BRIEF REPORT

Challenges Following Hospital Discharge for Children With Medical Complexity

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ABSTRACT

OBJECTIVES: The transition from hospital to home is a period of risk, particularly for children with medical complexity. Our aim was to identify and address discharge challenges through execution of postdischarge phone calls.

METHODS: In this prospective study, we designed and executed a postdischarge phone call for patients discharged from an inpatient complex care team between May and November 2018. The call included dichotomous and open-ended questions to identify challenges regarding health status, follow-up appointments, medications, home nursing, medical supplies and/or equipment, and discharge instructions. These were recorded in the electronic health record. Details regarding identified challenges and corrective actions were categorized by 2 reviewers and adjudicated by a third reviewer if disagreement occurred.

RESULTS: Descriptive statistics were used to summarize these findings. Sixty-seven phone calls were completed within 1 week of discharge. Two-thirds of calls identified at least 1 challenge, and more than one-third of calls identified 2 or more challenges for a total of 90 challenges. The most common challenges involved health status (26.7%), follow-up appointments (21.1%), and medications (20%). The majority of challenges were addressed by either caregivers or the multidisciplinary team, with the exception of home nursing challenges.

CONCLUSIONS: Discharge challenges were commonly identified by caregivers of children with medical complexity. The majority of postdischarge challenges were addressed, with some addressed by families themselves. These results can inform health care providers about challenges to anticipate and suggest future interventions to mitigate anticipated challenges for a safe discharge and transition of care for these at-risk patients.

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Children with medical complexity (CMC) account for 10% of pediatric hospital admissions yet account for 25% of all pediatric hospital days and >50% of readmissions.[1,2] Identified as an area of importance by providers and families of CMC, suboptimal hospital-to-home transitions increase the risk of unsatisfactory outcomes, including family stress, medication errors, poor outpatient follow-up, and increased readmissions. CMC attributes necessitate thorough discharge planning processes to ensure safe transitions home. Although inpatient care models, discharge efficiency strategies, and caregiver perspectives on hospital-to-home transitions have been studied in CMC,[3–7] we identified an opportunity to actively explore and mitigate challenges experienced by this population in the immediate postdischarge period in real time. Thus, our objective was to identify challenges experienced by CMC in the week after hospital discharge, categorizing which challenges were addressed by the family and care team.

METHODS

Study Design and Population

This single-center, prospective study used postdischarge phone calls to identify and address hospital-to-home transition challenges. Eligible patients and families were discharged from our multidisciplinary inpatient complex care team[7] between May and November 2018 (Fig 1). Patients met criteria for this team if they were technology dependent, required 3 or more active consults during admission, or were followed by our outpatient complex care medical home or hospice care team.

Postdischarge Phone Call

To identify challenges, we created a phone call script that was based on a previously published predischarge needs assessment.[6] Dichotomous and open-ended questions elicited challenges in key discharge coordination areas including health status, medications, home care needs, medical supplies and/or equipment, and follow-up appointments (Supplemental Table 4). The script was refined via discussions with our multidisciplinary complex care colleagues and pilot testing with families. We defined the postdischarge period as the week after hospital discharge. Inpatient complex care team advanced practice registered nurses (APRNs) completed the phone calls and

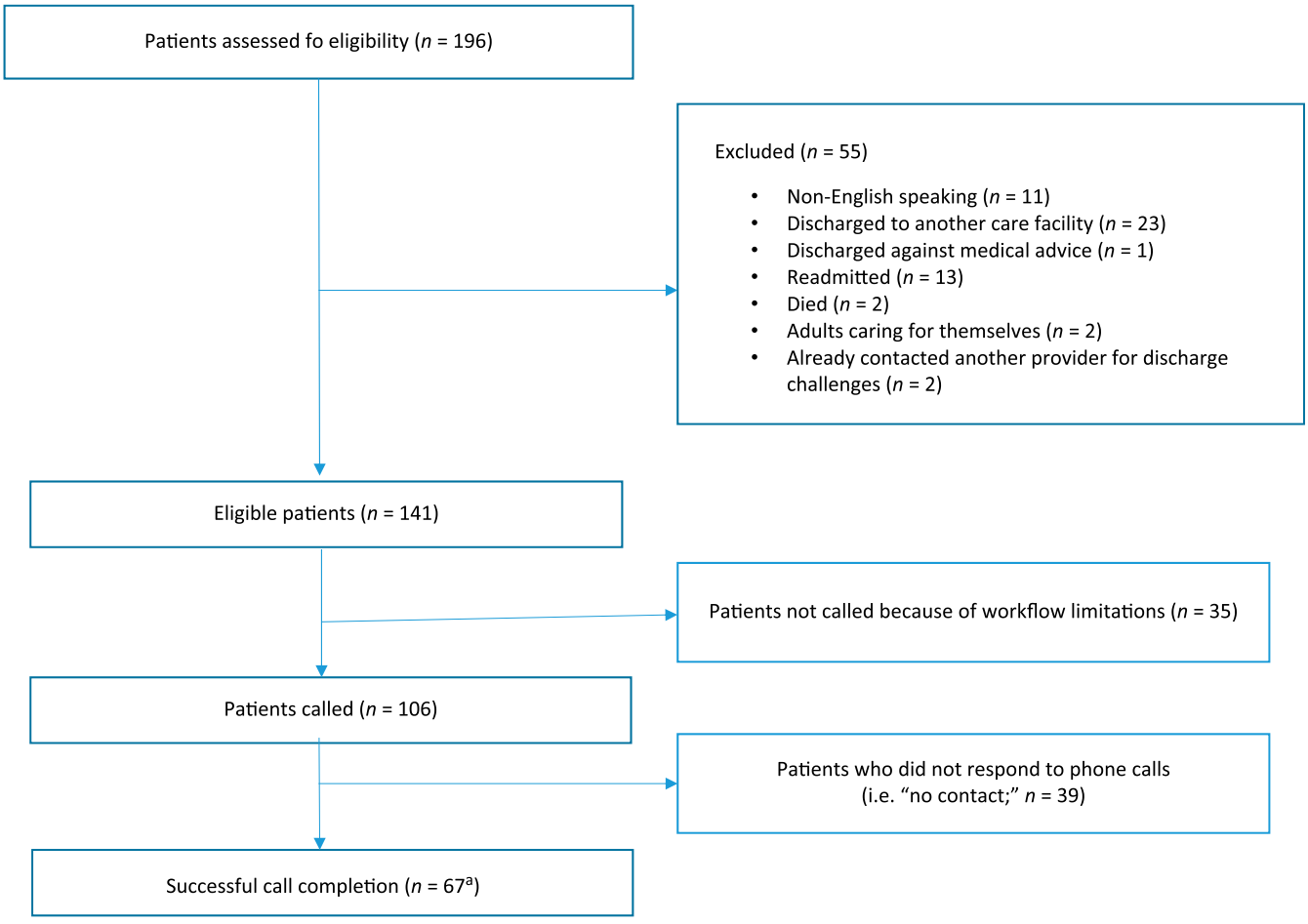

FIGURE 1 Study participant flow diagram. [a] Of these 67 hospitalization encounters, 15 patients were admitted more than once and were contacted for multiple discharge occurrences.

TABLE 1 Patient Demographics

	Patients, n (%)
Male sex	25 (56.8)
White race	36 (81.8)
Public insurance	31 (70.5)
Reason for admission	
Gastrointestinal (eg, constipation)	25 (37.3)
Respiratory (eg, pneumonia)	18 (26.8)
Neurologic (eg, seizures)	13 (19.4)
Other	11 (16.4)
Length of stay, median (IQR)	5 (2–11)
Complex chronic conditions	
Gastrointestinal	42 (95.5)
Neurologic and/or neuromuscular	41 (93.2)
Congenital and/or genetic defect	39 (88.6)
Cardiovascular	31 (70.5)
Respiratory	28 (63.6)
Metabolic	28 (63.6)
Miscellaneous	24 (54.5)
Renal and/or urologic	22 (50)
Neonatal	11 (25)
Hematology	8 (18.2)
Immunodeficiency	
Malignancy	5 (11.4)
Technology assistance	
Gastrointestinal	42 (95.5)
Respiratory	20 (45.5)
Neurologic	11 (25)

recorded details in the electronic health record. APRNs attempted to contact families at least 24 hours after discharge; each family was called up to 3 times before considering a family "no contact." Efforts were made to address challenges with assistance from multidisciplinary team members (eg, pharmacist to help resolve medication challenges).

Measures

At the time of study enrollment, the electronic health record was reviewed to gather information regarding patient demographics and clinical characteristics including complex chronic conditions and technology dependence.[8,9] Two study members (A.L. and A.M.) independently described calls in which a challenge was identified, categorized the challenge, and assessed whether challenges were addressed. A third reviewer (J.T.) arbitrated disagreements.

Analysis

Categorical variables were summarized by using counts and frequencies; continuous variables were summarized by using medians and interquartile ranges (IQRs). Descriptive statistics were used to enumerate the number of discrete challenges identified, calculate the proportion of challenges identified in each category, and examine the proportion of challenges addressed (by the multidisciplinary team and/or families). Our institutional review board reviewed and approved this study.

RESULTS

Sixty-seven discharge calls were completed (63% call completion rate) (Fig 1, Table 1). Twenty-nine (43%) completed calls occurred within 24 to 72 hours of discharge; the remaining 38 (57%) occurred 72 hours to 1 week after discharge.

Challenges were identified in 69% of the 67 completed calls. A total of 90 discrete challenges were identified given that 37% of calls endorsed >1 challenge. Seventy-nine percent of identified challenges were addressed, with 27% mitigated by families themselves (Tables 2 and 3).

The most common challenges involved medical signs and/or symptoms (27%; $n = 24$) including secretion management, feeding regimen, and seizures. All medical challenges were addressed, with families addressing 21% ($n = 5$) themselves. Although caregivers identified ongoing symptoms after discharge, they were not necessarily alarmed by these changes from baseline level of health. Many caregivers noted overall improvement despite having continued symptoms. In only 1 instance did a call that elicited a medical concern result in readmission.

Twenty-one percent ($n = 19$) of challenges were related to follow-up appointments. Seventy-nine percent of these families ($n = 15$) had not yet called to schedule a follow-up appointment (eg, because of the quantity of appointments), 16% ($n = 3$) were awaiting a return call from the provider's office, and 5% ($n = 1$) reported transportation needs.

Medication challenges comprised 20% ($n = 18$) of total challenges. Specific challenges included not having all required medicines, difficulties with insurance, dosage confusion, or incorrect storage. Of note, patients had a median of 21 (IQR 13–29) medications at time of discharge.

Home nursing challenges (17%; $n = 15$) included staffing availability for approved hours or initiating care with a home nursing company. Although our team care manager (CM) was contacted in 2 instances, we were unable to definitively remediate any of these access-related home nursing challenges because of nursing shortages.

Medical supplies and equipment issues, primarily related to needing supplies or equipment (eg, gastrostomy tubes, tracheostomy ties), comprised 14% ($n = 13$) of challenges. The CM often helped address these challenges.

The 30-day readmission rate was 27% during the study period, which is not significantly changed when compared to the baseline readmission rate of 22% ($P = .19$) for our complex care service 6 months before initiation of the study.

DISCUSSION

At our institution, we are fortunate to have a multidisciplinary inpatient complex care team that coordinates efforts toward successful hospital-to-home transitions for CMC. However, the majority of families identified postdischarge challenges. Challenges varied in scope, yet many could have important sequelae in the postdischarge period. These challenges are likely a reflection of the complex medical needs of CMC. We were struck by the resourcefulness of families in troubleshooting challenges.

A prospective study by Wells et al[10] in which home nursing visits to identify discharge challenges for CMC were completed within 72 hours of discharge similarly found that caregivers faced postdischarge challenges related to medical concerns, medications, nursing, and medical equipment. This study also took steps toward resolving challenges. Although phone calls may be less sensitive than home nursing visits in detecting challenges, our study provides a potentially

TABLE 2 Identification of Postdischarge Challenges

	Challenges Identified, *n* (%)	Total Challenges Addressed,[a] *n* (%)	Challenges Addressed by Family, *n* (%)
All challenges	90 (100)	71 (78.9)	24 (26.7)
Medical issues (eg, fever, seizures)	24 (26.7)	24 (100)	5 (20.8)
Follow-up	19 (21.1)	19 (100)	14 (73.7)
Follow-up not yet scheduled	16 (17.8)	—	—
Parents uncertain of follow-up needs	2 (2.2)	—	—
Transportation issues	1 (1.1)	—	—
Medications	18 (20)	15 (83.3)	2 (11.1)
Do not have all needed medications	7 (7.8)	—	—
Awaiting previous authorization	7 (7.8)	—	—
Other (eg, dosage confusion, incorrect storage)	4 (4.4)	—	—
Home nursing	15 (16.7)	0 (0)	0 (0)
Hours not staffed	11 (12.2)	—	—
Setting up new home nursing	4 (4.4)	—	—
Medical supplies and equipment	13 (14.4)	12 (92.3)	3 (23.1)
Need supplies	—	—	—
Nutrition and/or elimination	5 (5.6)	—	—
Miscellaneous (eg, pulse oximetry probes, gauze)	4 (4.4)	—	—
Respiratory	2 (2.2)	—	—
Concern and/or question about supplies and/or equipment	2 (2.2)	—	—
Discharge instructions unclear	1 (1.1)	1 (100)	0 (0)

—, not applicable.
[a] Total challenges addressed include challenges addressed by both the multidisciplinary complex care team and families.

more feasible and sustainable method for assessing postdischarge challenges.

In their quasi-experimental study, Heath et al[11] explored the impact of phone calls within 72 hours of discharge on pediatric readmission rates. Phone calls assessed for challenges related to the patient's health status, medication concerns, durable medical equipment, and follow-up appointments. However, the patients were not necessarily medically complex, and more than half of the challenges discovered by Heath et al[11] were medication related. Although this study found improvements in 30-day readmission rates, readmission rates in our study remained unchanged and consistent with previously published readmission rates for CMC.[12]

The most commonly identified challenges in our postdischarge calls were related to health status. This may suggest that patients are discharged once improved to an acceptable level of health, agreed on by the medical team and caregivers, rather than a complete return to baseline health. Furthermore, ongoing or new symptoms noted as a challenge during the phone call did not always lead to caregiver concern. This may represent the variability in caregiver experiences, support systems, or coping strategies that result in different reactions to similar challenges. Clinicians should take this into account when providing discharge counseling.

Lack of home nursing was another commonly identified challenge. Home nursing is a critical element for a safe hospital-to-home transition for technology-dependent patients.[13,14] This highlights the disparity between essential needs of the growing number of CMC and our current health care system, reflecting nationwide trends related to limited available workforce providing quality home care.[13,15–18]

Many challenges had already been addressed by the caregiver at the time of the postdischarge call. This underscores the resourcefulness and ability to navigate the complex health care system that caregivers of CMC develop through their experience with their children. Desai et al[5] identified similar findings in a qualitative study exploring the needs of caregivers and patients with varying medical complexity during hospital-to-home transitions. Health care self-efficacy arose as a central domain, with caregivers describing themselves as the individual solely responsible for caring for their child after discharge.[5]

This study is not without limitations. Although our study population embodies the demographics of patients admitted to our inpatient complex care service, we recognize that as a single-center study, it may not accurately reflect the population at other institutions. Given this convenience sample, this work may not be generalizable to other sites without a similar inpatient complex care model; however, our hope is that identified themes stimulate consideration from all inpatient providers caring for CMC, regardless if a specific team or structure exists. Variability in call timing is another potential limitation; phone calls

TABLE 3 Illustrations of Caregiver Challenges in the Postdischarge Period

Challenge Category	Challenge Addressed by Caregiver	Challenge Addressed by the Multidisciplinary Team	Challenge Not Addressed	The Parent Perspective
Medical issues	One caregiver was concerned about their child's GT site. She contacted the gastroenterologist who ordered a culture and prescribed an antibiotic.	The caregiver of a child with diabetes insipidus noted increased urine output and mental status changes. The APRN completing the phone call contacted endocrinology for recommendations and ordered a sodium level.	N/A	Many caregivers noted that their child was at an acceptable level of health despite ongoing symptoms: "She's good. She has had a couple of seizure episodes, but overall, she's been good. She didn't need the valium because they weren't back to back."
Follow-up	One patient's ventilator had been alarming. By the time the discharge phone call was made, the mother had contacted and scheduled an appointment with their primary pulmonologist, and plans for a future sleep study had been formulated.	One patient was discharged with a large cast, and the caregiver felt the patient could not comfortably be transported to appointments in the family car. The APRN assisted in coordinating ambulance transportation to appointments.	N/A	Many caregivers preferred to make their own appointments to better align with their busy schedules: "Mom prefers to make appointments and will work on them."
Medications	One caregiver had a difficult time getting Marinol (dronabinol) but was able to pick up the prescription the day before the phone call.	A patient had not received a necessary medication after discharge despite correct prescribing and completion of a previous authorization. The APRN completing the phone call contacted the pharmacy and discovered that the medication was out of stock. The attending physician prescribed an alternate medication until the original medication arrived at the pharmacy.	One caregiver was told the reflux medication and the antibiotic were prescribed to her home pharmacy, but they were prescribed to the hospital's outpatient pharmacy. The caregiver picked up the reflux medicine when the patient came back for a planned scope but for this reason did not complete the full course of antibiotics prescribed.	Many caregivers were resourceful, making do with what they had while medication issues were sorted out: "The Keppra dose was increased while inpatient, but no new script was sent. [I am] giving correct dosing but will run out soon."
Home nursing	N/A	N/A	Our CM works diligently to fill home nursing hours for our patients if they are approved, but often shortages in the area inhibit this. In one instance, a caregiver requested thrice weekly skilled nursing visits until home nursing could be filled. Our CM contacted the patient's primary physician with information about the company this patient had used before for nursing, but the company could not fulfill this request.	Many caregivers noted lack of home nursing as a chronic challenge. One parent noted, "Our nurses are great, but we aren't fully staffed." Another caregiver noted they were "poorly staffed, but this is an ongoing issue, not a new problem."
Medical supplies and equipment	One caregiver noted issues with their child's wheelchair. They brought the wheelchair to the child's school physical therapist who was able to resolve the issue.	The APRN completing a phone call contacted the CM when a caregiver requested an extra GT. The CM coordinated discussions between the patient's insurance and their home care company. When it was determined that insurance would not approve an additional GT at the time, the CM provided out-of-pocket pricing information to the family.	N/A	Some families expressed frustrations with the navigation of a complex health care system for relatively basic items: "I'm having to work between Medicaid and the other insurance company to get the new formula."
Discharge instructions	N/A	In one instance, a caregiver found discharge instructions unclear. The APRN completing the call was able to clarify instructions during the phone call.	N/A	N/A

GT, gastrostomy tube; N/A, not applicable.

made shortly after discharge may not be fully inclusive of all potential challenges, whereas families called 3 to 7 days after discharge may not have reported issues already identified and self-resolved. We should consider respondent selection bias, as 63% of eligible caregivers completed postdischarge calls. Although likely multifactorial, caregivers may have answered more readily knowing the call purpose and the potential that our team could assist them. Lastly, calls were attempted to only 75% of eligible patients and only included English-speaking patients because of a limitation of our study design; APRNs were asked to complete calls during busy clinical shifts without dedicated time.

In future work, we hope to identify patient and family characteristics that may indicate higher risk of postdischarge challenges, such as limited English proficiency, as well as assess the effect of postdischarge phone calls on reuse of health services and other outcomes important to patients and families. We plan to translate our findings back to patient care through improved discharge planning, such as codesigning discharge planning tools with our families of CMC.

Our findings emphasize that the growing population of CMC have needs, both in the hospital and at home, that are at times challenging to accommodate in our current health care system.[17] Given CMC's significant health care use, it is imperative that health care providers continue to pursue safe and efficient hospital-to-home transitions and that our health care system adapts to accommodate this important cohort of patients.

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