

Telemedicine Video Visits for Children with Medical Complexity in a Structured Clinical Complex Care Program

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Introduction

Children with medical complexity (CMC) are the most medically fragile and costly pediatric population. Due to the complexity of their needs, CMC often receive fragmented care; care fragmentation contributes to high rates of hospital utilization.^{1,2} To address these issues and deliver higher value care, interdisciplinary complex care programs for CMC have been developed to provide high intensity care coordination.²⁻⁴ Care coordination by complex care programs focused on frequent follow-up and outreach post-hospitalization and between clinic visits is mostly conducted via phone calls.⁴ A limitation of phone-based care coordination between parents and providers is the lack of face-to-face interactions, thus limiting opportunities for evaluation of a child's clinical status and relationship building between parent and provider. Face-to-face, real-time care between providers and parents that brings the clinical expertise of complex care programs directly into CMC patients' home is possible via an approach called telemedicine video visits (TMVV).⁵

TMVV's role in the care of acute and chronic pediatric conditions^{5,6} has been demonstrated for infants following neonatal intensive care unit discharge,⁷ families receiving palliative care services,⁸ and children in the emergency department with acute febrile or respiratory illnesses.⁶ In addition to these early promising studies, because of improvements in the hospital-to-home transition process, parents have reported preference for TMVV to in-person care.⁹ These positive attributes position TMVV to have an outsized impact on CMC cared for within interdisciplinary complex care programs.¹⁰ Due to complex care programs' responsibility for coordination of the array of community-based services (eg, home health) and multi-specialty care required to manage CMC's multiple chronic conditions, long-term medical

technology (eg, feeding tube), and intensive home care needs,¹¹ care coordination approaches with greater versatility than phone calls are necessary. Furthermore, delivery of care coordination via TMVV directly into the home is particularly important for CMC because specialty care at the nearest tertiary care center is often >60 miles away, with travel to these clinics complicated by the difficult nature of transporting children dependent on mechanical ventilation or other medical technologies.¹²

Despite the potential benefits, the literature is limited about the role of TMVV for CMC. Early CMC-specific evidence of feasibility and positive clinical impact has been demonstrated in single-center studies of TMVV^{5,9}; however, it remains unclear how best to integrate TMVV into a structured complex care program's routine care of CMC.¹³ Thus, our objective was to describe the implementation of TMVV as part of routine care delivery for CMC receiving care at a tertiary care center-based, structured clinical complex care program.

Methods

Participants and Clinical Setting

This retrospective study was conducted at Duke Children's Hospital, a 190-bed pediatric tertiary care center within a large academic hospital in Durham, NC. In addition to the hospital, Duke Children's operates a network of primary and specialty care services that

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To qualify as a child with medical complexity (CMC), all 5 of the following criteria must be met:

1. "Yes" response for CSHCN Screener © question indicating "need for more care than usual"
2. "Yes" response to 3 of 4 of the remaining CSHCN Screener © questions
3. Need for medical technology* to maintain daily functioning
4. Seen ≥ 3 subspecialists in the past 12 months
5. High resource utilization**

*Medical technology defined as long-term need for any 1 of the following:

1. Ventriculoperitoneal shunt
2. Long-term enteral feeding tube (e.g., G-tube, J-tube, GJ, etc.)
3. Long-term central venous catheter (e.g., Broviac)
4. Mechanical ventilation and non-invasive positive pressure ventilation (e.g., BiPAP)
5. Tracheostomy

**High resource utilization defined as any 1 of the following in the past 12 months:

1. ≥ 6 ED visits
2. ≥ 2 admissions (single institution only)

Figure 1. Enrollment criteria for and services provided by the Duke Children's complex care program.

provides over 190,000 annual ambulatory clinic visits. Children with medical complexity (CMC) defined by internally developed complexity criteria based on the Children with Special Healthcare Needs (CSHCN) Screener¹⁴ (Figure 1) were eligible for care by Duke Children's Complex Care Service (CCS), a complex care program launched in 2014 to serve CMC with most of their specialty care at Duke.¹⁵ Since its inception, 155 CMC have been enrolled for enhanced care by CCS. Patients are cared for by an interdisciplinary team consisting of 2 nurses, 1 nurse practitioner (NP), 1 social worker, with 2 program coordinators, with clinical supervision from 6 pediatric hospitalists who rotate concurrently to support the CCS team while rounding on the inpatient wards. At the time of this analysis (August 2018), there were 100 patients enrolled in the program with a wide range of clinical conditions and diagnoses. CCS participants received multiple interventions, including intensive coordination of care, creation of a comprehensive care plan, regular communication, health system navigation, and direct care delivery from an interdisciplinary clinical team.

Telemedicine Infrastructure

Building on the foundational elements of the CCS care model, in 2016, TMVV was added on as an available intervention. TMVV clinical encounters consisted of face-to-face, real-time videoconferencing between a parent and child in their home and a tertiary care

center-based complex care provider (physician or nurse practitioner). Complex care providers used clinical discretion to determine the need and timing for each video visit. No standardized criteria or protocols were used to determine the need for video visits because during this time, the CCS program was an early adopter of TMVV at our institution and was assisting in early pilot work along with our health system's institutional telehealth office. TMVV maintained patient confidentiality via several key features: (1) each TMVV occurred in a private exam room; (2) the desktop touchscreen monitor (Cisco© DX80) with high-definition camera, internet-connected phone, and microphone used for each TMVV were encrypted; (3) third party software (Cisco Jabber©) used for all TMVV was secured behind our institutional data security firewall; (4) all TMVV were integrated within our institution's electronic health record (EHR; Epic©; Verona, WI) and secure online patient portal (Epic MyChart©). An activated online patient portal account, a mobile device or home computer, and home internet access were requirements for parents to participate in TMVV. Prior to each scheduled TMVV, parents received a test call from the health system's telehealth technical support team to confirm access to the TMVV platform and appropriate home internet speed.

Study Design and Analysis

We conducted a retrospective analysis of all TMVV conducted as part of routine clinical care by CCS providers

Table 1. Demographics of Children Who Received Telemedicine Video Visits (TMVV).

Age, years (mean, range)	7.8 (0.66-15.4)
Race (number, %)	
Caucasian/White	8 (47.1%)
Black/African American	4 (23.5%)
Other	5 (29.4%)
2 or more	3 (17.6%)
Ethnicity (number, %)	
Hispanic/Latino	3 (17.6%)
Non-Hispanic/Latino	14 (82.4%)
Primary language spoken at home (number, %)	
Spanish (interpreter used)	2 (11.8%)
English	15 (88.2%)
Payer (number, %)	
Public	10 (58.8%)
Private	7 (41.2%)
Months enrolled in CCS (mean, range)	12.5 (0-45)
Unique qualifying CCC codes* (number, %)	
0-3	2 (11.8%)
4+	15 (88.2%)
Medical technology (number, %)	
Feeding tube	17 (100%)
Ventriculoperitoneal (VP) shunt	3 (18%)
Positive pressure ventilation (home vent or BiPAP)	2 (12%)
Central line	2 (12%)
Tracheostomy	1 (6%)
Other	2 (12%)

*CCC (pediatric complex chronic conditions) data derived from patient-level EHR data of hospital and outpatient encounters completed prior to first video visit.

between January 2016 and August 2018. We utilized a structured data collection tool to manually abstract information from clinical notes in the EHR. All data were analyzed using descriptive statistics. For patients that returned to the ED within 30 days of their TMVV, 2 practicing pediatricians (D.M., L.P.) independently reviewed the EHR notes from the completed TMVV and the first post-TMVV ED visit to assess preventability of the visit on a 4-point scale developed for the Institute for Healthcare Improvement's STAAR (State Action on Avoidable Rehospitalizations) Readmissions Diagnostic Worksheet and previously validated in the pediatric population.¹⁶ Description of subsequent post-TMVV ED visits were limited to internal health system EHR data. The Duke Health Institutional Review Board reviewed and approved this study.

Ethical Approval and Informed Consent:

This study was reviewed and approved by the Duke University Health System IRB (Protocol ID: Pro0010019, Reference ID: 293748).

Results

Demographics

25 TMVV were conducted with 17 CMC receiving care with the Complex Care Service (CCS) at the time of their TMVV (mean duration of CCS enrollment before TMVV = 12.5 months; Table 1). At the time of TMVV, all participants had long-term feeding tubes, 18% had ventriculoperitoneal (VP) shunts, 18% received long-term respiratory support—for example, tracheostomy, mechanical ventilation, or positive pressure ventilation, and 93% had 4 or more complex chronic conditions (Table 1).¹⁷

Visit Characteristics

Physicians conducted 64% of TMVV; a nurse practitioner conducted 36% of TMVV. Visits averaged 33 minutes (range = 12-60) and the median time from the TMVV until the next scheduled clinic visit was 7 days (IQR = 3-17). 88% of TMVV were for hospital follow-up and occurred on a median of 12 days (IQR = 7, 20)

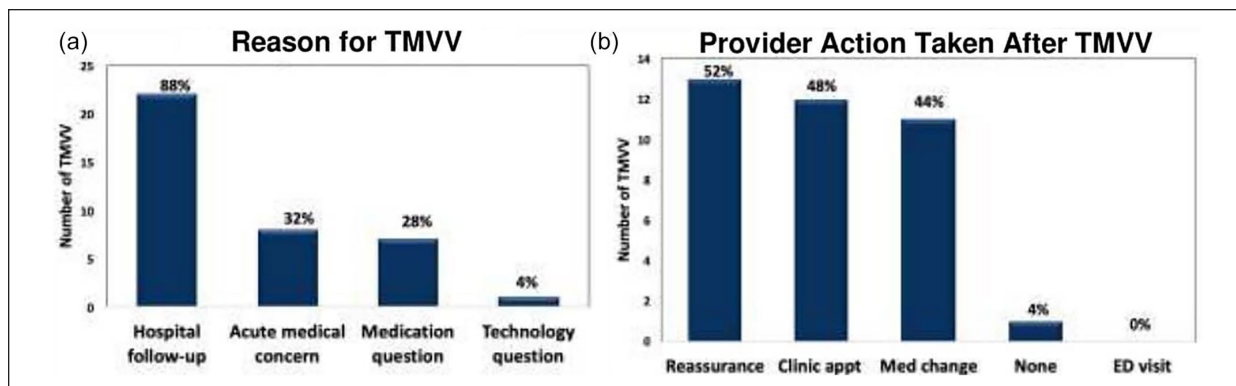


Figure 2. (A, B) Characteristics of TMVV.

post-discharge. Analysis of TMVV notes revealed that in 32% of visits parents had acute medical concerns, medication changes were made in 44% of visits, a specialty clinic appointment was scheduled in 48%, and a change to the patient's care plan was made in 36% (Figure 2). All TMVV were documented within the EHR using a standard telemedicine visit note, which was entered in the EHR as an encounter. Based on review of complex care providers' EHR documentation, the child was directly visualized in 96% of visits; however, no patients were documented as acutely "sick" or "ill-appearing."

Post-TMVV Emergency Care Utilization

Immediately after each TMVV no children were sent by the complex care provider directly to the emergency department (ED). Among those who subsequently returned to the ED within 1 year post-TMVV ($n = 20$), the median time from the TMVV to the next ED visit was 44 days (IQR 15-105), with 4 (25%) returning to the ED within 1 week post-TMVV and 9 (45%) presenting to the ED within 1 month post-TMVV. 71% of ED visits within 1 month post-TMVV were for respiratory distress and 14% were for medical technology failure. The presenting complaints for all 9 ED visits within 1 month post-TMVV were determined by independent physician chart reviews to be somewhat or very unlikely to have been preventable.

Discussion

To our knowledge, this study was the first to describe the implementation of TMVV for CMC within a tertiary care center-based complex care program. Each TMVV provided real-time video interaction between a complex care provider and the parent/child in their home, and all visits were integrated within the EHR. The results of this

study provided evidence of the feasibility of implementing TMVV for CMC within an existing complex care program, and utilizing TMVV to address common post-hospitalization clinical issues.

This study's insights into how to utilize TMVV for CMC differed from other studies in the literature. First, instead of telephone contact, which was the basis for most telemedicine visits in 1 prior study,¹⁸ we used video exclusively for all encounters. Second, in contrast to other studies, we integrated TMVV into routine clinical care and the EHR. Integration of TMVV into the EHR made clinical documentation visible to other providers and payers. Finally, compared to prior studies our population of CMC was more medically complex. 88% of participants had 4 or more complex chronic conditions, compared to only 41% in peer institutions' complex care programs.² Additionally, all of our patients had long-term medical technology dependence, compared to 69% in peer programs.²

In addition to feasibility of TMVV for CMC, we observed evidence of safety of the intervention. First, video visits for post-hospitalization follow-up all occurred in a timely manner (median 7 days). This timeframe aligns with consensus guidelines about recommended post-hospitalization follow-up.¹⁹ Second, while our ED return rate was higher than previously reported data from other complex care programs,² this can be explained by stringent inclusion criteria for the CCS model that selected a more complex and chronically ill patient population. Third, when patients returned to the ED post-TMVV, it was for unrelated concerns, such as respiratory distress due to an acute respiratory infection, and none of these visits were rated by attending physicians as preventable.

This study had several limitations. First, this was a single center study with a small sample size of patients with higher medical complexity relative to other centers'

definition of CMC.² Centers without a complex care program for CMC may not be able to directly apply these findings because our study participants were already engaged with the existing complex care program. Second, the study's focus on our complex care program's implementation of TMVV did not allow for measurement of TMVV's impact on health outcomes. Third, we did not implement a structured protocol to guide the content of each TMVV; instead, each visit's content was driven by the complex care provider's clinical decision-making. Fourth, because all participants had existing access to key technological resources—for example, home internet and a device—and adequate digital literacy to navigate the online patient portal, the positive findings we observed may have reflected our population's baseline level of comfort with technology. Future work should explore the degree to which access to digital resources is a barrier for telehealth participation by CMC, and seek to understand what health outcome disparities result from differential technology access. Finally, the retrospective nature of this study made it challenging to measure downstream effects on health-care utilization; further prospective studies are needed to quantify the benefits of TMVV in this population.

Several strengths of this study highlighted the applicability of the approach to other pediatric complex care programs. Allowance of complex care providers to use clinical decision-making to determine timing of video visits and integration of TMVV into the EHR facilitated pragmatic adaptation for real-world clinical practice. A key factor for successful real-world clinical complex care is continuity of care, particularly after hospitalizations; embedding TMVV within an existing complex care program facilitated care continuity. Furthermore, continuity via videoconferencing as the main telemedicine method, instead of phone calls, provided parents and providers with real-time, bi-directional interactions. Finally, real-time videoconferencing interactions are possible using a broad range of existing platforms and are not restricted to the specific platform or technological tools that we utilized. Close partnership with our health system's institutional telehealth office was key to successful technical implementation and integration of TMVV with our EHR.

This study demonstrated that TMVV were feasible, safe, and could be integrated into the EHR within the framework of an existing complex care program for CMC. Future directions for this research include the implementation of a standardized approach to post-hospitalization TMVV by complex care providers, measurement of TMVV's impact on outcomes, understanding experiences and preferences of parents/caregivers with TMVV, and exploring the role of TMVV to reduce

health disparities among CMC. TMVV has the potential to revolutionize how medically complex patients interact with the healthcare system. Further understanding of how to apply this technology for the most vulnerable patients will facilitate delivery of the patient-centered care that complex patient populations require.

Authors' Note

This research was shared as an abstract at the 2019 Pediatric Academic Societies meeting in Baltimore, MD.

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Author Contributions

MHR and DYM conceptualized and designed the manuscript; collected, analyzed, and interpreted data; drafted the initial manuscript; reviewed and revised the manuscript; and approved the final manuscript as submitted. TGS analyzed and interpreted data; reviewed and revised the manuscript; and approved the final manuscript as submitted. LSP collected data; reviewed and revised the manuscript; and approved the final manuscript as submitted.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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