Caregiver Perceptions of Hospital to Home Transitions According to Medical Complexity: A Qualitative Study

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ABSTRACT

OBJECTIVE: To explore caregiver needs and preferences for achievement of high-quality pediatric hospital to home transitions and to describe similarities and differences in caregiver needs and preferences according to child medical complexity.

METHODS: Qualitative study using semistructured telephone interviews of 18 caregivers of patients aged 1 month to 18 years discharged from Seattle Children's Hospital between September 2013 and January 2014. Grounded theory methodology was used to elucidate needs and preferences identified to be important to caregivers. Medical complexity was determined using the Pediatric Medical Complexity Algorithm. Thematic comparisons between medical complexity groups were facilitated using a profile matrix.

RESULTS: A multidimensional theoretical framework consisting of 3 domains emerged to represent caregiver needs and preferences for hospital to home transitions. Caregiver self-efficacy for home care management emerged as the central domain in the framework. Caregivers identified several needs to promote their sense of self-efficacy including: support from providers familiar with the child, opportunities to practice home care skills, and written instructions containing contingency plan information. Many needs were consistent across medical complexity groups; however, some needs and preferences were only emphasized by caregivers of children with chronic conditions or caregivers of children with medical complexity. Distinct differences in caregiver preferences for how to meet these needs were also noted on the basis of the child's level of medical complexity.

CONCLUSIONS: Caregivers identified several needs and preferences for enhancement of their sense of self-efficacy during hospital to home transitions. These findings inform quality improvement efforts to develop family-centered transition systems of care that address the needs and preferences of broad pediatric populations.

KEYWORDS: caregivers; health transition; hospitalized child; patient-centered care; patient discharge; qualitative research

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WHAT'S NEW

This study identified important caregiver needs and preferences for achievement of high-quality hospital to home transitions in general pediatric populations. Similarities and differences in findings according to child medical complexity will inform tiered, quality improvement interventions that are consistent with family transition needs.

IMPROVING THE QUALITY of hospital to home (H2H) transitions is essential to address deficits in care coordination for children who interface with the US health care system.[1] Recent evidence has shown that H2H transitions are plagued with a high incidence of adverse events,[2–4] poor communication between patients and providers,[5] and inadequate information transfer between providers.[6–8] In response, several expert panels have provided recommendations to improve the quality of H2H transitions.[9–13] However, critical gaps remain in our understanding of effective transition processes for improving health outcomes for H2H transitions in pediatric patients.[14,15] Understanding the needs and preferences of families during H2H transitions is the first step to fill these knowledge gaps.

Qualitative research methods are valuable for providing a detailed exploration of the underlying constructs that affect H2H transitions for families.[16] This formative work provides in-depth insight into the complex interaction between families and the health system that help to explain successes and failures during these transitions. By understanding which values, needs, preferences, and goals are important to families during transitions, we can develop meaningful theoretical models for how to achieve high-quality H2H transitions

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that eventually might be tested using quantitative methods.[17]

Previously published qualitative studies related to H2H transitions have only been conducted in adult and elderly populations or in disease-specific pediatric populations.[18–23] Although these studies might inform quality improvement interventions for specific populations, qualitative studies are needed in general pediatric populations to develop broad, standard processes of care on a hospital-wide or health system level. For example, what are the goals of families for H2H transitions? Are there baseline needs that all families have to achieve successful H2H transitions? What are their preferences for meeting these needs? Do these needs and preferences differ based on the child's level of medical complexity?

The aim of this qualitative study was to explore caregiver needs and preferences for achieving high-quality H2H transitions in a medically diverse population of pediatric patients. We also aimed to describe similarities and differences in needs and preferences expressed by caregivers of children with different levels of medical complexity to inform quality improvement strategies that might be applicable to broad populations of hospitalized children.

METHODS

RECRUITMENT

English-speaking caregivers of patients older than 1 month of age and hospitalized on the medical or surgical unit at Seattle Children's Hospital from September 2013 to January 2014 were recruited for this study. Eligibility was determined using hospital electronic medical record data before recruitment. A trained research assistant contacted eligible caregivers by telephone shortly after their child's hospital discharge and scheduled interviews with those indicating interest in participating in the study. Interested caregivers were mailed a study information letter and Health Insurance Portability and Accountability Act authorization form that needed to be signed and returned before conducting the interview. Verbal informed consent was obtained from the caregiver immediately before conducting the interview. Caregivers were recruited and enrolled until well defined themes and patterns emerged from the data, and consistent similarities and differences were noted among caregivers of children with different levels of medical complexity. This was determined during the interview process by the research investigator (A.D.), who conducted all of the interviews. Caregivers were mailed a $20 incentive after interview participation.

All study procedures were approved by the Seattle Children's Research Institute institutional review board.

INTERVIEW CONDUCT

In depth, semistructured interviews were conducted by telephone within 3 months of hospital discharge and lasted approximately 30 to 45 minutes. Interviews were audio-recorded and transcribed in their entirety by an independent transcriptionist. Interview questions were developed with the primary aim of gaining a better understanding of caregiver needs and preferences for H2H transitions. For this reason, questions were general and open-ended. Caregivers were asked to primarily describe their most recent H2H transition experience, their transition needs, their preferences for meeting these needs, and what the ideal H2H transition would be for their family. Caregivers who experienced multiple H2H transitions were also encouraged to compare their most recent experience with previous transition experiences. Interview questions and probes were iteratively revised as new themes emerged from caregiver responses and as response patterns became more well defined.

DEMOGRAPHIC DATA

Caregiver and patient demographic characteristics were obtained from administrative data and from the Seattle Children's Hospital Outcomes Assessment Program database, which is a survey database that routinely collects patient and family demographic data on admission. Level of medical complexity was determined using the Pediatric Medical Complexity Algorithm,[24] which is used to classify patients as having either no chronic conditions (eg, febrile seizure) or chronic conditions (eg, epilepsy) on the basis of up to 3 years of retrospective International Classification of Disease Ninth Revision Clinical Modification codes beginning with the date of admission. Patients with chronic conditions can be further classified into having noncomplex chronic conditions (eg, epilepsy) or medical complexity (eg, epilepsy with chronic respiratory insufficiency). We used the following classification for this study: children with no chronic conditions, children with chronic conditions (whether or not complex), and children with medical complexity as shown in Figure 1.

DATA ANALYSIS

Data analysis was initiated after completion of all interviews. Interview transcriptions were analyzed using a combination of immersion and crystallization techniques and grounded theory methodology. Immersion and crystallization involves reading and rereading transcripts through an iterative process until meaningful and substantiated patterns and themes emerge from the data.[25] Grounded theory is an exploratory method in which theoretical constructs are formulated through in-depth analysis of the qualitative data.[26,27] Using these methodologies, transcripts were initially read in their entirety by 2 authors (A.D. and L.K.D.) to gain insight into broad themes and concepts that emerged from caregiver responses. We then developed a coding scheme through a series of iterative steps in which we revised and refined the code structure multiple times as we discovered new insights into the relationship between themes. We initially used open coding techniques in which 2 authors (A.D. and L.K.D.) read each transcript line by line and independently assigned codes to each concept or idea. Codes were then

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