Marital status						
Married /partnered	26	55	30	60	27	53
Single parent	10	21	19	38	23	45
Missing	11	23	1	3	1	2
Annual household income						
Less than $22,000 per year	5	11	12	24	18	35
$22,001 to $50,000 per year	15	32	18	33	22	43
$50,001 to $88,000 per year	6	13	11	22	4	8
More than $88,000 per year	10	21	7	14	6	12
Missing	11	23	2	4	1	2
Level of education						
High school/GED	2	4	10	20	9	19

	Control		Telephone		Video	
	n = 47		*n* = 50		*n* = 51	
Characteristic	***n***	**%**	***n***	**%**	***n***	**%**
Some college/2-year	16	34	22	44	22	43
4-year college	8	17	9	18	7	14
More than 4 years college	9	19	1	2	6	12
Missing	12	26	8	16	7	14

Table 3

Condition Complexity Subcategories and Frequencies in the Sample (N = 148)

	n	%
Complex chronic condition (CCC) subcategories		
Neuromuscular/neurologic impairment	124	84
Cardiovascular	45	30
Respiratory	90	61
Renal	26	18
Gastrointestinal	29	20
Hematologic and immunodeficiency	16	11
Metabolic	9	6
Other congenital or genetic defect	61	41
Malignancy	5	3
Type of neurologic impairment (NI)		
Brain and spinal cord malformations	36	24
Mental retardation/cognitive impairment	69	47
Central nervous system degeneration/disease	40	27
Cerebral palsy	34	23
Epilepsy	45	30
Muscular dystrophies and myopathies	10	7
Technology assistance (TA) type		
Gastrostomy	49	33
Tracheostomy	8	5
CSF shunt	17	11
Renal support	2	1
Cardiac support	5	3
Other	26	18

Note. Children could have more than one CCC type, NI type, and TA type. Categories and subcategories based on the publication by Cohen, Berry, Camacho, et al. (2012); see text for additional details..

Table 4

Outcome Measures and Items

Measure	Item
Global rating of health care[a]	How would you rate your child's overall health care?
Global personal doctor rating[a]	How would you rate your child's personal doctor?
Family centered care[b]	How often were your child's providers sensitive to your family's values and customs?
	How often did your child's providers help you feel like a partner in his/her care?
	How often did you get the specific information you needed from your providers?
	How often did your child's providers listen carefully to you?
	How often did your child's providers spend enough time with your child?
Getting needed care[b]	How often was it easy to get appointments for your child with specialists?
	How often was it easy to get the care, tests, or treatment you thought your child needed?
Getting care quickly[b]	When your child needed care right away, how often did your child get care as soon as you thought he or she needed?
	How often did you get an appointment for health care at the clinic as soon as you thought your child needed?
Provider communication[b]	How often did your child's providers explain things in a way that was easy to understand?
	How often did your child's providers listen carefully to you?
	How often did your child's providers show respect for what you had to say?
	How often did your child's providers explain things in a way that was easy for your child to understand?
	How often did your child's providers spend enough time with your child?
Care coordination adequacy[b]	How often did you get as much help as you wanted with arranging or coordinating your child's care?
Help needed[c]	How much help from others has your family needed in the past 12 months?
Help received[c]	How much help has your family received in the past 12 months?

Note. All items except help needed and help received are from the Consumer Assessment of Healthcare Providers and Systems (CAHPS) children with chronic conditions item set.

Response options:

[a] 11-point Likert item: 0 (“worst possible”) to 10 (“best possible”);

[b] 4-point Likert item: 1 (never), 2 (sometimes), 3 (usually), 4 (always);

[c] visual analog scale with end anchors: “none” and “a lot”.

Table 5

Comparison of Mean Scores by Group at Baseline for Satisfaction and Help Discrepancy Measures

Measure	**Range of Possible Scores**	***Mean (SD)***			**ANOVA** ***p-value***
		Control	**Telephone**	**Video**	
Child’s health care	0–10	8.2 (1.6)	8.5 (1.4)	8.3 (1.4)	0.754
Child’s personal doctor	0–10	9.2 (1.1)	9.5 (0.8)	9.6 (.07)	0.272
Family centered care	5–20	17.6 (2.7)	18.2 (1.9)	18.0 (2.0)	0.557
Getting needed care	1–4	3.3 (0.6)	3.0 (0.7)	3.1 (0.9)	0.438
Getting care quickly	1–4	3.2 (0.7)	3.1 (0.8)	3.2 (0.7)	0.774
Provider communication	1–4	3.6 (0.4)	3.7 (0.4)	3.7 (0.3)	0.422
Care coordination adequacy	1–4	2.1 (0.9)	2.2 (0.9)	2.2 (0.9)	0.844
Help discrepancy	−150 – +150	16.0 (40.7)	16.6 (41.9)	21.8 (42.6)	0.811

Table 6

Results of t-tests for Provider Communication Items at Baseline by Number of Complex Chronic Conditions

Item	**Group**						**t-test for mean difference**	
	Multiple CCCs			**Single CCC**				
	M	***SD***	***n***	***M***	***SD***	***n***	***t***	***p-value***
Explained things clearly for caregiver	3.80	.36	84	3.86	.46	14	−.46	.646
Listened carefully	**3.86**	**.42**	**84**	**3.57**	**.51**	**14**	**2.30**	**.023**
Showed respect	3.86	.47	84	3.64	.50	14	1.57	.120
Explained things clearly for child	3.36	.87	74	3.08	1.0	12	1.02	.311
Spent enough time with child	**3.75**	**.49**	**84**	**3.36**	**.50**	**14**	**2.78**	**.006**

Note. CCC: complex chronic condition. Response options range from *never* (1) to *always* (4).

Table 7

Analysis of Variance Tests for Differences by Group at Year 1 and Year 2

Measure	Year 1 *Mean (SD)* Control	Year 1 *Mean (SD)* Telephone	Year 1 *Mean (SD)* Video	ANOVA *p-value*	Year 2 *Mean (SD)* Control	Year 2 *Mean (SD)* Telephone	Year 2 *Mean (SD)* Video	ANOVA *p-value*
Child’s health care	8.0 (1.8)	9.0 (1.8)	8.7 (1.2)	0.079	**8.4 (1.3)**	**9.1 (0.8)**[*]	**8.7 (1.4)**	**0.036**
Child’s personal doctor	**8.8 (1.4)**	**9.6 (0.7)**[**]	**9.3 (0.9)**	**0.009**	**9.0 (1.2)**	**9.7 (0.6)**[**]	**9.5 (0.8)**	**0.009**
Family centered care	**17.3 (2.6)**	**18.9 (1.7)**[**]	**18.2 (1.9)**	**0.008**	18.4 (2.1)	18.8 (1.4)	18.3 (2.1)	0.490
Getting needed care	3.2 (0.7)	3.3 (0.8)	3.2 (0.7)	0.658	3.3 (0.6)	3.4 (0.7)	3.3 (0.8)	0.796
Getting care quickly	3.4 (0.6)	3.5 (0.7)	3.4 (0.6)	0.751	3.5 (0.6)	3.3 (0.8)	3.5 (0.6)	0.338
Provider communication	**3.6 (0.5)**	**3.8 (0.3)**[*]	**3.7 (0.4)**	**0.038**	**3.6 (0.4)**	**3.8 (0.2)**[*]	**3.8 (0.4)**	**0.036**
Care coordination adequacy	2.3 (0.9)	2.8 (1.0)	2.7 (0.8)	0.169	**2.3 (0.9)**	**2.8 (1.0)**	**2.9 (1.0)**[*]	**0.039**
Help Discrepancy	22.5 (35.5)	9.6 (44.7)	22.3 (40.7)	0.304	14.6 (31.9)	11.0 (34.5)	12.5 (49.0)	0.931

Note. Results of post hoc comparisons (adjusted using the Tukey-Kramer method for multiple comparisons) are indicated for items in bold using asterisks to indicate level of significance.

[*] Indicates mean is significantly higher than mean for control group at p<.05

[**] Indicates mean is significantly higher than mean for control group at p<.01

Table 8

Intervention Effect Over Time: Group Means from Adjusted Random Intercept Models[a]

Measure	**Mean (SE)**			**p-value**
	Control	**Telephone**	**Video**	
Child's health care	**8.1 (0.2)**	**8.8 (0.2)***	**8.3 (0.2)**	**0.019**
Child's personal doctor	**8.8 (0.2)**	**9.6 (0.2)****	**9.3 (0.1)***	**0.001**
Family centered care[b]	18.0 (0.4)	19.0 (0.4)	18.2 (0.3)	0.055
Getting needed care	3.2 (0.2)	3.4 (0.1)	3.2 (0.1)	0.337
Getting care quickly	3.5 (0.1)	3.4 (0.1)	3.5 (0.1)	0.893
Provider communication	**3.6 (0.1)**	**3.9 (0.1)****	**3.8 (0.1)**	**0.007**
Care coordination adequacy	**2.4 (0.2)**	**2.9 (0.2)***	**2.7 (0.1)***	**0.026**
Help Discrepancy	17.7 (8.0)	11.5 (7.7)	20.1 (6.3)	0.555

[a] Adjusted for baseline score, year, age at start, gender, number of CCCs, NI, and TA. Pairwise comparisons adjusted for multiple comparisons using Tukey-Kramer method.

[b] Interaction between year and group: unadjusted p=0.0364; Control is lower than Telephone group in Year 1 (see Table 7).

Post hoc comparisons:

* Indicates mean is significantly higher than mean for control group at p<.05

** Indicates mean is significantly higher than mean for control group at p<.01