Parent Perspectives During Hospital Readmissions for Children With Medical Complexity: A Qualitative Study

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ABSTRACT

OBJECTIVES: Children with medical complexity (CMC) have high readmission rates, but relatively little is known from the parent perspective regarding care experiences surrounding and factors contributing to readmissions. We aimed to elicit parent perspectives on circumstances surrounding 30-day readmissions for CMC.

METHODS: We conducted 20 semistructured interviews with parents of CMC experiencing an unplanned 30-day readmission at 1 academic medical center between December 2016 and January 2018, asking about topics such as previous discharge experiences, medical services and resources, and home environment and social support. Interviews were recorded, professionally transcribed, and analyzed thematically by using a modified grounded theory approach.

RESULTS: Children ranged in age from 0 to 15 years, with neurologic complex chronic conditions being predominant (35%). Although the majority of parents did not identify any factors that they perceived to have contributed to readmission, themes emerged regarding challenges associated with chronicity of care and transitions of care that might influence readmissions, including frequency of hospital use, symptom confusion, lack of inpatient continuity, resources needed but not received, and difficulty filling prescriptions.

CONCLUSIONS: Parents identified multiple challenges associated with chronicity of medical management and transitions of care for CMC. Future interventions aiming to improve continuity and communication between admissions, ensure that home services are provided when applicable and prescriptions are filled, and provide comprehensive support for families in both the short- and long-term may help improve patient and family experiences while potentially decreasing readmissions.

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Dr Leary contributed to the conceptualization and design of the study, conducted analyses, drafted the initial manuscript, and reviewed and revised the manuscript; Ms Krcmar aided in codebook design and software application, conducted analyses, and reviewed and revised the manuscript; Ms Yoon assisted with data collection, conducted analyses, and reviewed and revised the manuscript; Dr Freund contributed to the conceptualization and design of the study and reviewed and revised the manuscript; Dr LeClair contributed to the conceptualization and design of the study, supervised data collection, conducted and supervised analyses, and critically reviewed the manuscript; and all authors approved the final manuscript as submitted.
Children with medical complexity (CMC) represent a growing population of children who are relatively medically fragile, requiring more intensive care and sometimes technology assistance.\(^1\) In comparison with the general pediatric population, CMC are more dependent on effective functioning of family, social, and health system networks to improve their care and outcomes.\(^2,3\)

Although CMC represent only 1% of the pediatric population, they account for approximately one-third of child health care costs, which are largely attributable to inpatient hospitalizations and readmissions.\(^4,5\) In this context, a comprehensive understanding of the circumstances surrounding readmission for CMC is desirable to facilitate the development of interventions. Some previous studies have used claims or administrative data to determine risk factors for readmission among CMC,\(^6,9\) but fewer qualitative studies have evaluated more nuanced and contextually complex circumstances surrounding their hospitalizations and transitions of care, none of which were conducted within the specific context of unplanned readmissions.\(^7,8\)

We therefore aimed to elicit parent perspectives during hospital readmissions regarding the care of CMC with the goal of identifying opportunistic areas to target interventions to improve care and experiences while potentially decreasing readmissions for CMC and their families.

METHODS

Hospital and Participant Characteristics

The sample was drawn from 1 urban academic medical center consisting of a pediatric hospital nestled within a larger adult care system. The pediatric hospital is a 128-bed teaching institution with learners including medical students, pediatric medical and surgical residents, and subspecialty fellows. The hospital did not have a pediatric complex care program at the time of this study, but twice weekly an interdisciplinary group (pediatric hospitalists, subspecialists, nurses, case managers, social workers, and clinical documentation specialists) conducted a roundtable meeting, during which members discussed admitted CMC to help with coordination of care and discharge planning and improve physician documentation. Potentially eligible participants were identified through review of daily hospital readmission logs containing information about patients experiencing a 30-day readmission, such as name, age, hospital location, primary diagnosis and diagnostic codes, and whether the readmission was scheduled or unscheduled. We applied Feudtner’s complex chronic conditions taxonomy using the diagnostic codes to determine which patients met eligibility for being medically complex.\(^10\)

Exclusion criteria included patient age \(>17\) years and those with parents who were nonproficient in the English language. Patients were purposively sampled to include a variety of pediatric ages and complex chronic condition categories.

Data Collection

Between December 2016 and January 2018, 20 semistructured interviews were conducted by trained research assistants, none of whom were part of the patients’ medical teams, during weekdays and daytime hours. Once potentially eligible children were identified, the study team worked with the floor nurses to find a time when a parent was present to obtain consent and conduct the interview. Children \(\geq 7\) years old were also required to give assent for their parent to be interviewed. If eligible participants were initially unavailable, the research team continued to attempt to make contact daily until the participants were enrolled, declined participation, or were discharged. The study team developed and adapted the interview guide (Supplemental Fig 2) on the basis of the analysis from the team’s previous study of adult readmissions.\(^22\) The adult interview guide had been developed with input from multiple stakeholders, including the hospital’s Patient and Family Advisory Council and Readmissions Task Force, which consisted of physicians, nurses, pharmacists, case managers, social workers, quality-improvement experts, and patient relations representatives. Questions probed patient and/or family experiences with original discharge, reasons for return to the hospital, adequacy of home care, and socioeconomic resources. Example modifications for use in the pediatric population included additional questions probing other dependent care required of parents and alterations in daily activities after discharge for both the children (eg, sports and school) and parents (eg, work). The pediatric interview guide was pilot tested with a medically complex pediatric patient and family to ensure comprehension and ability to elicit complete and meaningful responses.

To describe the study cohort, the qualitative data were augmented with sociodemographic and clinical information from the electronic health record, including age, race, insurance type, and original discharge disposition.

Analysis

Interviews were professionally transcribed verbatim, and all identifying information was removed. Transcripts were then uploaded to Dedoose software for analysis by using a modified grounded theory approach. A deductive codebook was created on the basis of the interview guide, and then 4 members of the research team participated in development of the codebook in an iterative process.\(^23\) Three team members first reviewed a subset of 3 transcripts; each coder reviewed 2 transcripts, and each transcript was reviewed by 2 coders. We revised and added codes on the basis of consensus and solidified code definitions. This process was repeated for an additional 3 transcripts, after which it was determined that no new codes were arising and that codes were being applied in a consistent manner among team members. The codebook was finalized, and 3 members of the research team coded remaining transcripts independently. The lead author reviewed all coding, and disagreements were resolved through consensus. The data were then analyzed thematically by reviewing excerpts corresponding to the most frequently used codes to determine recurrent themes.\(^24\) Two members of the research team continued to
meet periodically throughout the data collection process to discuss the interviews and arising themes and to determine when thematic saturation had been reached, after which interviews were discontinued. This study was approved by the medical center's institutional review board.

RESULTS

There were 108 CMC who experienced an unplanned 30-day readmission during the period under study (Fig 1). After exclusion of 9 CMC with parents who were nonproficient in English, approximately half were discharged from the hospital before approach, and 15 were not approached to purposively sample patient ages and complex chronic disease categories. Of the remaining eligible subjects, one-third were unavailable at the time of study team approach, resulting in 20 interviews. No parents who were approached declined participation. Interviews lasted 40 minutes on average.

Participant Demographic and Clinical Characteristics

Patients ranged in age from 0 to 15 years, with 60% being girls, 65% being of white race, and nearly half being publicly insured (Table 1). Neurologic complex chronic conditions were most predominant (35%), followed by cardiovascular, gastrointestinal, and hematologic conditions. The majority of patients (65%) had been discharged without services after their most recent admission. The median time to readmission from the index admission was 5 days. Compared with this enrolled population, those who were eligible but not enrolled were younger (median age 3 years), more likely to be publicly insured (55%), and less likely to have been discharged without services (45%).

Emergent Themes

Although parents did discuss the acute circumstances surrounding their children's readmissions when asked directly, they also discussed their experiences caring for CMC more broadly. Recurring themes emerged regarding challenges associated with either chronicity of care, including (1) frequency of hospital use, (2) symptom confusion, and (3) lack of inpatient continuity, or transitions of care, including (1) resources needed but not received and (2) difficulty filling prescriptions (Table 2).

The majority of participants did not self-identify any factors that they perceived to have contributed to the present readmission, and no recurrent themes emerged regarding parent-described reasons for readmission. Multiple parents even stated that they felt that some hospitalizations were inevitable for their children, given the children's underlying complex conditions and poor physiologic reserve. For example, 1 parent stated, "Her heart defect's just getting worse and worse, so it's not a shock that we came back." Another parent expanded on this perceived inevitability, stating, "Honestly, her coming back and forth, I don't think the hospital here, or anything [we could've] done at home, would've made it preventable." The few factors that individual parents stated may have contributed to readmission included perceived premature departure from the hospital, poor communication of care plans, misdiagnosis of chronic disease progression, and inability to fill prescriptions or obtain medical devices (Table 2).

Chronicity of Care for CMC

Frequency of Hospital Use

Many family members discussed the sheer frequency of hospitalizations that they experienced caring for a child with a complex chronic condition and the associated challenges, such as routine disruption. Some parents expanded on this issue, expressing that they felt they were forced to become medical experts because of the constant care required of them and frequent interactions with the health care system. Other parents reported that the high frequency of hospitalizations made them even more eager to go home during admissions, and 1 even expressed that this contributed to their readmission, stating, "She came back because we rushed her out of here. It wasn't a hospital issue; it was us, 100%.

Symptom Confusion and Lack of Clear Diagnoses

Many parents reported that during the long course of a complex chronic condition, they and their medical providers grew accustomed to seeing patterns of recurring...
symptoms in their children, and this presented a challenge in the diagnosis of new acute problems versus complex disease progression, making it difficult to determine when escalation of medical care was necessary. For example, 1 parent stated, “Basically, she was bound up [constipated] from the anesthesia, and it projected the same symptoms as a shunt malfunction.” Other parents, however, reported the converse situation, when actual symptoms associated with their complex disease were confused with more simple diagnoses; 1 parent expressed that this directly contributed to their child’s readmission.

Lack of Inpatient Continuity

Multiple parents described, in the setting of their children’s frequent hospitalizations, a lack of continuity, both between admissions and during the course of a single admission, given the variety of care settings and medical teams involved in their children’s care. For example, 1 parent described discontinuity between admissions related to poor communication and expressed that the family’s ensuing frustration caused their hastened departure from the hospital, stating, “You keep changing doctors and reexplaining yourself, and nobody has a clear idea of what to do. … Last time, we were, like, ‘No, we’re not gonna just stick around and wait’… because it was, like, going all over again, going through the same stuff.” Other parents expanded on this issue, describing lack of continuity due to difficulties with communication and “complex” data gathering for both the medical teams and caregivers. Some parents described a similar sense of discontinuity even inadmission related to the variety of care settings and subspecialty care required for their children. For example, 1 parent expressed poor communication of the medication administration plan between medical teams during transition from intensive care, reporting that the poor communication may have contributed to their child’s readmission.

In contrast to the aforementioned discontinuity, however, multiple families also reported that the chronicity of medical management for their children had allowed them to develop positive longitudinal relationships with their care teams and a sense of a medical home. For example, 1 parent stated, “We came here 6 years ago because of the doctor who specializes in his brain tumor. [The doctor] was the one that created a good relationship with him; he had his [surgery] at [another hospital], but he didn’t want to go back. He said ‘I wanna go to my hospital.’” Similarly, another parent expressed, “We’ve moved all her doctors from [another hospital] to here, so now we have all of her doctors in 1 group so that they can share the information, and it seems like [there is a] better quality of care.”

Transitions of Care for CMC Resources Needed but Not Received

When transitioning from hospital to home, multiple parents described services or resources that they perceived were needed but not provided or received. For example, 1 parent reported that the inpatient team had prepared necessary home services and prescriptions before discharge, but the plan could not be implemented once the family was home: 1 medication was not available through the hospital’s pharmacy, and delivery of a cough-assist device was delayed by the vendor.

At the same time, parents were thinking beyond the hospital-to-home transition and described challenges with resources more broadly, including lack of comprehensive and/or long-term services and transitions of services with age. For instance, 1 parent of a child with sickle cell disease stated, “As far as being able to help manage all these pain crises, them having some kind of [comprehensive, long-term] game plan, help [ing] cope with things, giving resources, the hospital being ‘the solution’ doesn’t feel like a solution.”

Difficulty Filling Prescriptions

Another common issue reported by parents in the setting of care transitions was difficulty filling prescriptions. A few families described challenges with prescriptions during the acute-hospital-to-home transition, including difficulty finding certain formulations and lack of availability of more complex medication regimens at any particular pharmacy. This was 1 of the few instances in which a participant identified a factor that she felt may have directly contributed to the present readmission.

However, parents also reported challenges filling prescriptions in the longer-term, when transitioning from the prescription at discharge to first refills and beyond. For example, 1 father described his experience with refills, “Sometimes, if the insurance is covering, that’s it. [But] sometimes, you need the doctor to write the prescription and send [it] to the insurance; sometimes if I need them right away, I buy out of pocket.” He reported only sporadically being reimbursed by insurance.

DISCUSSION

Relatively little is known from the parent perspective regarding experiences with care surrounding readmissions and factors...
TABLE 2 Domains and Emergent Themes Identified in Interviews With Representative Quotations

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<thead>
<tr>
<th>Domain</th>
<th>Theme</th>
<th>Representative Quotations</th>
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<tbody>
<tr>
<td>Challenges associated with chronicity of care</td>
<td>Frequency of hospital use</td>
<td>“For the past 2 months, we’ve been in and out [of the hospital] … We’ve been through this for a long time.”</td>
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<td></td>
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<td>“This is not our last time that we’re gonna be here. Maybe this year, we’re gonna come here at least… 10 times.”</td>
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<td></td>
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<td>“For sure, I could be a doctor [after this whole thing transpired].”</td>
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<td>Symptom confusion and lack of clear diagnoses</td>
<td></td>
<td>“I think everyone went with what she usually has, which is the sickle cell pain crisis; it was all of the same symptoms, same type of pain.”</td>
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<td>“I requested a GI consult, but they refused it, treating it as constipation and telling me that things have to work themselves out. Because of her history, I felt that she needed more than that; she suffered for, you know, two-and-a-half weeks longer than necessary.”</td>
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<td>Lack of inpatient continuity</td>
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<td>“Every time we come, we have different doctors; it’s just a mess because you have to explain yourself all over again and say, ‘You cannot do this because they already did that.’”</td>
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<td></td>
<td></td>
<td>“It is very complex. There’s no 1 place to go for correct information… because you can go to a lot of different places and get information, but it’s not always right.”</td>
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<td>Challenges associated with transitions of care</td>
<td>Resources needed but not received</td>
<td>Short-term: “I felt that we really could have used VNA already [after discharge], but it wasn’t until after the 2 week post-op visit to the surgeon, to the clinic, that [we were referred].”</td>
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<td>Short-term: “I really think it was the confluence of these 2 things, not being able to get the med and device not available until [3 days after discharge], that landed [the patient] back in the hospital.”</td>
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<td>Longer-term: “Right out of early intervention, you don’t know where to go for help; you kind of piece it together through friends. Something needs to be done between the time they get off of early intervention and 6 years later, when parents finally figure it out.”</td>
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<td></td>
<td>Difficultly filling prescriptions</td>
<td>Short-term: “I had to go to 2 different pharmacies to get the right 1. The liquid form of 1. And then it so happened that [the medication] didn’t work, so they prescribed a different medication, but because we’re so far from [the city], I couldn’t get [the prescription], so [the doctor] called in an emergency prescription to a local pharmacy for us.”</td>
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<td></td>
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<td>Short-term: “One of [the medications] wasn’t available. I was going to get it at [another local pharmacy] but never got that far. …[The patient] deteriorated so quickly.”</td>
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<td>Longer-term: “We had trouble with the refill. Originally, when we left here, [the hospital] gave it to us with no problem. We’re still having trouble getting it approved by insurance and finding a pharmacy that will compound it. It’s not been easy.”</td>
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Gl, gastrointestinal; med, medicine; VNA, visiting nurse association.

† Parent self-identified as a contributor to readmission.

Contributing to readmissions for CMC. Although we interviewed parents and their CMC specifically within the context of a 30-day readmission, the themes that emerged from the data were largely about the challenges associated with chronicity of care, including lack of continuity between hospital admissions, as well as challenges with care transitions, such as difficulty filling prescriptions and obtaining consistent resources as children age. Although some of these issues may be viewed as potential influencers of readmissions, few were self-identified by parents as having contributed to readmission. Having a better understanding of these parent-described challenges may allow practitioners and investigators to take a patient- and family-centered approach to intervention development to improve medical care and family experiences while also having the potential to prevent some readmissions for this vulnerable population.

Previous qualitative studies in both the general and medically complex pediatric populations determined that the majority of hospitalizations and readmissions are perceived as unavoidable, the perspectives of parents in our study support these findings, with the majority of respondents not identifying any factors that they believed contributed to their readmissions. Nelson et al. found that most parents of CMC at 1 freestanding children’s hospital recognized that their children had high susceptibility to hospitalizations because of their underlying conditions; these sentiments were also reported by parents in our population. Other studies have focused on parent priorities during the hospital-to-home transition for medically complex children, identifying items such as caregiver self-efficacy for care management and normalization of home routine as core caregiver goals. The authors of 1 Canadian study aimed to understand the “intense parenting” experiences of caregivers of CMC within the context of their home lives, describing the extraordinary and labor-intensive efforts required of...
parents while raising children with complex needs. Unlike the authors of previous studies, we explored the circumstances specifically surrounding hospital readmissions and identified parent-perceived challenges over a broader range of experiences, including in-hospital and hospital-to-home transitions, as well as long-term care experiences. Although parents did report some shorter-term issues, such as poor communication intrahospitalization, they also described longer-term challenges associated with the chronicity of their medical care, such as difficulty refilling prescriptions and obtaining consistent resources as their children aged. Accordingly, multiple parents stressed a desire for coordinated and comprehensive care, not just in the acute setting but fluidly throughout the medical journey.

Some of the parent-described challenges identified in our study may not be modifiable. For example, some diagnostic challenges between acute self-limiting problems and complications of chronic conditions may be unavoidable given the underlying patient complexity. However, other challenges identified by parents in our study may potentially be modifiable and could guide practitioners and investigators in more patient-centered and strategic approaches to intervention development. These parent-reported challenges may also offer support for hospital administrators and policy makers aiming to provide multidisciplinary and comprehensive care coordination for CMC as well as compensation for care coordination services. For example, because parents identified discontinuity between hospital admissions, hospital administrators and providers may consider the following: (1) creating inpatient complex care teams with core personnel who know families well, (2) creating inpatient consult services with early involvement of providers from outpatient medical homes, or (3) increasing visibility of and ease of access to the most vital information required for each patient's care within electronic health records. Filling prescriptions and obtaining insurance coverage for refills were also problematic for families in our study; practitioners and administrators may consider developing systems to help families identify pharmacies that are capable of filling their prescriptions before discharge and longer-term services to support families and primary care physicians as they navigate complications with insurance coverage. Other challenges with longitudinal care, such as difficulty obtaining necessary resources as children age, would be best tackled through a multidisciplinary approach with the integration of social and medical services. In addition to complex care coordination services, hospital administrators may consider basic social service education for providers or consistent use of screening tools to identify those in need of social services.

Our study findings must be considered within the context of several limitations. Because our study was performed at 1 pediatric hospital nested within a larger academic center, our results may not be reflective of caregiver perspectives in other regions or hospital settings. Also, by allowing for the inclusion of children with any type of complex chronic condition, different themes may have arisen than would have occurred within specific CMC subgroups (e.g., technology-dependent children). We were unable to reach many families of patients with short readmissions; although the characteristics of our enrolled participants more closely reflect the institution's broader population of CMC compared with those not enrolled, it is possible that families not enrolled may have provided different perspectives. We were only able to interview 1 family with a child who was originally discharged to a subacute facility, and it is reasonable to believe that families working with other facilities may experience additional challenges. Finally, staffing limitations restricted the time of day and language in which interviews could be performed; it is possible that parents who were unavailable during daytime hours and/or those who were nonproficient in English may have additional or different viewpoints from those described.

CONCLUSIONS

Parents of CMC identify multiple challenges associated with chronicity of medical management and transitions of care. Future interventions aiming to improve continuity and communication between admissions, ensure that home services are provided when applicable and prescriptions are filled, and provide comprehensive support for families in both the short- and long-term may help improve care and patient and family experiences while potentially decreasing readmissions.

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We thank Anays Murillo for her assistance with the creation and organization of Table 2.

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