Mobile Complex Care Plans to Enhance Parental Engagement for Children With Medical Complexity

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Abstract
Care plans can reduce care fragmentation for children with medical complexity (CMC); however, implementation is challenging. Mobile health innovations could improve implementation. This mixed methods study’s objectives were to (1) evaluate feasibility of mobile complex care plans (MCCPs) for CMC enrolled in a complex care program and (2) study MCCPs’ impact on parent engagement, parent experience, and care coordination. MCCPs were individualized, updated quarterly, integrated within the electronic health record, and visible on parents’ mobile devices via an online portal. In 1 year (September 1, 2016, to August 31, 2017), 94% of eligible patients (n = 47) received 162 MCCPs. Seventy-four percent of parents (n = 35) reviewed MCCPs online. Forty-six percent of these parents (n = 16) sent a follow-up message, and the care team responded within 8 hours (median time = 7.2 hours).

In interviews, parents identified MCCPs as an important reference and communication tool. MCCPs for CMC in a complex care program were feasible, facilitated parental engagement, and delivered timely communication.

Keywords
care plans, parent engagement, children with medical complexity, mobile health

Introduction
Children with medical complexity (CMC) are an increasingly common population characterized by multiple chronic conditions, severe functional limitations, dependence on long-term medical technology to maintain basic quality of life, and need for multispecialty care.¹,² These patients and their caregivers frequently interact with multiple inpatient, emergency department, specialty, and primary care providers. Providers caring for CMC within a medical “neighborhood” often struggle to coordinate their complex needs, resulting in care fragmentation.²,⁴ This has serious consequences, including parent/family stress, unmet patient medical needs, and high hospital utilization.⁶,⁹

In recent years, multiple pediatric tertiary care centers have developed successful complex care programs to support the needs of CMC and deliver better care at reduced cost.¹⁰-¹² Complex care programs utilize multidisciplinary teams to coordinate care for CMC across time and clinical settings (inpatient and outpatient). Such care coordination is intensive and requires substantial time and resources to organize key information for families and providers.

Care plans are often recommended to communicate medical needs and care goals for CMC.⁶,¹³,¹⁴ Ideally, care plans should incorporate multiple electronic health record (EHR) components (e.g., medication lists, hospitalization summaries), be jointly developed with parents, remain up-to-date as health statuses change, and...
be accessible to providers and families across care settings. Writing care plans is labor-intensive, and parent engagement is challenging. The ubiquity of mobile devices offers the potential for mobile health applications to improve care plan implementation and enhance parent engagement.

We developed a novel mobile complex care plan (MCCP) integrated within our EHR to facilitate communication between care providers and parents of CMC. The purpose of this study was to characterize the feasibility of MCCP implementation and its impact on care for CMC.

**Methods**

**Participants and Setting**

Duke Children’s Hospital is a 190-bed pediatric tertiary care center within a large academic hospital in Durham, NC. During the 12-month study period (September 1, 2016, to August 31, 2017), Duke Children’s Hospital had over 6000 pediatric inpatient admissions. CMC hospitalized during this timeframe were eligible to enroll into the Complex Care Service (CCS), a complex care program for CMC with specialty care centered at Duke. Using structured criteria adapted from published studies (see Appendix A), CCS staff identified eligible CMC and approached their parents in-hospital to offer program enrollment. CMC enrolled into the CCS program received care coordination from a multidisciplinary team (nurses, physicians) via several core interventions: health system navigation (eg, coordinating multiple appointments), direct communication (eg, 24/7 phone access to the clinical team, regularly occurring follow-up contacts), direct care delivery (eg, clinic visits, inpatient consultations when hospitalized), and care plans. CCS nurses wrote care plans at time of program enrollment, and physicians reviewed plans before posting them in the EHR and sharing with parents. CCS nurses followed a structured template (see Appendix B) and updated care plans quarterly.

The MCCP workflow was paperless, allowed bidirectional information transfer, and integrated within the EHR (Epic©, Verona, WI). MCCPs and updates were electronically transmitted to parents via the EHR’s online patient portal (OPP). This allowed parents to review MCCPs on their computer or mobile device and electronically reply to the CCS team. The most up-to-date care plan was always visible to providers in the EHR. Because communication occurred electronically through the online portal, MCCP eligibility was limited to enrollees with an activated OPP account, home Internet connection, and a personal mobile device/home computer. The CCS team offered to assist with OPP account activation, but no additional efforts were made to increase activation rates for purposes of this study.

**Study Design and Analysis**

The study period was 12 months following implementation of MCCPs (September 1, 2016, to August 31, 2017). We utilized mixed methods to evaluate feasibility and impact of MCCPs. Feasibility was defined as ≥70% of CCS-enrolled patients being eligible to receive MCCPs by having an activated OPP account and ≥60% of eligible patients’ parents receiving a mobile care plan. We created a report to measure quantitative data from the EHR and OPP. The date/time when parents opened MCCPs online was a proxy for parent engagement, time elapsed until the CCS team responded to parent messages was a proxy for communication timeliness, and date/time when parents opened messages from the CCS team was a proxy for reading messages. We analyzed quantitative data using descriptive statistics and conducted analyses in SAS (version 9.4; SAS Institute Inc, Cary, NC).

Qualitative methods involved semistructured interviews with a convenience sample of parents of eligible patients (ie, those with an activated OPP account). The interview guide addressed 3 key questions: (1) how families engaged with MCCPs, (2) how MCCPs benefited care for a medically complex child, and (3) what factors facilitated or inhibited families’ use of MCCPs. Interviews were conducted telephonically in January 2017 to overcome potential barriers to participation in face-to-face interviews. Our convenience sample included 14 parents eligible to receive MCCPs; 9 parents completed interviews (50% participation rate). Of these interviewees, 6 had reviewed a MCCP and 1 had received but not yet reviewed a MCCP. Though we did not limit participation by gender, all interviewees were mothers. Audio recordings of interviews were transcribed, and NVivo software (version 11; QSR International, Doncaster, Victoria, Australia) was used to code transcribed data. Data coding included an iterative process whereby an initial schema was developed, based on the interview guide and initial review of the data. Subsequent data review led to refinement and reapplication of revised coding schemas. The Duke Health Institutional Review Board deemed this study exempt.

**Results**

**Participant Demographics**

Sixty-five patients were enrolled in the CCS at the time of analysis (September 1, 2017; 12 months post-MCCP implementation). Fifty of 65 CCS-enrolled patients (77%) had activated OPP accounts and therefore were
eligible to participate in the study. Participant demographics are shown in Table 1.

**Feasibility**

To quantify the prevalence of home Internet and computer/mobile device access, we conducted a preliminary feasibility analysis by surveying parents of all CMC enrolled in the CCS program as of February 1, 2017 (5 months into study period). At that time, 37 of 55 (67%) CMC enrolled in the CCS program responded. Thirty-six of 37 respondents (97%) reported owning a smartphone, 23 of 29 (79%) reported owning a home computer, and 31 of 34 (91%) reported having home internet access.

At the end of the study period (September 1, 2017), 50 of 65 CCS-enrolled patients (77%) had an active OPP account and were therefore eligible to receive MCCPs, and 47 of these 50 eligible patients (94%) had received a MCCP from the CCS team (Figure 1). During the study period, each eligible patient received multiple MCCPs (median = 3; interquartile range [IQR] = 2-4) and a total of 162 distinct MCCPs, including initial MCCPs and updates, were sent. Parents reviewed MCCPs approximately 1 day after receipt (median time to review [hours] = 24.2; IQR = 1.9-266.2).

Parent interviews revealed technical issues and limitations in the MCCPs’ perceived legitimacy with some providers external to the Duke Health system. Examples of technical issues faced by parents included online MCCP access and password challenges. One respondent reported that her home health agency providers were unwilling to accept a MCCP directly from parents, citing a requirement that all medical plans be faxed directly by providers.

### Table 1. Demographic Characteristics of Participants.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total participants, n (%)</td>
<td>50 (100)</td>
</tr>
<tr>
<td>Gender, n (%)</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>22 (45)</td>
</tr>
<tr>
<td>Male</td>
<td>27 (55)</td>
</tr>
<tr>
<td>Age (median; min, max)</td>
<td>7.7 (0.4, 18.5)</td>
</tr>
<tr>
<td>Race, n (%)</td>
<td></td>
</tr>
<tr>
<td>American Indian/Alaskan native</td>
<td>2 (4)</td>
</tr>
<tr>
<td>Asian</td>
<td>3 (6)</td>
</tr>
<tr>
<td>Black/African American</td>
<td>11 (23)</td>
</tr>
<tr>
<td>Caucasian/White</td>
<td>28 (60)</td>
</tr>
<tr>
<td>Multiracial or other</td>
<td>3 (6)</td>
</tr>
<tr>
<td>Hispanic ethnicity</td>
<td>5 (10)</td>
</tr>
<tr>
<td>Months enrolled in CCS program (median; min, max)a</td>
<td>16 (0.3, 35.6)</td>
</tr>
<tr>
<td>30-Day readmission rate (%)b</td>
<td>36</td>
</tr>
</tbody>
</table>

Abbreviations: min, minimum; max, maximum; CCS, Complex Care Service.

aDuration of enrollment in CCS program at time of analysis (September 1, 2017).
bThirty-day readmission rate during the 12 months prior to time of analysis (September 1, 2016, to August 31, 2017).

**Parental Engagement**

Parents reviewed 100 of 162 (64%) distinct MCCPs sent during the study period. Thirty-five of 47 parents (74%) who received at least one MCCP reviewed it online. Of these 35 parents who engaged with the MCCP, 16 (46%) responded to the CCS team after reviewing the original version (Figure 1).

Parents reported in interviews that MCCPs facilitated communication with providers, improved understanding of their child’s medical situation, and reduced stress. Parents reported using MCCPs as a reference for themselves and providers (internal and external) and for communication between parents and internal (Duke) providers. Both paper and electronic care plan versions were seen as useful by parents, depending on context. For example, paper plans were felt to be more reliable than electronic when traveling.

**Communication Timeliness**

After reviewing their children’s MCCPs, 16 parents sent 27 distinct messages to the CCS team and received a response back from the CCS team within 8 hours (median [hours] = 7.2; IQR = 0.3-15.7). Parents did not open 74% of the CCS team’s responses.

Some parents felt the MCCP was less useful when preexisting close parent-provider relationships already provided parents with a clear understanding of the child’s health situation or when the child’s current health status was highly stable or unstable. Illustrative quotes from parent interviews are shown in Table 2.
Discussion

To our knowledge, this was the first study to describe feasibility, implementation, and impact of a MCCP for CMC cared for by a complex care program. We incorporated 3 essential features into a MCCP workflow: (1) electronic transmission of care plans directly to parents; (2) bidirectional electronic messaging between the care team and parents to facilitate parental engagement; and (3) integration within existing EHR and OPP platforms. We demonstrated that integration of MCCPs into care coordination for CMC was feasible, facilitated parental engagement, and delivered timely communication with the care team. In interviews, parents identified MCCPs as an important reference and communication tool that improved understanding of their child’s overall medical situation.

High-need, high-cost populations such as CMC stand to benefit from care plans that leverage technological solutions. Yet, it is unknown how to implement care plan best practice recommendations in real-world settings, and evidence for improved patient outcomes is limited. These evidence and implementation gaps exist because it is challenging to deliver the essential features of an ideal care plan. Plans for CMC should be available across all clinical settings, evolve over time as health status changes, summarize multiple complex conditions, and highlight patients’ and parents’ priorities.

This study had several strengths. First, use of structured criteria to define CMC allowed consistent identification of high-need, high-cost patients to receive MCCPs. While there is no gold standard definition for CMC, our criteria’s foundation was the validated CSHCN Screener. Second, we incorporated best practice recommendations into a standard template for MCCPs and adapted it to our local context with feedback from our hospital’s parent-family advisory council. Third, qualitative interviews provided insights into the parent experience with MCCPs beyond what quantitative analyses alone could have achieved.
Table 2. Illustrative Quotes From Parents About Experiences With Mobile Complex Care Plans (MCCPs).

**Finding 1: MCCP used as a reference and in communication between parents and providers.**

| Reference for parents and providers | “... it would just be much easier to access it (the MCCP) on my phone than to go digging through the backpack or to find out that, for some reason, we switched backpacks and the new paper didn’t make it over.” |
| Use in parent/provider communication | “I would probably keep it (the paper care plan) in her bookbag, just to have it there, should my phone go dead or something like that... it would be more of a backup plan.” |

**Finding 2: With the MCCP, parents experienced facilitated communication with providers, improved understanding of their child’s medical situation, and reduced stress.**

| Facilitated communication with providers | “I printed out a copy for the home health people so that they could have it. We also work with a transition palliative care team and shared it with them. It was just good to see that we were all on the same page.” |
| Improved understanding of child’s medical situation | “I think having that care plan in place; it provides a continuum of care. What we are doing here at home is gonna be carried out at the hospital. Or going from an ER to the floor—from going from the ER to being admitted. Again, it’s just providing that continuum of care that there’s not gonna be crazy changes. And everybody’s on the same page because of this complex care plan.” |
| Reduced stress | “... it’s just been such a relief to have the big picture involved... It’s really hard for me to remember everything... Having that kind of document to be able to give to anybody instead of having to remember it all in my head is really good.” |

**Finding 3: Challenges with MCCPs included technical issues and limitations in the care plan’s perceived legitimacy with providers external to Duke.**

| Technical issues | “... for some reason, I can’t pull it up on my phone. I don’t know why. I can only access it on my computer.” |
| Perceived limited legitimacy to external providers | “... my home healthcare people aren’t allowed to take it (the MCCP) as evidence... they just demand that everything comes in fax form.” |

**Finding 4: Relatively lesser utility of MCCP when the parent and providers had a close relationship, parents had a clear understanding of the child’s health situation, or when the child’s current medical situation was highly stable or unstable.**

| Parents already had clear understanding of child’s health situation | “... we had a lot of teaching and still get a lot of teaching... (the MCCP information is) pretty much already taught in the hospital before we do get to come home...” |
| Highly unstable current medical situation | “You’ve got to take each day by each day because we just don’t know what the next day is... a lot of times, 9 out of 10, there’s things that (... are) not even on the complex care plan at that time.” |
| Highly stable current medical situation | “It’s been a while since I’ve had to use it cuz he (the child) hasn’t had a lot of changes, thank goodness.” |

Abbreviation: ER, emergency room.
Fourth, integration of MCCPs into our existing EHR and OPP facilitated long-term sustainability.

Our study had several limitations. First, we implemented MCCPs within a complex care program at a tertiary care center with an EHR and OPP. While this may limit applicability in other settings, the growth of complex care programs and widespread adoption of EHR highlight the potential for translation to similarly structured sites. Second, implementation of MCCPs relied on complex care nurses, a clinical role that is not widely available. Third, we did not evaluate parents’ understanding of MCCPs’ content following online review. However, nearly half of parents who opened a MCCP sent a response to the CCS team, which likely required adequate understanding of MCCP content. While analysis of the content of parental responses could have clarified their understanding of MCCPs, interviews provided qualitative data to fill this analysis gap. Finally, convenience sampling in interviews may have inadvertently created a non-representative interviewee group. However, our interview participation rate of 50% was comparable to other qualitative studies of parents of CMC.20

Based on these findings, MCCPs remain an essential component of care coordination for CMC enrolled in our institution’s complex care program. Due to similarities between CMC and other high-need, high-cost populations (eg, elderly adults with chronic conditions), this MCCP approach could be adapted in the future to support complex care across the age spectrum.18,19

Conclusions

As the CMC population grows and their care coordination needs further intensify, care plans will play an increasingly vital role to prevent key information from “falling through the cracks.” As care plans are more widely implemented, complex care programs will need an efficient approach that engages parents. By fully leveraging the EHR and OPP, our novel MCCPs offer the potential for care plans to fulfill their promise of being a patient-centered, dynamic, and comprehensive blueprint for CMC, their parents, and their care team.

Appendix A

Criteria to Define Children With Medical Complexity (CMC)

1. To qualify as a CMC, all FIVE (5) of the following criteria must be met:
   a. “Yes” response for CSHCN Screener question indicating “need for more care than usual”
   b. “Yes” response to 3 of 4 of the remaining CSHCN Screener questions
   c. Need for medical technologyb to maintain daily functioning
d. Seen by ≥3 subspecialists in the past 12 months (at Duke Children’s Hospital/Medical Center)
e. High resource utilizationb

*bMedical technology defined as long-term need for any ONE (1) of the following:
   a. Ventriculo-peritoneal (VP) shunt
   b. Long-term enteral feeding tube (eg, G-tube, J-tube, GJ-tube, etc)
c. Long-term central venous catheter (eg, Broviac)
d. Tracheostomy
e. Mechanical ventilation-dependent (includes traditional ventilator or BiPAP)

(*Note: other equipment such as supplemental oxygen, CPAP, mobility aids/devices, insulin needles/syringes, glucometers, vagal nerve stimulator, etc, are not sufficient to meet the medical equipment criteria.)

*bHigh resource utilization defined as any ONE (1) of the following in the past 12 months:
   a. ≥6 emergency department (ED) visits
   b. ≥2 admissions (Duke Children’s only—including current hospitalization)
c. ≥1 intensive care unit (ICU) admission (Duke Children’s only—including current hospitalization)

Appendix B

Template and Standard Elements for Mobile Complex Care Plans

Complex Care Service Care Plan

Date of Last Care Plan Update:
First Name, Last Name:
Date of Birth:
Medical Record Number:
Care Plan Original Creation Date:

Briefly, patient is an X year-old with history of _____ (list key chronic conditions/problems).

“What Matters To Me” (Patient-Centered Goals—as reported by parents)
Long-term
Short-term

Emergency Care Plan

List urgent medical problems that could arise as a result of the patient’s underlying conditions. Specify
appropriate standard initial responses that parents/caregivers can take ("if this happens, take step 1 first, then take step 2, etc). Customize this section to the individual patient.

Parents/Guardians
Names of parent(s), home address, phone number(s), email, Duke MyChart status, names/ages of other family members living in the household

Primary Medical Team
Name of primary care physician (PCP), office address, office phone/fax number

Specialty Care Providers/Team
Names, specialty area, and clinic phone numbers for all specialists involved in patient’s care.

Outpatient Care Coordination Team
Names (provider, agency), area of expertise (eg, physical therapy, home nursing, home health, etc), and phone/fax numbers for all members of outpatient/community-based care coordination team

Preferred Pharmacy
Name, address, phone/fax number

Allergies (as of MM/DD/YYY)
List medication name and reaction type

Medications (as of MM/DD/YYY; review with parents to insure accuracy)

<table>
<thead>
<tr>
<th>Medication</th>
<th>Directions</th>
</tr>
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<tbody>
<tr>
<td>Name (including strength and type—liquid, tablet, capsule, etc)</td>
<td>Include dosing strength and liquid volume (if applicable). Avoid medical jargon and abbreviations.</td>
</tr>
</tbody>
</table>

Diet/Nutrition
Route (eg, by mouth, via feeding tube, etc)
Formula (if tube-fed): Name, strength/caloric density
Schedule: Number of formula feeds per day, volume per feed, and duration (bolus, continuous, etc)
Water Flushes (if applicable): Number and volume per day, frequency

Medical Equipment
List all long-term durable medical equipment needed to support activities of daily living (eg, feeding tube, tracheostomy, suction machine, home oxygen, adaptive stroller, etc)

Medical Synopsis

Patient-Specific Clinical Pearls. List unique clinically relevant features of the patient. For example, patient is globally developmental delayed and is nonverbal at baseline, but she will smile and vocalize. In the past she has become agitated when acutely ill with a urinary tract infection.

Summary of Recent Hospitalizations. List dates and brief summary of clinical course for acute hospitalizations during the past 12 months.

Surgeries/Procedures. List date and type of relevant surgical procedures—pay particular attention to surgeries with long-term implications (eg, gastrostomy tube placement, Nissen fundoplication, tracheostomy, ventriculoperitoneal shunt revisions)

Care plan initiation date: date of initial care plan creation MM/DD/YYYY
Reviewed with patient and/or family on: date when care plan late reviewed with parents MM/DD/YYYY
Last revised: date of last care plan revision MM/DD/YYYY

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Author Contributions
All authors have been involved in the study design, analysis, and manuscript revision. All authors read and approved the final manuscript. DYM is the guarantor who accepts full responsibility for the work and the conduct of the study, had access to the data, and controlled the decision to publish.

Declaration of Conflicting Interests
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